San Francisco’s Strategy For Excellence In Dementia Care

Research, recommendations, and an action plan to address the growing crisis in dementia care, and an economic analysis of that care.

Part One of Two

- Plan Purpose and Historic Context
- The Planning Process
- Mission, Values & Vision
- The Nature of the Crisis
- Improving the Service Network
- Objectives
- Recommendations
- Action Plan
- Impact of 2009-2010 State Budget

By Alzheimer’s/Dementia Expert Panel

For Department of Aging and Adult Services

December 2009
THE HUMAN FACE OF DEMENTIA

This Strategy for Excellence in Dementia Care is dedicated to ensuring that services and supports in San Francisco are organized around the needs of people with Alzheimer’s and related dementias and their caregivers, and not around organizational or service provider needs. Below are examples of people with dementia who might require care and support in San Francisco – now and in the future.

Vignette #1: MaeLynn Chang and Janice Lee

MaeLynn, age 74, has lived alone in her home in the Sunset district since her husband, MingTong, died several years ago. Her daughter, Janice Lee, lives in Antioch. While she sees her mother several times a week, the strain of getting back and forth to the City takes its toll. Of late, she has noticed that her mother has been unusually forgetful, last month failing to recall her birthday. More alarming, MaeLynn recently started the stove to make tea and then went to bed without turning off the burner, only to be awakened by the smoke alarm and the scent of a scorched pan.

Vignette #2: Roberto Gonzalez

Roberto Gonzalez is 81 years old and has lived alone for over 20 years since his wife, Maria, left him. He has no children and his closest relatives, two cousins, live in south Los Angeles. He rarely communicates with them, as there has been a history of family conflict. Until recently he had been active in the City of Refuge United Church of Christ near his single room occupancy hotel unit on Folsom Street in the South of Market neighborhood. Members of the church have been concerned about his behavior of late, including his missing services or appearing for services on odd days. One church member visited to speak with him and the resident manager only to discover Roberto’s normally meticulously neat room to be in disarray. The resident manager noted that Roberto had recently forgotten to pay his rent and when reminded, seemed confused. Despite living on a fixed income, Roberto had never failed to pay his rent on time.

Vignette #3: Richard Brown and Damien Thomas

Richard Brown and Damian Thomas have lived together for over 25 years. Richard is 14 years older than Damian and at 69 is beginning to show signs of memory loss. Richard is an artist and he is often alone as part of his creative process. Lately, however, he has begun to feel isolated. He recently had great difficulty figuring out how to operate the remote control for the television, a tool he had been using for many years. When trying to turn the sound to mute, Richard looked at Damian with a confused expression and then simply gave up. Damian works as a program manager at the Department of Human Services and is becoming concerned that Richard may be developing Alzheimer’s or some other form of dementia.

These vignettes provide examples of the kinds of San Francisco residents entering the world of cognitive impairment and dementia. They demonstrate the need for expanded community education; enhanced workforce training; improved service coordination; early diagnosis and improved access to treatment, care and services; and the need for ongoing caregiver support. This Strategy offers many recommendations to address these situations. When implemented, the recommendations will improve access to a full range of services for the increasing number of people with cognitive impairment and dementia, and to a variety of resources and supports for their caregivers.
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EXECUTIVE SUMMARY

San Francisco is facing a crisis in dementia care. In the Bay Area, one out of every two people 85+ has some type of dementia. Between now and 2020, San Francisco will experience a dramatic increase in the number of its citizens with Alzheimer’s disease and other dementing illnesses. Between 2010 and 2030, there will be a 49% increase in the number of people with Alzheimer's related dementias (from 23,445 to 34,837). This does not include the increase in the number of people with other forms of dementia and mild cognitive impairment (MCI).

An Alzheimer’s/Dementia Expert Panel, formed by Mayor Gavin Newsom in November 2008, investigated the growing crisis in dementia care. The Expert Panel was charged with developing a plan to address the demand for services related to Alzheimer’s/dementia care between 2010 and 2020, and an economic analysis of that care.

Background: The Department of Aging and Adult Services (DAAS) led and managed this initiative. In September 2008, DAAS retained the services of a research team consisting of Gibson & Associates, Resource Development Associates, and the Mental Health Association of San Francisco. This research team worked with the Expert Panel and DAAS staff to undertake an evaluation of San Francisco’s current dementia care services, project the need for additional services, and with guidance from the Expert Panel, prepare a plan and recommendations to address the needed services during the next 10 years (2010 to 2020). The work of the Expert Panel took place between December 2008 and May 2009. There were six Expert Panel meetings. Four sub-committees researched specific topics and reported back to the Expert Panel to assist in its deliberations. Each subcommittee met approximately five to seven times.

From the outset, the Expert Panel sought to create a Strategy for Excellence in Dementia Care that could serve as a road map, providing policy makers with short-term and intermediate recommendations that can be implemented within the current network of care as well as long-term recommendations that incorporate significant reforms. As the values and vision developed by the Expert Panel describe, as was evident in the research, and as was expressed by Panel members from the first meeting: service providers continuing to operate in silos (separate organizational structures) is no longer acceptable and a more integrated model of care is needed. San Francisco’s Strategy for Excellence in Dementia Care points to a future approach to service delivery that is characterized by:

- Expanded community education and training;
- Improved service coordination;
- Shared client information;
- Team-based care;
- Promotion & dissemination of the most current standards and guidelines for care;
- Education & training for service providers to implement those standards and guidelines; and
- Improved access to resources and services in the early stages of this disease and, hopefully, a delay in the need for more intensive services in later stages.

It is the Expert Panel’s hope that even its most visionary recommendations may in time be realized, as state and national health policy reform becomes more aligned with San Francisco’s historically progressive approach to the delivery of health care and social services. Panel members also made recommendations that could emerge without major policy changes at state or national levels, or without a massive infusion of financial resources. The resulting plan strikes this balance, including:
(1) low cost initiatives for education and training, and improved access to services, that could be implemented relatively easily; (2) a pilot project to improve care coordination; (3) promotion of guidelines and standards that, while challenging to implement, do not require significant new funding; (4) advocacy and policy recommendations that could enable the City to better manage its resources and invest in services that might reduce the use of more intensive, higher cost services; and (5) demonstration projects that require varying levels of public and private investment, but once established could lead to broad replication of research-based approaches.

The following objectives and recommendations are intended to address the growing crisis in dementia care, from early memory loss, to the progression to mild, moderate, and advanced dementia. However, if San Francisco could: (1) help people to learn about the initial signs of cognitive change; (2) provide increased resources and community-based services for those first experiencing memory loss and cognitive impairment; (3) offer training and support for caregivers and service providers; and (4) assist those experiencing dementia and their caregivers to manage symptoms and care issues in the early to moderate stages, the need for more intensive and costly services could be delayed.

The advance of the disease cannot currently be halted. This being the case, we should provide comprehensive, compassionate care for people with dementing illnesses and their care partners at each stage. Until there is a cure or treatment for cognitive decline, achieving these objectives and implementing these recommendations will allow us to better manage each individual’s complex medical conditions along with their cognitive impairments in a way that will improve quality of life.

OBJECTIVE 1: Improve capacity to meet the needs of the whole person by delivering integrated care.

RECOMMENDATION 1-1. Dementia care should be integrated into San Francisco’s existing long term care service delivery network, which emphasizes ongoing chronic care management. This will enable the needs of the whole person to be considered and addressed.

RECOMMENDATION 1-2. All agencies and programs delivering services in the long-term care service delivery network as well as first responders and urgent care clinical settings should become dementia capable. This will require education, training, and support for service providers and families. Agencies and programs serving people with dementia will need to consider the stigma related to dementia, the concerns of existing clients, and the dignity of new clients experiencing cognitive impairment or dementia.

OBJECTIVE 2: Improve public and professional awareness and understanding of dementia.

RECOMMENDATION 2-1. Public education should be expanded and enriched and should target those experiencing memory loss and those newly diagnosed with Alzheimer’s and related dementias, and their caregivers, as well as service providers, care managers, and health care professionals. Funding should be sought and obtained to enable the provision of this expanded public education.

Public education and training should be available on the following topics:
- Risk Reduction;
- Early Identification of Alzheimer’s and Related Dementias;
- What To Expect as the Disease Progresses;
- Services and Resources;
- Caregiver Wellness and Support;
- Disease Management - Mild, Moderate & Advanced Dementia;
- Advanced Care Planning;
- Ethical Issues; and
- Emergency Preparedness and Safety.

**OBJECTIVE 3: Develop an informed and effective workforce for people with dementia.**

**RECOMMENDATION 3-1.** The most current guidelines and standards for dementia treatment and care should be identified, promoted, and disseminated to professionals on a regular basis.

**RECOMMENDATION 3-2.** Training for professionals, including community-based service providers and care managers, should be expanded to facilitate implementation of the most current guidelines and standards for dementia care. Funding should be sought and obtained to enable the provision of this expanded training.

**RECOMMENDATION 3-3.** Targeted training for primary care physicians, hospitalists, and the medical staff of primary care health centers and clinics operated by the Department of Public Health, the San Francisco Community Clinic Consortium, UCSF, and Kaiser Permanente should be expanded related to medication prescriptions, diagnosis, end-of-life care, and managing difficult behaviors and critical crisis care issues.

**RECOMMENDATION 3-4.** An electronic medical record (using a “patient dashboard”) should be researched and developed for the use of health and social service staff which will: (1) enable cross-system information sharing; and (2) improve service coordination.

**OBJECTIVE 4: Expand capacity to deliver high-quality early diagnosis and intervention for all.**

**RECOMMENDATION 4-1.** Diagnosis of mild cognitive impairment (MCI) should be encouraged and facilitated with clearly established diagnostic criteria.

**RECOMMENDATION 4-2.** A standardized screening tool for chronic conditions and illnesses, which encompasses cognitive function, mood, activities of daily living, and caregiver or family observations, should be selected or developed. This should be used by health care professionals (primary care physicians, physician assistants, nurses, nurse practitioners, social workers and clinics) and psychologists, to assess the need for a comprehensive evaluation for adults with memory complaints or cognitive change, possibly including referral to a specialist for thorough diagnosis.

**RECOMMENDATION 4-3.** A range of clinical geriatric fellowships should be developed at UCSF for physicians, nurses, and social workers training in geriatric practice, with fellows committing to a number of years working in community health services (primary care health centers and clinics operated by the Department of Public Health and the San Francisco Community Clinic Consortium), performing assessments, and managing the care of people with Alzheimer’s and related dementias.
RECOMMENDATION 4-4. Barriers and financial disincentives in medical care should be removed that deter physicians from providing geriatric assessments, diagnoses, and ongoing care by increasing reimbursement rates for these services.

RECOMMENDATION 4-5. Barriers and financial disincentives should be removed that limit access to services that are based on a single diagnosis.

OBJECTIVE 5: Ensure availability of high-quality, culturally responsive information for those diagnosed with dementia and for their caregivers.

RECOMMENDATION 5-1. To enable easy access to quality information, people with cognitive impairment and dementia as well as their caregivers will benefit from the professionally staffed “central door” of San Francisco’s “no wrong door” approach.

OBJECTIVE 6: Create expanded and easy access to care, support and advice following diagnosis.

RECOMMENDATION 6-1. A team approach to dementia care and service delivery should be piloted, employing care managers with dementia expertise operating as the “single-point-of-contact” for people with dementia using primary care health centers and clinics operated by the Department of Public Health, the San Francisco Community Clinic Consortium, UCSF, and Kaiser Permanente. This will result in a better informed and coordinated delivery of services.

RECOMMENDATION 6-2. Structured peer or volunteer support and learning networks should be developed for people with dementia and their caregivers, especially in early and mid stages. The establishment and maintenance of such networks will provide direct informal support delivered by trained volunteers. These networks can also provide practical and emotional support, reduce social isolation, and promote self-care.

OBJECTIVE 7: Implement a range of effective caregiver support strategies to better address the multiple needs of informal caregivers.

RECOMMENDATION 7-1. Immediately upon a diagnosis of dementia being made, a practice should be established where doctors and their staff refer caregivers as well as family members to supports, such as education, counseling, caregiver assessment, and services.

RECOMMENDATION 7-2. Additional respite care services should be developed for people with Alzheimer's and related dementias. Increased respite care should be part of the supports (that include education, counseling, assessment, and services) for caregivers and family members. Funding should be sought for additional respite care.

OBJECTIVE 8: Improve the quality of hospital and nursing home care for people with dementia.

RECOMMENDATION 8-1. A meeting of acute care hospitals should be convened to review all existing care plans for patients with any type of dementia, identify best practices for the care of hospitalized adults with dementia, and implement best practices to improve their care.
RECOMMENDATION 8-2. Nursing home placement should not only be for the purpose of safety and containment of dementia-related behaviors, but also for person-centered care with an array of services that address all of the needs of the person and not solely the diagnosis of dementia.

OBJECTIVE 9: Expand and improve the quality of community-based care for people with dementia.

RECOMMENDATION 9-1. An expanded range of community-based services should be developed for people in the early stages of cognitive impairment or Alzheimer’s and related dementias, based upon evidence-based practice and emerging research.

RECOMMENDATION 9-2. The full range of adult day services (Adult Day Health Care, Social Day Care, and Alzheimer’s Day Care Resource Centers), appropriate for people at different stages of the disease, should be expanded and improved. Day care programs and staff should be informed, trained, and capable of addressing the needs of individuals with cognitive impairment or Alzheimer’s and related dementias and their caregivers.

RECOMMENDATION 9-3. Services and supports should be developed for people with cognitive impairment or Alzheimer’s and related dementias who have no family, or who do not have family members living in close proximity to San Francisco.

RECOMMENDATION 9-4. A crisis intervention and assessment setting should be developed for the placement of people with cognitive impairment or Alzheimer’s and related dementias who are no longer safe in their own environments and/or who have behavioral issues.

RECOMMENDATION 9-5. Advocacy for changes in the mental health system should be undertaken at the local and state level to eliminate the carve-out of mental health services for people with a primary diagnosis of dementia. San Francisco’s mental health system and medical/health care system should be encouraged to collaborate more effectively in serving clients with both dementia and mental illness, or those with Alzheimer’s who develop mental health-related conditions.

RECOMMENDATION 9-6. A plan should be developed to provide and fund services, particularly respite care, for people with Alzheimer’s and related dementias who are above Medi-Cal eligibility. The needs of these individuals, who are often unable to get the services they require, should be addressed.

OBJECTIVE 10: Improve the quality of services in residential care homes and expand the range of models of residential care for people with dementia.

RECOMMENDATION 10-1. A range of residential care settings should be developed for people who require both residential and nursing care services.

RECOMMENDATION 10-2. Residential care settings should be designed and operated not only to ensure individual safety and contain dementia-related behaviors, but also to offer person-centered care with an array of services that address the whole person.

OBJECTIVE 11: Improve access to end of life care for people with dementia.
RECOMMENDATION 11-1. Advocacy should be undertaken for changes in local, state and national policies to enable individuals with late stage Alzheimer’s and related dementias to be able to more easily access hospice care. This will require establishing diagnostic criteria that are more in line with the progression of late stage dementia, allowing for the extension of time limits, and ensuring palliative care is available to people with dementia.

OBJECTIVE 12: Advocate for effective state and national support for the implementation of this Strategy.

RECOMMENDATION 12-1. Education and advocacy for universal coverage for long-term supports and services should be undertaken so that this is part of national health care reform. Work to assure that Medicare and Medicaid regulations are coordinated to allow for the best possible patient care.

RECOMMENDATION 12-2. The City should advocate for legislation that would require the State Department of Health Care Services and State Department of Social Services to develop expertise in dementia care.

RECOMMENDATION 12-3. The City should explore federal waivers for assisted living programs to enable the retention of Medi-Cal funds for these services and the ability to manage them locally.

RECOMMENDATION 12-4. An enhanced nursing home diversion services project should be considered. This project would be developed in collaboration with the California Department of Aging, funded by a grant from the federal Administration on Aging.

RECOMMENDATION 12-5. The feasibility of a managed chronic care demonstration project for older adults and adults with disabilities, including those with Alzheimer’s and related dementias, should be explored.

OBJECTIVE 13: Foster policies and practices that create a community sensitive to the needs of individuals with memory loss.

RECOMMENDATION 13-1. Efforts should be undertaken to make San Francisco more accommodating of people experiencing forgetfulness and cognitive impairment. These efforts should be connected to the local, national, and international movements toward creating age and disability friendly communities.

OBJECTIVE 14: Facilitate and support an Oversight Committee responsible for implementing this Strategy, and advocating for improvement of prevention, education and services related to dementia.

RECOMMENDATION 14-1. A Dementia Care Excellence Oversight Committee should be established for: (1) overseeing the implementation of this Strategy and its recommendations; (2) monitoring the progress of workgroups, (3) monitoring the participation of partners; (4) undertaking advocacy efforts to influence state and national legislation; (4) overseeing the exploration and initiation of pilot projects and demonstration projects; (5) identifying guidelines and standards of care for all components of the network of services for individuals with dementia; and (6) fostering adherence to these standards by all appropriate service providers.
ACTION PLAN AND NEXT STEPS
(See complete Action Plan on page 73)

San Francisco’s response to the growing crisis in dementia care should be comparable to the City’s comprehensive and effective response to the AIDS epidemic back in the 1980s. To be successful, the implementation of this Strategy for Excellence in Dementia Care will require a unified, proactive, long term response. This effort should not be the responsibility of any single city department. Should this be the case, implementation will falter or fail. Instead, this effort will require the involvement of many city departments, non-profit agencies, social service agencies, health care providers, residential care and institutional care providers, and advocacy groups. Success will also require that ongoing staffing for the seven recommended workgroups is provided by several different city departments.

Leadership required to advance this Strategy

Visible leadership will be required to make this Strategy a reality. The overarching leadership and direction for its implementation across city departments should come from the Mayor’s Office. A Dementia Care Excellence Oversight Committee, whose members should be appointed by the Mayor, will oversee all implementation activities. The Department of Aging and Adult Services will take part of the leadership role. However, other city departments, agencies, and organizations will need to be actively involved and commit resources, staffing, advocacy, and time to this effort.

Other city departments, agencies, and organizations recommended for participation and leadership include: the Department of Public Health, University of California at San Francisco (UCSF), the Alzheimer’s Association of Northern California and Northern Nevada, Family Caregiver Alliance, San Francisco Medical Society, Sutter Health, Catholic HealthCare West, Brown & Toland Physicians Medical Group, Hill Physicians Medical Group, On Lok Lifeways, Kaiser Permanente’s national office in Oakland, and the Long-Term Care Coordinating Council. Expert consultation on specific issues will be required from members of the Expert Panel periodically for a limited time. For example, they may need to provide access to the UCSF Department of Medicine.

Recommended workgroups required to implement this Strategy

1. Training And Education
2. Guidelines And Standards
3. Additional Services And Settings
4. Medical Resources
5. Shared Electronic Medical Records System
6. Waivers, Pilot Projects, And Demonstration Projects
7. Advocacy

Conclusion

There is no cure for dementia on the immediate horizon. A wave of baby boomers is approaching the age where Alzheimer’s and related dementias will begin to emerge. There will be a crisis in dementia care and San Francisco must respond. The Alzheimer’s/Dementia Expert Panel spent months deliberating on research, local data, and input from caregivers and other stakeholders. The recommendations provided in this report are the product of that focused and intensive work. San Francisco must act with urgency, move forward to implement these recommendations, and realize our vision of care for people with dementia so that they can live in dignity and thrive.
October 2009

Dear Citizens of San Francisco,

The City and County of San Francisco has long been a leader of innovation in services and support for seniors and persons with disabilities. Today, we need that spirit of innovation more than ever as the approaching "age wave" may bring a potential crisis in Alzheimer's and dementia care to our county.

San Francisco has the highest percentage of seniors of any county in California and the highest portion of seniors living alone. I know that many caregivers give their lives to care for a loved one with dementia. Last year, in June 2008, based on the findings and recommendations of the Long Term Care Coordinating Council, I put money in the budget to fund a comprehensive assessment of the demand for services related to Alzheimer's and dementia care, and to assess the need for support for caregivers. In November 2008, I appointed an Alzheimer's/Dementia Expert Panel charged with investigating this pending crisis and helping San Francisco to plan for the future. I want to express my gratitude to the many leaders and experts who helped produce the incredible analysis and thoughtful recommendations that follow.

I invite you to join me so that we can work together to implement some very practical and innovative solutions. We value your involvement and need your commitment as we address this public health challenge.

It is my hope that San Francisco's Strategy For Excellence in Dementia Care is something that can be shared throughout California and across the rest of the country.

Sincerely,

Gavin Newsom
Mayor
November 2009

MESSAGE FROM ALZHEIMER'S/DEMENTIA EXPERT PANEL CO-CHAIRS

The Alzheimer's/Dementia Expert Panel, appointed by Mayor Newsom in November 2008, was charged to undertake an evaluation of San Francisco's existing dementia care services as well as to provide a plan and recommendations for service improvements and for additional services required over the next 10 years, from 2010 to 2020. The Mayor also requested that our planning include an economic analysis of this care and support.

Our first meeting took place in December 2008 and we concluded our deliberations in May 2009. Early in our work, the Expert Panel members were told that we should provide our best recommendations for improvements in dementia care that could be made in the short term and for longer term improvements based on opportunities that may exist in the future, regardless of the extremely challenging financial situation in FY 2009-10 confronted by San Francisco and by the State of California.

We believe our plan and recommendations, which we call a Strategy for Excellence in Dementia Care, meets our charge from Mayor Newsom. It has been an honor and a pleasure to work on this vitally important effort with all of the Expert Panel members, which included family caregivers, advocates, long term care experts, aging experts, Alzheimer's experts, labor, care coordination experts, medical care providers, researchers, as well as public and non-profit service providers.

Accordingly, on behalf of the Alzheimer's/Dementia Expert Panel, we are very pleased to present San Francisco's Strategy for Excellence in Dementia Care. We have provided 14 objectives and 35 recommendations that, when implemented, will significantly improve services and respond to the growing crisis in dementia care. It is our hope that this Strategy will guide most or all of the improvements that we have recommended over the next 11 years.

San Francisco has a history of innovation in terms of providing long term services and supports for older adults and adults with disabilities. We envision this undertaking to improve dementia care as the logical next step in meeting the needs of the most vulnerable among us. This is the compassionate thing for San Francisco to do.

Kathy Kelly, Co-Chair  Jay Luxenberg, MD, Co-Chair
Executive Director  Medical Director and Geriatrician
Family Caregiver Alliance  Jewish Home, San Francisco
November 2009

MESSAGE FROM THE EXECUTIVE DIRECTOR,
DEPARTMENT OF AGING AND ADULT SERVICES

It is with great pleasure that the Department of Aging and Adult Services joins the Alzheimer’s/Dementia Expert Panel to present *San Francisco’s Strategy for Excellence in Dementia Care*, which will guide greatly needed improvements in services and supports for people with Alzheimer’s disease and related dementias, and for their caregivers.

With this *Strategy*, we intend to: (1) help people to learn about the initial signs of cognitive change; (2) provide increased resources and community-based services for those first experiencing memory loss and cognitive impairment, and for their caregivers; (3) offer training and support for caregivers and service providers; (4) assist those experiencing dementia and their caregivers to manage symptoms and care issues in the early to moderate stages, so that the need for more intensive and costly services could be delayed; and (5) improve the residential and nursing care options for those with late stage dementia and for their caregivers, so that they both may live with dignity throughout their lives.

Among the many recommendations included, I believe that:

- An expansion of community education can increase public and professional awareness, enhance understanding and reduce stigma, remove some of the barriers to seeking treatment, and create a more compassionate community environment in which people with dementia can live and thrive.
- Providing training and education to those who work with and treat people with dementia, including professionals (home care workers, assisted living staff, nursing facility staff, physicians, and other health care providers), community-based service providers, and care managers, can help to improve skills to enable the delivery of effective, responsive and compassionate care.
- A strategic investment in early intervention, and in caregiver education and support, can significantly delay the need for high-end services and supports that are costly and in short supply.
- Expanded community-based services, and improved coordination and integration of services can make possible timely access to care, and transitions between levels and types of care less disruptive.
- Changes in restrictive policies and fiscal regulations can result in greater flexibility, which can enable a more person-centered range of services.
- Implementation of the most current guidelines and standards can improve the degree to which service providers deliver the highest quality services, and can make a significant difference in the lives of people with dementia, and their caregivers.

I am very proud of the hard work accomplished by San Francisco’s Expert Panel members, which produced this *Strategy*. I am also truly excited that its implementation will make a great difference in the lives of people who have Alzheimer’s and related dementia as well as in the lives of those of us who care for them. The work continues and implementation begins.

Anne Hinton
Executive Director
Department of Aging and Adult Services
# Alzheimer’s/Dementia Expert Panel Members

1. **Department of Public Health:**
   - Laguna Honda Hospital
     - **Gail Cobe**, RN, Clinical Nurse Specialist, Dementia Program
   - San Francisco General Hospital
     - **Edgar Pierluissi**, MD, Medical Director, ACE Unit
   - Community Behavioral Health Services
     - **Robert Cabaj**, MD, Director, Community Behavioral Health Services

2. **Department of Aging and Adult Services**
   - **Anne Hinton**, ED, Department of Aging and Adult Services

3. **Family Caregiver Expert**
   - **Kathy Kelly**, ED, Family Caregiver Alliance, CO-CHAIR

4. **Long Term Care Ombudsman**
   - **Benson Nadell**, Ombudsman, Family Service Agency

5. **PACE Model Experts**
   - **Robert Edmondson**, ED, On Lok, Inc
   - **David Werdegar**, President & CEO, Institute on Aging

6. **Homecare Expert**
   - **Margaret Baran**, ED, IHSS Consortium

7. **Labor**
   - **Richard Thomason**, Policy Director, SEIU United Healthcare Workers West

8. **Aging Experts**
   - **Anni Chung**, ED, Self Help for the Elderly
   - **Gay Kaplan**, RN, Director of Services, Curry Senior Center
   - **Martin Lynch**, ED, LifeLong Medical Care, Berkeley

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I. BACKGROUND

I.A. PLAN PURPOSE & HISTORIC CONTEXT

Plan Purpose

San Francisco is facing a crisis in dementia care. In the San Francisco Bay Area, one out of every two persons 85+ has some type of dementia. Between now and 2020, San Francisco will experience a dramatic increase in the number of its citizens with Alzheimer’s disease and other dementing illnesses. An Alzheimer’s/Dementia Expert Panel, formed by Mayor Gavin Newsom in November 2008, investigated this growing crisis between December 2008 and May 2009. The Expert Panel was charged with developing a plan and recommendations that respond to the need for services between 2010 and 2020, and an economic analysis of that care.

Historic Context

Dementia is expected to skyrocket in coming decades. Barring a medical breakthrough, the 2009 World Alzheimer’s Report projects that dementia will nearly double every 20 years. The report puts North America’s total cases at 4.4 million, although the Alzheimer’s Association of the United States estimates that more than 5 million people in this country alone are affected.

While advances are being made for the treatment of Alzheimer’s disease and related dementias, currently there is no cure and treatments can only slow dementia’s progression, not stop it or ease its symptoms, and not eliminate them. The human and fiscal burdens imposed by dementia are extraordinary. Demographic projections make clear that as the oldest segment of our adult population doubles over the next 20 years, the demand for services and supports will far outstrip our current capacity. To avoid a catastrophic human and fiscal crisis of unparalleled scope, significant changes in education and training, caregiver support, diagnosis, service delivery, fiscal regulations, and policy are essential.

This plan has been designed to serve as a roadmap for local policy makers, administrators, advocates, service providers, and caregivers. The framers of this plan were keenly aware of the national, state and local fiscal crisis that for the foreseeable future will limit investments in health, education, infrastructure and other public initiatives. However, dementia will not wait for the City’s fiscal house to be restored. The demographic bubble, with thousands more aging adults in need of services, is not going to wait for our fiscal crisis to recede. Therefore, this plan must not collect dust or by 2020 we will have hundreds of individuals with dementia underserved, many becoming homeless, caregivers overburdened and exhausted, and our health and social service systems awash in red ink. It doesn’t have to be this way.

Our understanding of the nature of the crisis in dementia care emerged in 2007 from the initial investigation of dementia by the Behavioral Health Access Workgroup, a subcommittee of the Long Term Care Coordinating Council (LTCCC). This investigation, and the Workgroup’s subsequent findings and recommendations to the LTCCC, including the recommendation that the Mayor’s Office “establish a Dementia Care Task Force to evaluate service needs and make recommendations...”
for how to address the demand for additional services”, provided a great amount of information and formed the foundation for this more detailed investigation.

*Living with Dignity (LWD) Strategic Plan, 2009-2013.* This strategic plan examined current long term care services, and the need for program development and policy reform to better meet the needs of older adults and adults with disabilities suffering from chronic illnesses and chronic conditions. During the strategic planning process, as a result of the initial investigation into dementia referenced above, the LTCCC identified a critical need to focus on the unique issues of people with dementia, and their caregivers, and the services available to address those needs.

*San Francisco Baby Boomers – A Breed Apart?* This study, released in July 2008, conducted on behalf of the Department of Aging and Adult Services (DAAS), projected a growing baby boomer population bubble about to explode in San Francisco. It is now expected this population will be creating an ever larger aging population at significant risk of developing dementia.

The baby boomer study used data from the July 2007 State Department of Finance projections, which estimate that the population of “older old” seniors in San Francisco (age 85+) is projected to nearly double by 2030. The report estimates:

- By 2020, the projected number of San Franciscans with dementia will increase by approximately 36% or 7,000 people, with roughly 5,000 of these being over 85 and most likely to be suffering from advanced dementia, requiring more services, supports and institutional care.

- By 2030, the aging baby boomers in San Francisco will swell the population age 65 to 85 from 13 to 18%, as compared to 2000 Census figures. Specifically, the population of “older old” seniors in San Francisco (age 85+) is projected to nearly double by 2030.

Given that prevalence data projects more than 50% of people over 85 are likely to have some form of dementia, these projections indicate a significant and growing demand is developing for more extensive services and supports. When dementia prevalence projections are applied to this population increase, it is evident a growing number of San Franciscans will need a range of services and supports either because they are cognitively impaired or are caring for a loved one who is.

Collectively, these documents raised concerns that a human and fiscal crisis of staggering proportion related to dementia care is imminent. Accordingly, in June 2008, the Mayor provided funding to DAAS to support the formation of an Alzheimer’s/Dementia Expert Panel. The charge for this Panel was to evaluate current dementia care services, assess the need for additional services, investigate national and international research and best practice models, and develop a plan and recommendations to address the need for services during the next 11 years (to 2020), including an analysis of projected costs.

Many of the recommendations found in this plan are not expensive and are possible even today. However, some of the recommendations proposed may be quite costly and will require policy changes, changes in funding regulations (waivers), and/or significant investments that may not be realistic today. Even for the long-term recommendations, if they are to be implemented, there is groundwork to be done in the next few years.
I.B. THE PLANNING PROCESS

The Department of Aging and Adult Services (DAAS) led and managed this planning process. In December 2008, DAAS convened the Alzheimer’s/Dementia Expert Panel appointed by Mayor Newsom, comprised of Alzheimer’s experts, aging experts, medical providers, community-based service providers, advocates, researchers, economic experts, public agency administrators, and family caregivers. The diversity of the Panel ensured varied perspectives were incorporated throughout deliberations. San Francisco is blessed with an extraordinary level of local dementia-related expertise respected throughout the nation, with experts in research, policy, public administration and service provision, which has been a great benefit to the planning process and the resulting plan.

The Expert Panel created four subcommittees where more substantive discussion of a wide range of issues could occur, with the subcommittees reporting their findings back to the full Panel. The four subcommittees included:

- **Evidence Based Practice & Emerging Research**, which reviewed findings from the most recent research regarding dementia, including: (1) evidence-based best practices for: dementia care services, treatment, and prevention; (2) the role of the family and the larger community; (3) strategies to provide caregivers with support; (4) protective factors and prevention strategies; and (5) promising practices and emerging trends. This involved a national and international literature review. See key findings from the literature review on page 36 and the comprehensive research summary in Appendix I.

- **Services & Systems**, which enumerated San Francisco’s existing dementia care services and supports (for mild, moderate and advanced levels). The subcommittee considered additional services needed to care for adults with dementia. Categories of services enumerated include: (1) adult day services; (2) advocacy and protection; (3) care management; (4) caregiver services and supports; (5) diagnostic assessment; (6) education; (7) information and referral; (8) in home supportive services; (9) legal services; (10) mental health services; (11) money management services; (12) nursing care and hospital services; (13) ongoing medical treatment; (14) public policy; (15) research and development; (16) residential care; and (17) respite care. See discussion of services and supports on page 41 and the full list of services and supports in Appendix II.

- **Finance**, which examined the cost of operations of the current network of dementia care services and supports. It considered the costs to: (1) expand existing services; and (2) implement new initiatives and services currently not in place. It then projected these costs forward 10-12 years to anticipate how the costs might change to meet the needs of the expanding population. The subcommittee also identified a range of funding resources that could be accessed to support the recommended model system of dementia care services. See discussion of the costs of dementia care on page 28 and additional detailed financial information in Appendix IV.

- **Education & Prevention**, which developed a range effective educational programs for community members regarding dementia. Protective factors including brain fitness and risk factors, early identification and early access to services were evaluated. Nine content areas were identified to be part of a comprehensive education and prevention effort. Many content areas are intended to address issues related to stigma regarding dementia. The subcommittee also addressed the need for educating professionals (e.g. doctors, psychiatrists, social workers, nurses, caregivers-paid and family), and others who find themselves dealing with those who should be providing more in terms of care. See a summary of education and prevention recommendations on page 50 and the considerably detailed findings and recommendations in Appendix III.
Each of the subcommittees met between five to seven times, with each producing a summary of its deliberations and reporting to the Expert Panel during the seven-month process. The Expert Panel met six times, reviewing the work products of the four subcommittees and incorporating them into the components of this plan and recommendations.

Earlier, in September 2008, DAAS retained a research team consisting of: (1) Gibson & Associates, (2) Resource Development Associates, and (3) the Mental Health Association of San Francisco. This team worked with the Expert Panel and DAAS staff to research best practice models for dementia care, undertake an evaluation of the City’s dementia care services, explore the need to improve existing services, and prepare a plan and recommendations to address the demand for services during the next 10 years (2010 to 2020). Specifically, the research team:

- Facilitated all Expert Panel meetings;
- Supported the work of all subcommittees;
- Compiled a review of the literature, identifying evidence-based research, promising practices, and emerging trends, for each type of dementia-related service, and facilitated the Evidence-Based-Practice and Emerging Research Subcommittee's consideration of these findings;
- Conducted 42 key informant interviews with policy-makers representatives of public and private agencies and more than 25 caregivers and caregiver organizations. Through this work, and the work of the Services & Systems Subcommittee, assisted in the development of a comprehensive inventory of current services and supports for each stage dementia;
- Analyzed a variety of statistical models for capturing current costs and projecting future costs of caring for individuals with dementia; and
- Prepared the initial draft of this report, in collaboration with DAAS staff.

Over the seven month planning process, the Expert Panel discussed the strengths and weaknesses of the current service delivery network, identified principles and concepts that should characterize how San Francisco addresses the crisis in dementia care, and

- Developed a mission statement and vision statement, and a list of core values that are to guide implementation of the plan;
- Reviewed the summary of the research developed by the research team and vetted by the Evidence-Based Practice & Emerging Research Subcommittee;
- Evaluated an analysis of current costs for services and projected costs as the population of older adults grows over the next 20 years completed by the Finance Subcommittee;
- Learned from the Services & Systems Subcommittee about its summary of the current available dementia services and supports;
- Reviewed the report from the Education & Prevention Subcommittee with recommendations for extensive training and education; and
- Made program and policy recommendations to improve dementia care services and develop new services as necessary.

DAAS staff and the research team used notes from all Expert Panel and subcommittee meetings to generate a preliminary list of 25 recommendations that was considered and revised by the Expert Panel in April 2009. Subsequently, 12 additional recommendations were proposed as a result of the
Expert Panel breaking into small groups in May 2009, with all but one being advanced to this report. Once the recommendations were approved, DAAS staff and the research team worked collaboratively in developing the initial draft of *San Francisco’s Strategy For Excellence in Dementia Care*, identifying models cited in the literature review, considering necessary implementation steps, and proposing partners and resources necessary to implementing each recommendation.

Following the completion of the Expert Panel’s deliberations in May 2009, the recommendations were presented at an Alzheimer’s/Dementia Summit, held in City Hall in July 2009. This offered an opportunity for the community to learn about the crisis in dementia care and to provide additional input into the recommendations prior to the completion of the initial draft *Strategy*.

Subsequently, the initial draft *Strategy* was revised, edited, formatted, and completed by DAAS staff, with continuing participation from research team members. This draft was reviewed and edited by internal review team consisting of DAAS leadership and Expert Panel members: (1) Ruth Gay, Director of Public Policy and Advocacy, Alzheimer’s Association of Northern California and Northern Nevada; and (2) Adam Boxer, MD, PhD, Alzheimer’s Disease Researcher and Assistant Professor of Neurology, UCSF Memory and Aging Center, and UCSF Alzheimer’s Disease and Frontotemporal Dementia Clinical Trials Program. It was also examined by an external review team consisting of: (1) Andrew Scharlach, PhD, School of Social Welfare, UC Berkeley; and (2) Kristine Yaffe, MD, Chief of Geriatric Psychiatry and Director of the Memory Disorders Clinic at the San Francisco VA Medical Center. Input from the internal and external review teams was incorporated before the final version of *San Francisco’s Strategy for Excellence in Dementia Care* was published.

### I.C. MISSION, VALUES & VISION

**The Mission:**

The mission of this *Strategy* is to improve the quality of life for people with Alzheimer’s disease and related dementias and for their caregivers, through an easily accessible, coordinated network of formal and informal, non-judgmental services and supports that will address the chronic care management needs of both older and younger individuals throughout the course of cognitive decline.

**The Values emphasize:**

- Services and supports that will be developed and delivered using a person-centered and family-centered approach, based on an assessment of the unique needs and preferences of the person and their loved ones, and that enable each of them to thrive.

- The importance of chronic care management, through home and community-based services as well as institutional services, that will offer a new framework for providing care and support for people with Alzheimer’s and related dementias.
That the most appropriate dementia care, services and support will be provided in the least restrictive and most integrated setting, depending on need and choice.

That people with dementia will remain integral members of their communities, as appropriate to their health and safety.

The importance of caregivers, both informal unpaid caregivers (family, partners, friends, neighbors, community members) and formal paid caregivers (homecare workers, home health care workers).

That dementia care today places an undue burden on women as informal unpaid caregivers. We value the lives and contributions of women beyond care giving and we seek to reduce this burden.

The need to ensure high quality, culturally and linguistically appropriate dementia care, services and support.

That Alzheimer’s and related dementias impact the whole person and their actual or chosen family. With this in mind, the physical, mental, and spiritual issues of persons with dementia and their caregivers need to be attended.

The Vision:

Our vision is to create a better-coordinated, more integrated network of services and supports that will enable people with mild cognitive impairment (MCI), Alzheimer’s and other dementias, and their loved ones, to flourish throughout the progression of these disorders. San Francisco will develop and promote an integrated model of dementia care, in which the needs of people with dementia and their caregivers will be addressed within the full range of medical, health, social, and caregiver needs of all older adults and adults with disabilities.

Services and support for people with MCI, Alzheimer’s and other dementias, and for their caregivers, will be integrated into San Francisco’s existing long-term care service delivery network, which includes a range of home, community-based, and institutional services. Within this structure: (1) existing services will become dementia capable through education and training; (2) specific dementia care services will be expanded or developed as needed; (3) existing systems will provide services, care and support particularly for people with moderate and advanced dementia; and (4) new chronic care service delivery systems will be specifically designed and developed for older adults that will also address dementia care.

The community will be provided with training and education about dementia care resources, and about activities and other opportunities for risk reduction. The community will be well educated, sympathetic and supportive of people with Alzheimer’s disease and related dementias, and their caregivers. Information will be easily accessible in each neighborhood throughout the city.
This vision goes beyond providing what dementia care, services and supports that people with dementia and their caregivers need, to a broader, more fundamental issue: what people require for a good life. This includes: (1) the formation of personal and social support networks that promote the contributions of people with dementia, with the goal of strengthening our neighborhoods and communities; and (2) the creation of age- and disability-friendly communities that offer accessible and affordable housing, improved public safety, improved access to parks and recreation, and opportunities to be meaningfully engaged in the community.
Key Concepts

Chronic Care Management:
A central concept throughout the *Strategy* is a commitment to a shift in how dementia services are delivered, moving toward the development of a strengthened capacity to serve individuals in the community and relying less on institutionalization. Chronic care management is an approach to community-based care that captures this approach.

Widespread recognition of the need for ongoing chronic care management through home and community-based services is relatively new in the long term care arena. As older adults and adults with disabilities are living longer with functional impairments and chronic illnesses, they increasingly prefer to receive services in a community setting rather than an institutional setting. The evolving approach to chronic care management across the country, which relies substantially on community-based services and less on institutionalization, offers a new framework for thinking about how to provide services to people with chronic conditions.

The Community-Based Long Term Care Report of 1998 identified chronic illness as “an illness or disability that persists for a long time, whether or not it causes death.” Furthermore, they are “ongoing and not amenable to cure. They may range from mild to manageable to severe (potentially life threatening) physical or mental conditions. However, chronic conditions are changeable, so prevention of actual episodes and maintenance of functional ability are the primary goals. Those who may need help range from young spinal cord injury survivors to older adults with Alzheimer’s disease.”

System versus Network:
In early meetings, the Expert Panel members considered the merits of working toward a system of services versus a network of services regarding Alzheimer’s/dementia care. A system is all-inclusive and can accommodate the needs of the individual or other entity in some facet at various levels of service. All users are served through connectiveness of these levels of service. Systems are often closed to outside input to their structure with the exception of laws, regulations and government constraints. A network is a relationship between individual service providers and systems that serves a common group or classification of individuals. Each has its own structure, standards of practice and operational modality. The network communicates on the common ground between each of its members. The network serves to be a communication link between entities that expand the knowledge base of all groups connected thus the effectiveness of each separate party. The connectiveness of all the participants makes the whole a stronger entity. The network can advocate for the needs of the classifications it represents.

The final decision was that a network structure is the better choice for Alzheimer’s/dementia care in San Francisco. The Expert Panel believes it provides options for more creativity and enables building on existing strengths. It can be tailored to neighborhoods, diverse geographies, and differing populations. Furthermore, systems can operate within a network. Accordingly, dementia care services and supports in San Francisco either already are or will become an integrated part of the larger long term care service delivery network.
II. THE NATURE OF THE CRISIS – A DEMOGRAPHIC AND FISCAL IMPERATIVE TO ACT

There is no cure available for Alzheimer’s disease and other forms of dementia nor is one expected in the near future. Only a limited number of interventions are available to delay the onset of dementia, leading us to focus on methods to slow the progression of the disease, avoid preventable co-morbid conditions or at least treat them more effectively. This section describes the demographic and fiscal crisis that looms in San Francisco. It provides background information about mild cognitive impairment (MCI), Alzheimer’s disease and other forms of dementia, including descriptions of various stages of impairment. It then describes San Francisco’s unique demographic risk factors as they relate to the dementia crisis. Finally, it provides projections of dementia-related population growth and of associated local costs of care.

II.A. BACKGROUND ON DEMENTIA

Throughout this plan we refer to dementia, MCI, and the various stages of Alzheimer’s disease, and also make periodic reference to other forms of dementia. It is important to define these terms so the reader is able to understand how dementia develops and the various forms it can take.

Dementia is an acquired, persistent, intellectual impairment involving multiple cognitive domains, such as:

- memory, usually the ability to remember events, facts, people or locations that were experienced recently;
- executive function, which includes the ability to think abstractly, make sound judgments and plan and carry out complex tasks;
- language, such as the ability to generate coherent speech or understand spoken or written language;
- visuospatial function, or the ability to recognize or identify objects, people or places or to navigate through well known locations; and
- behavior, such as lack of motivation, depression, hallucinations, delusions or personality changes.

Impairments in these cognitive abilities must be severe enough to cause a decline in an individual’s day to day function, such as performing duties necessary for work, household chores or even self-care. Dementia can be caused by a variety of diseases and conditions that result in dysfunction and damage to brain cells.

Alzheimer's disease is the most common form of dementia, accounting for approximately 59 - 75% of all cases. It is a progressive and fatal brain disease. As many as 5.3 million Americans are living with Alzheimer’s disease. Alzheimer's destroys brain cells, causing problems with memory, thinking and behavior severe enough to affect work, lifelong hobbies or social life. There are medical treatments and other interventions that benefit people with Alzheimer’s disease. However, inevitably, Alzheimer’s gets worse over time, and is fatal. Today it is the sixth-leading cause of death in the United States.

There are many other causes of dementia other than Alzheimer’s. These include the following:
Vascular dementia (also known as multi-infarct dementia) is the second most common form of dementia; individuals often experience sudden deterioration, which may progress over time.

Parkinson's disease and related disorders, in which individuals develop severe problems of movement and balance, sometimes including cognitive and behavioral impairments.

Huntington's disease, a hereditary disease often appearing in early adulthood, passed on from parent to child, the symptoms of which include quick jerky movements of the face, limbs, and trunk, cognitive and psychiatric impairments.

Dementias associated with physical disorders such as diabetes, thyroid disease, brain tumors, or Acquired Immune Deficiency Syndrome (AIDS).

Dementias related to alcohol or substance abuse; these may be a combination of direct chemical damage to the brain combined with nutritional or vitamin deficiencies.

Although advancing age is recognized as the strongest risk factor for developing dementia, Early (Younger) Onset forms of dementia are increasingly being recognized and can be particularly devastating as they affect individuals at the height of their careers or when they have caregiving responsibilities for young children or elderly parents. The term younger-onset refers to dementia that occurs in a person who is under age 65 when symptoms begin. People who have younger-onset dementia may be in any stage of dementia – early, middle or late. Experts estimate approximately 500,000 Americans in their 30s, 40s and 50s have Alzheimer's disease or another dementia. In this age group, a different dementia called frontotemporal dementia is as common as Alzheimer's.

All forms of dementia advance in stages. While the exact progression and symptoms vary depending upon the form of dementia, the stages are generally characterized as moving from very early (or MCI) to mild to moderate to advanced or late stages.

Mild Cognitive Impairment (MCI) is a less severe, or very early stage of illnesses which can cause dementia. Individuals with MCI have an acquired intellectual impairment that is NOT sufficient to cause a decline in function, for which an individual can compensate. Some people with MCI go on to develop dementia, but many do not. Because some causes of dementia are reversible, MCI represents a window of opportunity during which interventions that stall or prevent the onset dementia may be initiated.

A person with MCI may have problems with memory, language or another essential cognitive function that are severe enough to be noticeable to others and show up on tests, but not severe enough to interfere with daily life. A common form of MCI is characterized by short-term memory problems, but few other symptoms of dementia (e.g., problems with language, judgment, changes in personality or behavior) that impair a person’s daily functioning.

Stages of dementia. Experts have documented common patterns of symptom progression that occur in many people with Alzheimer's disease and have developed several methods of “staging” based on these patterns. Staging provide a useful frame of reference for understanding how the disease may unfold and for making future plans. But it is important to be aware that not everyone will experience the same symptoms or progress at the same rate. People with Alzheimer's die an average of four to six years after diagnosis, but the duration of the disease can vary from three to 20 years.
People with non-Alzheimer’s dementias will progress differently and may not adhere to stages in the same way as people with Alzheimer’s might. However, all dementia diseases are progressive and people will continue to be impacted by the disease, even though they may transiently stabilize in the course of any of these diseases. It is hoped that with the development of new treatments, some of the symptoms, or even progression of the disease may be altered or arrested.

The stages below apply specifically to what is recognized for people with Alzheimer's disease.

**Early Stage:** Early-stage is the part of Alzheimer’s when problems with memory, thinking and concentration may begin to appear in a doctor’s interview or medical tests. People in the early-stage typically need assistance with simple daily routines. At the time of a diagnosis, an individual is not necessarily in the early stage of the disease; he or she may have progressed beyond the early stage.

**Moderate or mid-stage Alzheimer's:** Gaps in memory and thinking are noticeable, and individuals begin to need help with day-to-day activities. At this stage, those with Alzheimer’s may be unable to recall their own address or phone number or the high school or college from which they graduated; become confused about where they are or what day it is; have trouble with less challenging mental arithmetic; need help choosing proper clothing; still remember significant details about themselves and their family and still require no assistance eating or using the toilet.

**Moderately severe Alzheimer's:** Memory continues to worsen, personality changes may take place and individuals need significant help with daily activities. The person may: lose awareness of recent experiences as well as their surroundings; remember their own name but have difficulty with their personal history; distinguish familiar and unfamiliar faces but have trouble remembering the name of a spouse or caregiver; need help dressing properly; experience major changes in their sleep patterns; need help handling details of the toilet; have increasingly frequent trouble controlling their bladder or bowels; experience major personality and behavioral changes, including suspiciousness and delusions or compulsive, repetitive behavior; and tend to wander or become lost.

**Severe, or late-stage Alzheimer's:** In the final stage of this disease, individuals lose the ability to respond to the environment, to carry on a conversation and, eventually, to control movement. At this stage, individuals need help with much of their daily personal care, including eating or using the toilet. They may also lose the ability to smile, to sit without support and to hold their heads up. Reflexes become abnormal, muscles grow rigid and swallowing is impaired.

**II.B. SAN FRANCISCO’S DEMOGRAPHIC FACTORS**

Developing a plan to serve people with dementia and their caregivers must be founded on an understanding of the characteristics of the community. The *Strategy for Excellence in Dementia Care* calls for a variety of community-based services, structures to support caregivers, and community education. Each of these must be designed to be responsive to the unique character and the variety of cultures that define the City. As such, a brief analysis of the City’s demographics is presented.

**Age.** Age is the strongest risk factor for the development of dementia. More than any factor, age also drives the emerging crisis in dementia care. San Francisco has a reputation for being a young and vibrant city, but in reality has one of the lowest proportions of children of any city in the country. San Francisco is increasingly becoming a city of senior citizens as baby boomers become seniors and the exorbitant cost of living drives young families out of the city in search of affordable housing. Seniors make up a higher proportion of the city’s population (17.6% at the time of the 2000 Census) than they do statewide or nationally (14% and 16.5%, respectively).
As they age, current projections indicate that San Francisco’s baby boomers\(^1\) will cause a significant increase in the senior population that mirrors a national trend. Growth projections from the California Department of Finance estimate that the aging of the baby boomers will swell San Francisco’s population age 65 to 85 from 13 to 18% by 2030 as compared to 2000. The population of “older old” seniors in San Francisco (age 85+) is projected to nearly double in the same time frame. This dramatic increase in the older population is projected to increase the number of San Franciscans who have dementia by 77% between the year 2000 and 2030, taxing an already over-extended network of providers.\(^2\)

**High Cost of Living.** San Francisco is among the wealthiest and most highly educated cities in the United States, but wealth and educational attainment are not evenly distributed throughout the community. San Francisco is also among the most expensive cities in the United States in which to live. According to the 2006 ACCRA Cost of Living Index, San Francisco is the second most expensive urban area in the nation, and has the country’s second highest median housing prices. The high cost of living exacerbates the added significant costs of dementia care for poor and even moderate income San Franciscans.

**Poverty.** In 1999, 11.3% of the City’s residents had incomes below the poverty line. Furthermore, the California Health Interview Survey reported that 20.4% of San Francisco adult respondents indicated that they are

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\(^1\) “Baby boomers” are the generation of adults born between 1945 and 1964.
\(^2\) This projection applies age-based Alzheimer's Association prevalence rates for Alzheimer’s disease to California Department of Finance population projections for San Francisco. A detailed table showing those projections can be found on page 31 of this report.
“not able to afford enough food.” Consequently, over 200,000 San Franciscans experience food insecurity, and many are burdened with having to prioritize even their most basic needs, at times forced to choose between satisfying one basic need at the expense of another. For individuals with dementia, poverty forces choices between paying rent, taking prescribed medications, or paying for needed in-home assistance. This struggle is especially prevalent in San Francisco’s communities of color: the income of white San Franciscans is more than twice as high as that of Hispanic/Latino or African American San Franciscans. For five San Francisco neighborhoods the proportion of low-income households is at least 51%: Bayview Hunters Point, Chinatown, South of Market, Tenderloin and Western Addition.

Vulnerability is not limited to those living in poverty. Many middle class individuals who are not eligible for Medi-Cal and are uninsured (or underinsured) with respect to long term care find themselves with fewer resources than do those living in poverty who qualify for Medi-Cal. A common misconception is that middle class San Franciscans are often “house rich and cash poor.” However, only 55% of senior-headed households and 38% of baby boomer-headed households owned their homes at the time of the 2000 Census. These home ownership rates are significantly lower than the national averages, 78% and 70%, respectively.

**Diversity & Neighborhoods.** One of San Francisco’s greatest attributes is its diversity, but neighborhoods are quite strictly divided along socioeconomic, racial, and cultural lines. San Francisco’s white, minority, and immigrant populations occupy distinct and separate neighborhoods. For six of these neighborhoods (Bayview Hunters Point, Chinatown, Excelsior, Oceanview Merced Ingleside, Portola and Visitacion Valley), the minority percentage is greater than 75%.

**Linguistic & Cultural Isolation.** Fully 36.8% of San Franciscans were born in another country compared with 26% for the state and 11% for the United States. This percentage is highest among San Francisco’s oldest residents. Only 58.2% of foreign-born residents speak English (CA = 62% and US = 81%) with 22% of San Franciscans speaking an Asian-Pacific Islander language and 10% speaking Spanish. This creates a demographic imperative to ensure that dementia-related outreach, education, services and supports are culturally and linguistically responsive.
Educational Attainment. Educationally, San Francisco has nearly twice the proportion of its population that has achieved a bachelor’s degree (45.2%) as compared to national rates (24.4%), but this educational level is not evenly distributed through the community. Some neighborhoods have very high percentages of residents with less than a high school diploma e.g. Chinatown (63.5%), Bayview Hunter’s Point (36.6%), Visitacion Valley (41.5%) and Excelsior (33.1%). These communities are also communities with high proportions of Asian, Latino and African American populations. The low level of educational attainment is particularly prominent among these populations and especially prominent in Chinatown and Excelsior among Chinese seniors who were born outside the United States.

Higher levels of education are associated with lower risk of dementia, particularly Alzheimer’s. However, once Alzheimer’s develops, individuals with higher levels of education tend to decline more rapidly. More highly educated individuals are more likely to be aware of the signs of dementia and the importance of seeking early diagnosis and treatment. Outreach, education, services and supports for individuals with dementia and their caregivers will need to be attentive to the educational levels of the populations being served.

Household Composition. Fewer than one in four seniors in San Francisco (compared to 40% in other cities) have an adult child living within 20 minutes travel-time, a figure likely to worsen in the years to come. San Francisco’s population currently has a significantly higher proportion of single person senior-headed households (40%) as compared to the statewide rate (33%). San Francisco’s Strategy for Excellence in Dementia Care must consider strategies that compensate for: (1) the absence of informal caregivers within close proximity, and (2) isolation of seniors that may result in later identification of the early signs of dementia.

Homelessness. “San Francisco has the worst, most visible expression of homelessness in our country,” according to Phillip Mangano, the Director of the Federal Interagency Council on Homelessness. In 2004, San Francisco was estimated to have 3,000 chronically homeless persons. New York City, nine times larger, had just 2,700. A 2006 University of California study showed that the median age of the homeless population in San Francisco and other cities is growing, along with the number of years the homeless have been on the street. The 2009 Homeless Count survey found that 28% of homeless persons were age 51 or older (24% were age 51-60, 4% were 61 and older). Experts believe that around 70% of homeless people abuse drugs or alcohol and 30 to 40% are mentally ill. For those who may also be experiencing the early stages of dementia, there is a risk that service providers and the public will misinterpret behavior and miss the opportunity to offer appropriate services and supports. They may struggle to access services depending on whether their primary diagnosis is dementia or mental illness, and finding housing with supports for the full constellation of challenges they face may prove very difficult.

Caregivers. Informal caregivers supporting family members or friends with dementia represent a final consumer population with respect to support services. While caregiving has its satisfactions, for many, the burden of care is substantial. Caregiving poses physical, emotional, and economic challenges. Traditionally, most caregivers have been the wives or adult daughters of the individual with dementia; 75% of caregivers are women. This imposes a disproportionate level of stress, both emotionally and economically, on a particular segment of the community.
Many caregivers are themselves elderly. Of those caring for someone aged 65 or older, the average age of caregivers is 63 years old with one-third of these in fair to poor health. Compared to other caregivers, those who care for people with severe memory problems are more likely to: experience financial hardship, report health difficulties, experience emotional stress, and suffer from sleep disturbances. The needs of caregivers are often overlooked by the health system. Health providers often fail to provide education and support to caregivers and to assess the caregiver’s capacity to provide sustained support to the individual with dementia.

II.C. PROJECTIONS OF POPULATION GROWTH & COSTS OF DEMENTIA CARE

The Expert Panel undertook a number of research activities to achieve a better understanding of the fiscal impact of the crisis in dementia care. This section presents:

1. The panel’s baseline analysis of current City funding for seniors with dementia;
2. Projections of the growth of the population of San Francisco residents with Alzheimer’s and related dementias in order to provide a sense of scale for the likely future growth in demand for services; and
3. Findings from a comprehensive study and analysis of the total costs of services for individuals with Alzheimer’s and other forms of dementia.

The costs of formal care and the value of informal care are projected to increase by 79 percent and 77 percent respectively between 2008 and 2020. Meanwhile, the Expert Panel’s analysis of city spending suggests the current General Fund (GF) burden related to seniors with Alzheimer’s disease and other dementias is already approximately $52.3 million. This research suggests that there is a strong fiscal incentive to facilitate early intervention, especially education and support for caregivers, in order to reduce the amount of time individuals spend in higher, more costly levels of care.³

Analysis of Current City Funding for Seniors with Alzheimer’s and Related Dementias

Table I, on the next page, presents the total public cost of services for San Francisco’s current senior population and an estimate of the proportion of those services devoted to individuals with dementia. For each city program, the table shows: the total budget regardless of participant age; the amount of

³ Mittelman MS; Ferris SH; Shulman E; Steinberg G; Levin B. "A family intervention to delay nursing home placement of patients with Alzheimer disease. A randomized controlled trial [see comments]". JAMA. 1996; 276: 1725.
funding coming from San Francisco’s General Fund (GF); the approximate amount of GF dollars estimated to be spent on individuals with dementia at different ages based on population size and Alzheimer’s prevalence rates; and the total estimated GF cost for individuals with dementia, $52.3 million.

These estimates suggest that nearly 60% of all GF dollars spent on seniors age 65 and older in San Francisco support individuals with Alzheimer's or related dementias. However, few of these services are delivered to individuals because they have dementia. Many are entitlement programs that individuals would receive or be eligible for simply because they are older and living in poverty. If dementia were cured tomorrow, some of these costs would not change. This being the case, these figures provide a baseline context and sense of scale for the city resources currently dedicated to this population.
Table I: Estimated City Support for Seniors Aged 65+ Across City Departments and Programs

<table>
<thead>
<tr>
<th>Dept</th>
<th>Programs</th>
<th>Total FY 0809 Original Budget</th>
<th>Total FY 0809 Local GF Original Budget</th>
<th>Total of senior (65+) funding Local GF only</th>
<th>$$$ funding Seniors aged 65-74 with Alz &amp; other dementias (estimate)</th>
<th>$$$ funding Seniors aged 75-84 with Alz &amp; other dementias (estimate)</th>
<th>$$$ funding Seniors aged 85+ with Alz &amp; other dementias (estimate)</th>
<th>Total of Estimated Support for Alz &amp; other forms of Dementia</th>
</tr>
</thead>
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<td>DAAS</td>
<td>In-Home Supportive Services</td>
<td>$120,233,501</td>
<td>$71,400,000</td>
<td>$51,765,000</td>
<td>$411,325</td>
<td>$6,332,982</td>
<td>$13,148,539</td>
<td>$13,892,846</td>
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<td></td>
<td>Adult Protective Services</td>
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<td>$2,394,977</td>
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<td>$26,897</td>
<td>$50,321</td>
<td>$506,237</td>
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<td></td>
<td>Office on Aging</td>
<td>$22,730,759</td>
<td>$15,911,531</td>
<td>$13,365,686</td>
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<td>$1,356,844</td>
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<td>$3,411,337</td>
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<td>Community Living Fund</td>
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<td>$4,000,000</td>
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<td>$379,934</td>
<td>$491,622</td>
<td>$904,721</td>
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<td><strong>DAAS Subtotal</strong></td>
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<td><strong>18,715,141</strong></td>
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<td>DPH</td>
<td>Community Health - AIDS - Prevention</td>
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<td>$55,587,423</td>
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<td>$303,858</td>
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<td></td>
<td>Direct Access to Housing - Leases and Operating subsidies</td>
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<td>$12,729,012</td>
<td>$1,909,352</td>
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<td>$497,004</td>
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<td>$1,647,962</td>
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<td>Primary Care / Ambulatory Care / Health Centers</td>
<td>$56,366,081</td>
<td>$47,615,807</td>
<td>$4,571,117</td>
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<td>$2,630,221</td>
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<td>Community Behavioral Health Services</td>
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<td>$55,581,144</td>
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<td>Laguna Honda Locked Units</td>
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<td>$20,670,000</td>
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<tr>
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<td>SF General Hospital - Inpatient</td>
<td>$4,500,000</td>
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<td></td>
<td></td>
<td></td>
<td>$800,000</td>
</tr>
<tr>
<td></td>
<td>SF General Hospital - Outpatient</td>
<td>$144,000</td>
<td>$44,000</td>
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<td></td>
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<td>$44,000</td>
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<tr>
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<td><strong>DPH Subtotal</strong></td>
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<td><strong>31,952,587</strong></td>
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<td>DHS</td>
<td>Homeless Program - Ramen Hotel (Seniors Only)</td>
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<td>$739,750</td>
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<td>$7,706</td>
<td>$21,677</td>
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<td>Single Adult Shelters</td>
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<td>$9,723,224</td>
<td>$414,209.34</td>
<td>$20,656</td>
<td>$2,554</td>
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<td>$23,209</td>
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<tr>
<td></td>
<td>Public Assistance / CAAP</td>
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<td>$50,100,000</td>
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<td>$770</td>
<td>$5,595</td>
<td>$2,854</td>
<td>$9,219</td>
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<td><strong>DHS Subtotal</strong></td>
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<td></td>
<td><strong>68,427</strong></td>
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<tr>
<td>MUNI</td>
<td>Paratransit Program</td>
<td>$20,000,000</td>
<td>$13,100,000</td>
<td>0</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>$1,572,000</td>
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<tr>
<td></td>
<td><strong>Grand Total</strong></td>
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<td></td>
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<td><strong>52,305,155</strong></td>
</tr>
</tbody>
</table>

Notes:
1 - These figures are from FY 07/08. Estimates are based on the program population with a primary diagnosis of dementia. Age break-downs were not provided.
2 - Data from March 2008.
3 - Data from May 2009.
Projections for the Growth in the Population of Seniors with Alzheimer’s and Other Dementias

The first step toward understanding the projected growth in costs associated with dementia care is to consider the projected growth in the population of individuals with Alzheimer’s and other dementias. The aging of the ‘baby boomer’ generation will vastly increase the number of seniors at high risk of developing dementia.

“Baby boomers” are adults born between 1945 and 1964, making them age 35 to 54 at the time of the 2000 Census. As they age, current projections indicate that San Francisco’s baby boomers will cause a significant increase in the senior population that will mirror the national trend. Growth projections from the California Department of Finance estimate that the aging of the baby boomers between 2000 and 2030 will swell the population age 65 to 85 from 13 to 18 percent of the total population in San Francisco. Furthermore, the population of “older old” seniors in San Francisco (age 85+) is projected to nearly double by 2030.

The table below shows the projected growth in Alzheimer’s related dementias in San Francisco based on known prevalence rates by age group. From the 2000 Census baseline, these figures show a projected 36 percent increase in the population with Alzheimer’s related dementia by 2020, and 77 percent increase by 2030, fueled by the tremendous projected growth in the older old cohort. These figures do not include other dementias and cognitive impairment that are unrelated to Alzheimer’s.

<table>
<thead>
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<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>65 to 74</td>
<td>2.75%</td>
<td>53,857 (1,481)</td>
<td>52,070 (1,432)</td>
<td>55,762 (1,533)</td>
<td>81,725 (2,247)</td>
<td>88,239 (2,427)</td>
</tr>
<tr>
<td>75 to 84</td>
<td>26%</td>
<td>38,181 (9,927)</td>
<td>40,161 (10,442)</td>
<td>39,457 (10,259)</td>
<td>42,017 (10,924)</td>
<td>63,025 (16,387)</td>
</tr>
<tr>
<td>85+</td>
<td>57%</td>
<td>14,503 (8,267)</td>
<td>18,649 (10,630)</td>
<td>20,445 (11,653)</td>
<td>23,865 (13,603)</td>
<td>28,111 (16,023)</td>
</tr>
</tbody>
</table>

NOTE: The Alzheimer’s Association estimates that Alzheimer’s accounts for approximately 60% of all dementias. According to Dementia Estimates and Projections, a report by Access Economics, Alzheimer’s accounts for 59% of all dementias. For details of this report, see Appendix 1, page 11.

4 Alzheimer’s Association of Northern California and Northern Nevada.
5 2000 Census Data
6 2007 American Community Survey
7 2007 California Department of Finance Projections
8 2007 California Department of Finance Projections
9 2007 California Department of Finance Projections
Projections for the Growth in All Costs Related to Dementia Care: 2008-2030

To achieve a more complete understanding of the fiscal implications of the dementia care crisis across all funding sources, the Finance Subcommittee reviewed and adapted the results of a comprehensive study and analysis of the total costs of formal care and the value of informal care attributable to Alzheimer’s disease for persons living in the community as well as for persons living in institutions in the Bay Area. Data for the study were collected from non-institutionalized and institutionalized Alzheimer’s patients, their primary caregivers, and staff of the institutions in which institutionalized patients resided. A broad range of Alzheimer’s patients and their caregivers were included in the study, representing the largest primary data collection effort to date using a sample of persons with Alzheimer’s disease studied for cost implications. The study excluded costs associated with conditions other than Alzheimer’s disease -- primary caregivers determined whether a formal service or an aspect of informal care was required because of the patient’s demented condition.

The study estimated economic costs for both formal and informal care, which represent the value of resources used or forgone as a result of the disease.

Formal services refer to those rendered for a price in the traditional medical and social service marketplace, where dollars are explicitly exchanged for services. Formal services are financed primarily by individuals and their families; over 60 percent of the services provided to patients in either care setting were paid out of pocket. Included in formal care costs are expenditures for hospital and nursing home care, physician services, social services, medications, and other items or services used for the care of the person as a direct result of Alzheimer’s disease.

Informal services refer to services, care and support rendered outside those markets and for which providers are not reimbursed. As such, the value of informal services does not represent costs actually paid, but rather the value of the services performed. Informal care provided to the patient as a result of Alzheimer’s disease was valued using a replacement cost approach by imputing a market value for services performed; if unpaid caregivers were not available, caregiving services would probably be purchased from paid providers, or else people living with dementia in the community would be placed in institutions such as skilled nursing facilities. While caregivers’ indirect productivity losses were not estimated in the study, other studies have identified significant indirect productivity losses for both the individual with dementia and the informal caregiver. This suggests that the value of informal care reported here is an underestimate when productivity losses are taken into account. The inclusion of an accounting for the value of informal care is critical as a means for demonstrating the tremendous role that informal caregivers play in supporting individuals with Alzheimer’s disease and related dementias. While informal care contributes to the health

and well-being of individuals with dementia and is often considered to be rewarding for the caregiver, it is important to note here that the burden of providing informal care is significant, and falls disproportionately upon unpaid, female caregivers. It is worth noting that smaller family size, coupled with the increasing labor force participation by those who provide most of the care – women – will result in fewer available informal caregivers in the future, which will lead to more of these imputed costs becoming actual formal care expenditures.

For a more detailed discussion of the methodology of the study, see Appendix IV.

The Finance Subcommittee utilized California Department of Finance demographic projection data to calculate the number of San Francisco adults at ages 55 and older and then projected the number of those adults who would be at each stage of dementia using commonly accepted prevalence data. Table III summarizes these current and projected costs (for 2020 and 2030), broken down by the following categories:

1. Community settings, residential care settings, institutional settings and all settings;
2. Informal care costs, formal care costs and total care costs; and
3. Mild/moderate impairment and severe impairment cost differentials for community-residents with dementia.

To portray the fiscal realities more accurately, Table III (on the next page) includes calculations that account for the large number of San Franciscans living alone without a loved one nearby. These individuals are unlikely to receive significant informal caregiver support, but the subtotal for informal care costs are projected from estimates of the total San Francisco population projected to have dementia, regardless of whether or not they live alone. To avoid over-estimating the imputed cost of informal care by assuming that all individuals with dementia would receive this support, researchers created a “Living Alone Multiplier” (Column B) and subtracted the imputed cost for informal care that had been attributed to these isolated individuals who would likely not receive informal care. While this adjustment results in lower total costs as seen in column J, it should be seen as a shifting of cost from the informal care sector to the formal care sector, a transfer of burden unique to the City of San Francisco as a result of the higher proportion of older adults living alone. It should also be noted that the population size for people with dementia differs from the figures in Table II because Table III uses a methodology to estimate the number of people with all types of dementia, not just those with Alzheimer’s and related dementias.

Table III warrants discussion. In the most optimistic circumstances, the above analysis projects a near catastrophic increase in the cost for care for individuals with dementia. Current formal care costs in all settings are just over $920 million annually, but they are projected to increase to $1.65 billion by 2020 and to $2.8 billion by 2030, even excluding the imputed cost of informal care. While the vast majority of these costs are Medi-Cal reimbursed, the projected increase in costs is still staggering.
### Table III: Projections of Formal Costs of Care and the Value of Informal Care for People with Dementia in San Francisco 55+*

<table>
<thead>
<tr>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
<th>F</th>
<th>G</th>
<th>H</th>
<th>I</th>
<th>J</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Informal Care</td>
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<td>Formal Care</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td># of People</td>
<td></td>
<td>Cost per Person</td>
<td>Subtotal</td>
<td>Cost per Person</td>
<td>Subtotal</td>
<td>TOTAL COST</td>
</tr>
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</tr>
<tr>
<td>2008</td>
<td>Subtotal</td>
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<td></td>
<td>mild-mod impairment</td>
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<tr>
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<td></td>
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<td></td>
<td>severe impairment</td>
<td>5,606</td>
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<td>SF Living Alone Multiplier</td>
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<td>2,169</td>
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<td>Average Cost</td>
<td>2,169</td>
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<td>2020</td>
<td>Subtotal</td>
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<td>Institutional</td>
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<td>2008</td>
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<td>All Settings</td>
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<td>2008</td>
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<td>$1,111,951,401</td>
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<td>2030</td>
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<td>36,809</td>
<td></td>
<td></td>
<td></td>
<td>$3,387,541,511</td>
<td>$2,841,697,506</td>
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*Adjusted for SF Medical and General Annual Inflation.  
RCFE = Residential Care Facility for the Elderly
The primary drivers of costs in these projections are as follows:

1. **Increases in the total number of people with dementia.**
2. **Increases in the level of cognitive impairment while in community settings.** While living in the community, informal care represents the vast majority of the cost of care (this is an imputed cost since family members are not reimbursed for their care). Note that for individuals living in the community, the cost for formal care increases from just under $24,000 per individual while at the mild-moderate level of impairment and rises to just over $50,000 as the individual reaches severe impairment (Column H).

3. **Transitions from community to institutional settings.** As a person moves from the community to living in a Residential Care Facility for the Elderly (RCFE), the cost of formal care rises to over $47,000 and then to almost $120,000 upon a move to a nursing home or hospital.

4. **General inflation and high costs of formal care in San Francisco.** Costs of formal care (Columns H and I) are projected to increase from $923 million in 2008 to $1.655 billion in 2020, by over $700 million. They increase another $1.2 billion from 2020 to 2030, reaching a total of formal costs of over $2.8 billion. This is a projected increase of over 200 percent, compared to the 54 percent increase in the projected population of people with dementia.

This suggests that the most effective efforts to keep increasing costs in check will be those focused on delaying or preventing transitions from the community to institutional settings, as that is the factor that is most sensitive to local initiatives. Since institutional care costs are roughly $70,000 more per year than community or RCFE care for individuals with severe impairment, this translates into almost $6,000 per individual per month. Since in 2008 we estimate approximately 1,063 individuals will be institutionalized with dementia, for each month we delay institutionalization for that population San Francisco could save approximately $6.4 million ($6,000/mo X 1,063) in formal care costs. 11 Delaying institutionalization by six months could save almost $38 million. The success of this strategy will hinge upon ensuring that there is adequate availability of quality support for the individual and caregivers in the community, as the burden of support will shift to them.

Cost is not the only incentive for maintaining individuals in the community. The cost projections in Table III above assume that there are sufficient institutional beds available and preserved for people with dementia. However, San Francisco is losing these beds at an alarming rate. Due to inadequate reimbursement for long term care, nursing homes have been closing. No new nursing home facilities have opened in San Francisco in over 25 years. Laguna Honda Hospital (LHH), the city’s long term care facility, has reduced the number of its skilled beds from 1065 to 780 in anticipation of its move to the new LHH facility in 2010. Of the total of 780 beds, three floors of 60 residents each (or 180 beds) will be used for Alzheimer’s and dementia care. Thus, by the time the baby boomer bubble bursts onto the scene, the number of long term care beds will be insufficient to meet the demand. So, while projected cost savings are an important incentive for supporting caregivers and facilitating individuals remaining in the community as long as possible, a far greater incentive is that by 2020 there will not be enough institutional beds available to house the projected numbers of people who will need these beds.

11 Estimates of saving vary depending on whether diverted individuals reside at RCFEs or not.
III. IMPROVING THE SERVICE NETWORK

While researchers continue to work on a cure for dementia, or find ways to mediate or eliminate the worst symptoms, it is up to policy makers, administrators and practitioners to use the resources and knowledge available to preserve the quality of life of those with dementia, and to minimize the suffering and burden that dementia imposes on those afflicted and on caregivers. Research suggests that this approach is also fiscally sound as it often limits or delays the use of more costly services.

This section of the report begins by outlining what the Expert Panel discovered in its review of the literature and exploration of evidence-based research and promising practices. (For a more complete literature review, please see Appendix I.) It then provides a summary of the overarching assets and challenges for San Francisco’s service delivery network as it faces the crisis in dementia care. Finally, this section describes the key challenges for specific San Francisco service areas, as identified by the work of the Expert Panel.

III.A. LITERATURE REVIEW

From the start, the Expert Panel was committed to using research to inform the recommendations in its Strategy for Excellence in Dementia Care. To support that intent, the research team prepared a comprehensive review of the literature that captured: (1) the structures, principles and concepts that have been proven effective in caring for individuals with dementia; and (2) the specific programs, treatments, and models that are achieving their intended beneficial impacts. The Best Practice Summary that is found in Part Two of this Strategy, as Attachment I, was developed from an evaluation of over 160 documents, many of which were identified by the Expert Panel. A priority was given to documents published in 2003 or later. Research was reviewed from England, Scotland, Sweden, Australia, New Zealand, Korea, Canada, and the United States. The review included an examination of evidence-based approaches related to:

- Each component of care for those with cognitive impairments, e.g. diagnosis, pharmacological treatment, caregiver support, including education and prevention;
- How other public health and social welfare challenges have been addressed through the implementation of a ‘system of care’ approach that integrates and coordinates services and supports; and
- Dementia-focused capitated systems such as those in Canada, Australia, England and Scotland, as well as locally developed closed systems like On Lok’s PACE model.

Key Findings

Among the key findings identified in this literature review:

- Early identification of cognitive impairment can result in better planning among patient, caregiver and primary care physician;
- A range of pharmacological treatments, and home and community-based services, can slow the advance of cognitive impairment and significantly delay entry into institutional care;
• While there is increasing evidence that side effects of pharmacological interventions, particularly anti-psychotics, can complicate their effective use, an increasing amount is being learned about non-pharmacological treatments, which can slow the advance of cognitive impairment and address many co-morbid behavioral, and even physical health symptoms;

• Caregiver education and support can reduce stress on the caregiver, reduce morbidity for the caregiver, increase capacity to support the individual with cognitive impairment, reduce patient accidents and co-morbidity, and delay entry into institutional care;

• Environmental modifications (lights, signs, clear directions, alarms, and improvements that prevent falls or help with wandering) in the home and assisted living facilities, skilled nursing facilities and hospitals can reduce symptoms and slow the advance of cognitive impairment;

• Coordination of care between various agencies, programs, and systems can reduce stress for caregivers, facilitate transitions and discharges, reduce the impact of co-morbidity, and improve a range of outcomes for the patient with cognitive impairment and caregivers;

• Much is known about the effective treatment of dementia and related conditions. Routinely published guidelines describe protocols, interventions, and treatments that can slow the progression of dementia, better support caregivers, improve quality of life, and delay entry into higher levels of care. But these practices are inconsistently implemented. There is a critical need to develop consistent mechanisms for sharing the knowledge and practices found in these guidelines. Target audiences include primary care doctors, assisted living staff, adult day care center providers, family caregivers and others involved in the care and support of individuals with dementia and other cognitive impairments; and

• Within a service delivery network that effectively implements all of the above, a mutually reinforcing impact could be achieved that would significantly delay entry into skilled nursing and hospital care. This would shorten the length of time spent in these institutions, reduce stress and co-morbidity on caregivers, improve the quality of life of both the person with cognitive impairment and caregiver, and reduce public expenditures on institutional care.

The recommendations section of this Strategy makes frequent references to promising and evidence-based practices and literature findings. A complete summary of the literature review conducted can be found in Appendix I.
III.B. SAN FRANCISCO’S ASSETS AND CHALLENGES

The assets and challenges for San Francisco to improve and expand dementia care services that are summarized below reflect: (1) the key-informant interviews; (2) input obtained from all Expert Panel and Subcommittee meetings; (3) topics focused upon in research, data, and local, national and international reports; and most importantly, (4) the extensive knowledge and experience of the Expert Panel members themselves.

A variety of assets exist upon which to build the Strategy for Excellence in Dementia Care:

A long-standing commitment to addressing the needs of the under-served. San Francisco has a deep commitment to social justice and meeting the needs of its most vulnerable residents. No finer example can be found than the City’s response to the HIV/AIDS epidemic. Even more germane to this plan is Healthy San Francisco, San Francisco’s commitment to universal health care for residents under 65. But beyond these examples, San Francisco has historically pioneered policies that have addressed the needs of the under-served, protecting the rights of new immigrants, advancing the rights of the gay and lesbian community, and creating safety nets for its children. This ethos of commitment to doing whatever is necessary to help those in need is a solid foundation for this plan.

Strong leadership from the Office of the Mayor, the Department of Aging and Adult Services, and significant influence in the national political arena. Mayor Gavin Newsom has been a strong promoter of health care reform and advancing initiatives to support the under-served, with several of the initiatives mentioned above being developed under his leadership. Anne Hinton, DAAS Executive Director, has been a steadfast supporter of all efforts to improve dementia care services in order to provide assistance for people with dementia and for their caregivers. In Washington, San Francisco has its interests well represented by House Speaker Nancy Pelosi and two seasoned and influential California Senators, Dianne Feinstein and Barbara Boxer.

Models of Excellence and Research Expertise. San Francisco is fortunate to be the home of one of the most highly regarded research institutes in the nation, the University of California at San Francisco (UCSF). Neurologists and other specialists from UCSF are in the forefront of dementia research. The San Francisco Bay Area is also home to the nationally prominent Family Caregiver Alliance and the Alzheimer’s Association of Northern California and Northern Nevada, two of the most important advocacy and service providers in relation to Alzheimer’s and related dementias. Finally, San Francisco is home to a vital service provider community, offering some programs recognized nationally as models or best practices, such as On Lok’s PACE (Program of All Inclusive Care for the Elderly) program and the assisted living facilities and services provided by Age Song.

Multiple points of access to care. San Francisco has an extensive array of public and non-profit primary care health centers and community clinics. These health centers and clinics are located throughout the City, providing accessible, high quality, culturally responsive primary medical care. There is an equally strong network of adult day health care and social day care centers, as well as Alzheimer’s day care resource centers, which serve as access points for dementia services. San Francisco also has a wide range of community-based service providers, many of which are able to help link clients to various services they might need. Finally, there is the DAAS Integrated Intake Unit, which is the centralized access point in San Francisco for a range of information, referral and assistance services, as well as the enrollment point for: (1) In-Home Supportive Services, (2) Adult Protective Services, (3) Home Delivered Meals, and (4) the Community Living Fund.
A history of collaboration. San Francisco is accustomed to working through highly collaborative processes that seek ways to integrate resources, develop common goals, and advance excellence in practice. Partnerships between and among the public and private sector are the rule, not the exception. For example, DAAS, under the leadership of Executive Director Anne Hinton, has been on the forefront of advancing collaborative strategies for better meeting the needs for long term services and support for older adults and adults with disabilities through the implementation of the Living with Dignity Strategic Plan and the work of the Long-Term Care Coordinating Council.

A number of challenges need to be confronted to achieve the Strategy for Excellence in Dementia Care:

A common theme identified through key informant interviews, and the review of the literature, is: the greatest challenge historically has been the failure to develop a way to ensure that at every stage of dementia, in every component of care, we employ what is known to be the best practice. While guidelines exist, and the research points specifically to effective interventions and practices, too often these guidelines are not implemented. Opportunities are missed to slow the progression of the disease, avoid a preventable and debilitating co-morbid condition, or provide caregivers the respite and support they need. This is true in San Francisco and across the country.

Silos (separate organizational structures). Although San Francisco has multiple points of access to services, it is often a challenge to navigate the existing service network, including the variety of housing and residential services. To a significant degree, services function in silos that are more organization- or program-focused than person-focused. Caregivers commented and Expert Panel members affirmed that caregivers are often confused as to where they can get services and information, and that transitions between programs, and across systems, are often difficult. These silos are made more insulated by the absence of a common digital medical record that allows service providers throughout the city to more easily share information and coordinate care.

Inconsistent practice. Standards and guidelines have been developed by a number of sources, including an excellent set of guidelines for care developed by the Alzheimer’s Association. These summarize the most appropriate services, assessments, supports, educational information, and residential and home-based care options for every stage of the disease. However, as mentioned under Key Findings, the research review identified many studies indicating that adherence to standards and guidelines is inconsistent in relation to almost every aspect of dementia care. On the local level, Expert Panel members commented that inconsistent care is commonplace in relation to screening, assessment and diagnosis, referral to community-based care, and pharmacological interventions. Inconsistent implementation of guidelines can have significant negative impacts, greatly increasing costs and creating unnecessary human suffering as will be described in more detail in Section II.

Absence of coordinated or integrated care or care management functions. While access to primary care and adult day care was identified as a strength upon which to build, once individuals access care, they face a dizzying range of choices and the need to navigate multiple services and systems with different eligibility criteria, understand coverage limitations, and arrange multiple appointments and services. For people with dementia who have no informal support, the task will quickly become impossible. For those with involved loved ones, their burden will quickly become immense.

12 California Guideline for Alzheimer’s Disease Management, 2008, See Appendix VI.
**State and federal regulatory and financing barriers.** Medicare and Medi-Cal financing regulations make it difficult to deliver comprehensive care in a manner consistent with best practice. Numerous examples will be cited below, but to cite just two: Medicare does not cover ongoing dementia care, only acute and post acute care, and Medi-Cal does not sufficiently cover community-based care, so many people with dementia get placed in institutional settings prematurely.

**General absence of understanding of the needs of individuals with early memory loss.** The absence of understanding of early memory loss conditions extends through virtually every aspect of San Francisco life. Most generally, there is a lack of awareness of the symptoms and signs of mild cognitive impairment and the tremendous benefit of early detection and treatment. Among professions that most commonly might interact with individuals with mild cognitive impairment and early stage dementia and identify a problem, there is also lack of knowledge of the signs or of how one would most appropriately connect the individual with services, supports or an assessment. The research describes that even health professionals fail to identify dementia when treating other conditions even in the face of clear indication of confusion, forgetfulness or other symptoms.

**Stigma and discrimination.** Stigma, ignorance, fear and denial all conspire to prevent individuals with mild cognitive impairment and early stage dementia from accessing early treatment that can delay disease progression. Insurance coverage policies that can exclude individuals with a diagnosis of dementia from eligibility for coverage contribute to individuals delaying being assessed. Stigma and fear of how others will view a person with a cognitive impairment or dementia diagnosis causes many individuals to resist being assessed. Together these factors block many individuals from accessing treatment that could postpone the advance of the disease and prevent important treatment planning while individuals are still cognitively capable of making informed choices for themselves.

**Informal care relies upon the availability of largely uncompensated care provided by loved ones.** While living in the community, people with dementia require increasing levels of support that in the early stages could be limited to periodic check-ins and monitoring by phone. However, as the disease progresses, daily support from informal caregivers, and eventually around the clock support, are necessary to ensure safety, adhere to medication regimens, maintain a healthy diet, prevent wandering, and provide help with daily routines and functions. Additionally, informal caregivers must manage finances, negotiate health services and medical appointments, and also care for their own needs. Too often it this last item that gets most neglected. It is estimated that for each year of providing care for a loved one with dementia the informal caregiver’s life expectancy is reduced by one year. Research indicates that 75 % of informal caregivers are women. From a social justice perspective, this can be viewed as another example of gender inequity with largely unpaid female caregivers subsidizing the health care system.

**The absence of loved ones nearby will necessitate the provision of paid in-home support or premature institutionalization, either of which would impose significant additional costs for caring for individuals with dementia.** From a health planning perspective, the reliance on
informal caregivers poses a significant challenge in San Francisco, as the demographics summarized earlier project that approximately 40% of seniors do not have a family member living within a 20 minute drive of the City. The Finance Subcommittee developed a cost projection model to estimate the value of informal care provided by loved ones. Using this model, it projected that in 2008 the annual cost of informal care and support for San Franciscans living with individuals with dementia exceeded $1.1 billion (see Section II.C. of this report for the details of this analysis).

III.C. EXISTING SERVICES AND SUPPORTS: KEY CHALLENGES

The Services & Systems Subcommittee developed a comprehensive inventory of the current array of services and supports for people with dementia at each phase of the disease (see Appendix II). It identified all programs in the service areas listed below, categorizing each program by populations served (mild, moderate, or advanced) and by fee structure (entitlement, means-tested, or fee for service). The chart [on the next page] depicts this array of services and supports, which can be accessed by people with cognitive impairment and dementia, and their caregivers.

Nearly all service categories have at least one program serving people at all three stages of dementia (mild, moderate, advanced), with only a few exceptions: Mental Health services and In Home Supportive Services are not available for people with advanced dementia; respite care is not available for those with mild dementia; and nursing care and hospitals are not available for those with mild or moderate dementia.

San Francisco has myriad individual programs and facilities that provide excellent care to individuals with dementia and their caregivers. However, the network is not without its limitations. For example, there is no component of service with the capacity required to fully address the future demand as projected in Section II.C of this report.

The next page provides a visual depiction of dementia care services now in place in San Francisco. The table that follows provides a summary of the key challenges associated with specific service areas, as identified by the Expert Panel, key informant interviews, and a review of local reports. The recommendations for the Strategy for Excellence in Dementia Care respond to many of the challenges highlighted here. Key challenges associated with education and prevention are also included in the table, but a more comprehensive set of findings, recommendations, and curriculum proposals are located in Appendix III.

The extensive array of dementia care and caregiver services and supports has been listed in the following service categories:

- Adult Day Centers
- Advocacy and Protection
- Care Management
- Caregiver Services and Supports
- Diagnostic Assessment
- Education
- Information and Referral
- In Home Supportive Services
- Legal Services
- Mental Health Services
- Money Management
- Multipurpose Senior Centers
- Nursing Care and Hospitals
- Ongoing Medical Treatment
- Public Policy
- Research and Development
- Residential Care
- Respite Care
- Other Services

13 Service areas are only included in the table below when a variety of key challenges specific to that area were identified.
SAN FRANCISCO’S STRATEGY FOR EXCELLENCE IN DEMENTIA CARE

WHAT WE HAVE:
Dementia Care Services and Supports
Now in Place in San Francisco

Department of Aging and Adult Services (DAAS)

Caregivers

Person with Dementia

Information, Referral & Assistance
DAAS Integrated Intake Unit

- Adult Day Centers
- Advocacy & Protection
- Caregiver Services & Support
- Respite Care
- Nursing Facilities
- Nursing Services
- Residential Care Facilities
- Residential Care Services
- Multi-Purpose Senior Centers
- Aging & Disability Resource Centers
- Community Services
- Care Management
- Diagnostic & Assessment Services
- Education
- Money Management
- Mental Health Services
- Legal Services
- In Home Supportive Services
- Physician Services
- Ongoing Medical Treatment
- Hospital Services
- Research & Development
- End of Life Care
- Public Policy
<table>
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<tr>
<th>Service Area</th>
<th>Key Challenges</th>
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| Adult Day Centers  
(Social Day Programs, Adult Day Health Care Services and Programs, and Alzheimer’s Day Care Resource Centers) |  - Funding is limited, and heavily dependent on state and local budgets. Social Day Programs are not Medi-Cal funded, and Medi-Cal reimbursements do not cover the entire cost of Adult Day Health Care services.  
- Staffing ratios vary depending on funding sources, ranging from 1:5 to 1:35.  
- Communication with primary care physicians for shared treatment plans can be challenging.  
- Waiting lists are between three months and one year long. Access issues exist for: (1) *individuals with traumatic brain injury, co-morbid psychiatric conditions, and aggressive behavior*; (2) *middle-income individuals* who are ineligible for Medi-Cal but cannot afford to pay out of pocket; and (3) *younger adults with disabilities* who delay seeking services because they feel out of place at programs that serve mostly seniors.  
- Informal settings such as adult day centers, are not always appropriate for the needs of individuals at all stages of dementia, especially advanced dementia. |
| Care Management |  - An overall shortage of care managers forces crisis workers to step in (e.g., Adult Protective Services and the Long Term Care Ombudsman), often without reimbursement.  
- Professionals and the public often don’t know that services are available, so even those with resources are not necessarily connected to services. Those living alone are even less likely to seek services as their disease progresses.  
- Communication challenges include:  
  - A lack of cross-agency communication mechanisms often leaves confusion about which agency is taking the lead in coordinating services.  
  - Providers lack mechanisms for information-sharing (e.g., dementia-specific roundtables); many would benefit from an electronic clearinghouse with service listings and resources on current best practices.  
  - Communication between providers is hindered by a lack of comprehensive integrated electronic client records and lack of knowledge about HIPAA (Health Information Portability and Accountability Act) and other privacy regulations. |
| Caregiver Services and Supports |  - Caregivers do not receive information about available supports at the time of diagnosis, leaving them isolated and without support.  
- Many caregivers are uneducated about the value of seeking support; the feel guilty about asking for professional help.  
- There is a shortage of providers with linguistic capacity and culturally-specific caregiver training.  
- Caregiver assessment is not a universal practice. |
<table>
<thead>
<tr>
<th>Diagnostic Assessment</th>
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<tr>
<td>▪ San Francisco has no system of clinical standards, guidelines, or universal assessments and diagnostic tools.</td>
</tr>
<tr>
<td>▪ Wait lists for diagnostic assessments are long, and those without caregiver advocate can miss out.</td>
</tr>
<tr>
<td>▪ There is a shortage of resources for follow-up visits.</td>
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<tr>
<td>▪ There is a shortage of psychiatric services for diagnosing co-occurring and pre-morbid psychiatric disorders.</td>
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<tr>
<td>▪ Cultural and linguistic barriers impede the effective administration of diagnostic assessment: validated assessment tools may not be useful for all language and ethnic groups; geriatric psychologists do not usually speak languages other than English; Medi-Cal does not pay for interpreters; and caregivers do not always provide objective and accurate language interpretation.</td>
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<tr>
<td>▪ Medi-Cal reimbursements for diagnosis are too low, and there are no reimbursements for computer-based testing tools.</td>
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<th>Education and Prevention</th>
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<tr>
<td>▪ Primary care physicians, first responders, housing providers, and other providers need training to make services “dementia friendly” and to ensure that they can identify people with cognitive impairment and refer to appropriate services.</td>
</tr>
<tr>
<td>▪ There is no clear set of standards upon which provider training should be based.</td>
</tr>
<tr>
<td>▪ There are cost and logistical challenges in releasing parts of the workforce from work shifts or requiring staff to give up free time to attend training during off-work hours.</td>
</tr>
<tr>
<td>▪ Caregivers often receive either too little information or referrals at the time of diagnosis or so much that they become overwhelmed.</td>
</tr>
<tr>
<td>▪ San Francisco has no unified and coordinated approach to community-wide education. Such an approach would need to counter stigma, be culturally competent for ethnic and Lesbian, Gay, Bisexual, and Transgender (LGBT) communities, be responsive to different levels of health literacy, and be available in a variety of formats to maximize accessibility.</td>
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<thead>
<tr>
<th>Information and Referral</th>
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<td>▪ Call lines are short staffed and cannot respond to all inquiries, and it is difficult to recruit clinically-trained people to phone jobs.</td>
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<tr>
<td>▪ Lack of communication between Information &amp; Referral providers results in conflicting information and/or duplication of services.</td>
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<tr>
<td>▪ Follow-up is inconsistent.</td>
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</table>
| In Home Supportive Services (IHSS) | - There are few affordable services for people with limited budgets who do not qualify for In Home Supportive Services.
- Family members sometimes resist turning care over to someone else, either due to a sense of duty or fear of bringing a stranger into the home.
- IHSS providers lack training in identifying signs and symptoms of dementia. |
| Nursing Care and Hospitals | - There is a shortage of skilled nursing facilities (SNFs), particularly those with specialized Alzheimer’s units that accept Medi-Cal.
- No new SNF facility has been built in San Francisco in the last 25 years, and decreasing Medi-Cal reimbursements make it difficult to do so.
- Few beds are available for those who do not qualify for Med-Cal but cannot afford to pay out-of-pocket.
- Families face stigma when placing loved ones in SNFs.
- Sub-populations with co-occurring conditions are often underserved in SNFs (e.g., individuals needing psychiatric services; those with traumatic brain injury).
- No facilities target the LGBT community, and language and ethnic groups are not fully served.
- Staff faces challenges in helping individuals and families articulate goals of care, particularly related to end-of-life care. There is a critical need for support in advance directive planning, especially as it related to the tendency of hospitals to push for life-extending interventions that do not contribute to quality of life.
- Determining whether someone with dementia is eligible for hospice care is challenging. |
| Ongoing Medical Treatment | - Barriers to accessing community clinics and/or specialty providers exist for: (1) at-risk populations such as those who are homeless, or who have conditions such as HIV/AIDS, substance abuse, and mental illness; (2) middle income people without Medi-Cal or private insurance; (3) people without family advocates; and (4) minority communities whose cultural traditions make them less likely to seek treatment.
- Services are organized based on the stages of Alzheimer’s and related dementias, with few methods or procedures in place to assist in transitioning patients as they progress.
- Low Medi-Cal reimbursements and little research funding creates a disincentive to provide dementia treatment and study geriatric medicine, leading to shortages of specialists.
- Specialists and primary care providers often do not address co-occurring dementia when treating other geriatric conditions, sometimes due to a lack of up-to-date information or training.
- People with dementia have a hard time accessing dental, vision, and hearing care. |
| Residential Care | - Low and middle-income individuals cannot access services when Residential Care Facilities for the Elderly (RCFEs) do not accept Medi-Cal or Medicare.
- Few RCFEs are dementia-friendly or dementia-capable, and even fewer can handle residents with severe behavioral challenges and/or violent behavior associated with dementia.
- Family members require emotional support during transitions to residential care.
- Lack of cultural sensitivity can result in cultural isolation for residents.
- Communication between residential care providers and hospitals is weak. |
IV. RECOMMENDATIONS FOR EXCELLENCE: IN THE SHORT TERM AND IN THE FUTURE

When the Expert Panel set out to develop recommendations to improve care for people with cognitive impairment, and their caregivers, it recognized the scope of the response must go beyond addressing the dementia-related needs for services. People with cognitive impairment - or dementia - are also subject to a range of physical and behavioral conditions requiring access to primary, behavioral and specialty care. Accordingly, the Expert Panel decided to develop a more integrated Strategy that addresses: (1) the behavioral, housing, social, primary care, and specialty care needs of each person in need of care; and (2) the services and supports required by informal caregivers, who provide the majority of care while a person is living in the community. Also, the Expert Panel understood the Strategy needed to include recommendations for improvements that could be achieved in the near future while providing longer-term recommendations for more substantial, far-reaching reforms that could require years of work to achieve.

The following objectives and recommendations achieve this balance. They are intended to address the growing crisis in dementia care in stages, from early memory loss, to the progression to mild, moderate, and advanced dementia. However, if San Francisco could: (1) help people learn about the initial signs of cognitive change; (2) provide increased resources and community-based services for those first experiencing memory loss and cognitive impairment; (3) offer training and support for caregivers and service providers; and (4) assist those experiencing dementia and their caregivers to manage symptoms and care issues in the early to moderate stages, the need for more intensive and costly services could be delayed. The progression of the disease cannot be halted at present. Accordingly, San Francisco should provide comprehensive, compassionate care for people and their care partners at each stage of the disease. Until there is a cure or treatment for cognitive decline, achieving these objectives and implementing these recommendations will allow us to: (1) support caregivers; and (2) better manage each individual’s complex medical conditions along with their dementia in a way that will improve quality of life.

OBJECTIVES

The objectives are:

1. Improve capacity to meet the needs of the whole person by delivering integrated care.
2. Improve public and professional awareness and understanding of dementia.
3. Develop an informed and effective workforce for people with dementia.
4. Expand capacity to deliver high-quality early diagnosis and intervention for all.
5. Ensure availability of high-quality, culturally responsive information for those diagnosed with dementia and their caregivers.
6. Create expanded and easy access to care, support and advice following diagnosis.
7. Implement a range of effective caregiver support strategies to better address the multiple needs of informal caregivers.
8. Improve the quality of hospital and nursing home care for people with dementia.
10. Improve the quality of services in residential care homes and expand the range of models of residential care for people with dementia.
11. Improve access to end of life care for people with dementia.
12. Advocate for effective state and national support for implementation of this Strategy, as well as other improvements for people with Alzheimer’s and related dementias, and their caregivers.
13. Foster policies and practices that create a community sensitive to the needs of individuals with memory loss.
14. Facilitate and support an Oversight Committee responsible for implementing this Strategy and advocating for the improvement of prevention, education, services and supports related to dementia.

**OBJECTIVE 1: Improve capacity to meet the needs of the whole person by delivering integrated care.**

To effectively address the whole person requires integrated care that spans disciplines, systems, and treatment sites, and eliminates silos or barriers to care. Integrated care strategies are becoming increasingly important to address the needs of the whole person through the seamless provision of health and social care. The effective treatment of cognitive impairment requires a broad array of services delivered by professionals, paraprofessionals, and informal caregivers, in the home, in the community, and in health care and assisted living settings. This care involves medical, mental health, housing and financial systems support. The effort to improve the effectiveness of this multi-faceted network has led to “investigation of whole system approaches to improve the manner in which sectors, institutions, providers and services work in tandem as a long-term care enterprise.”

Locally, efforts are being made to integrate services across silos (separate organizational structures) through increased collaboration, shared planning, and shared budgeting. The first seven of the recommendations in San Francisco’s Strategy (Recommendations 1.1-3.4) focus upon improving the capacity of the existing network and creating conditions that would foster more collaboration and service delivery informed by best practices, thereby facilitating the network’s ability to address the full scope of needs of people with dementia.

**RECOMMENDATION 1-1. Dementia care should be integrated into San Francisco’s existing long term care service delivery network for older adults and adults with disabilities, which emphasizes ongoing chronic care management. This will enable the needs of the whole person to be considered and addressed.**

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People with Alzheimer’s and related dementias often have other chronic illnesses and conditions. Integrating expanded and improved dementia care services into the long term care service delivery network will enable issues of co-morbidity to be addressed. It has been shown that the treatment of co-morbid medical conditions such as cardiovascular disease, infection, pulmonary disease, renal insufficiency, arthritis, and diminution of vision and hearing can improve functionality and cognition in persons with Alzheimer’s disease. Also, effective management of behavioral conditions associated with dementia is essential, as more often than not it is the inability to manage behavioral conditions that leads to placement in assisted living or nursing home care. Accordingly, integration would mean ensuring that all community-based long term care services as well as community clinics, health centers and nursing homes all are able to serve people with dementia.

RECOMMENDATION 1-2. All agencies and programs delivering services in the long-term care service delivery network as well as first responders and urgent care clinical settings should become dementia capable. This will require education, training, and support for service providers and families. Agencies and programs serving people with dementia will need to consider the stigma related to dementia, the concerns of existing clients, and the dignity of new clients experiencing cognitive impairment or dementia.

More older adults with cognitive impairment or dementia will be served by community-based programs such as senior centers, adult day health care centers, social day programs, congregate meal programs, specialized group programs, and residential care facilities. To enable these programs and services to address the needs of older adults with cognitive impairment or dementia, and to respond to them with dignity and respect, training to become dementia capable will be necessary. The Dementia Care Excellence Oversight Committee should convene a workgroup charged with identifying and prioritizing training needs and methods of delivery. Additional funding will be required for training.

Service providers in the long term care service delivery network should be educated and trained to address the full range of health, medical, social, and spiritual needs of people with Alzheimer’s and related dementias, as well as the needs of their caregiver (family and other informal support). Such education and training should be based on the work of the Education & Prevention Subcommittee, which are summarized in Recommendation 2-1, and provided in detail in Appendix III.

OBJECTIVE 2: Improve public and professional awareness and understanding of dementia.

In order to create a more dementia-friendly community, public and professional awareness and understanding of dementia must be improved and the stigma associated with it addressed. This public education campaign would be aimed at increasing awareness among all San Francisco residents thereby increasing understanding of the importance of seeking screening and assessments; increasing the capacity of individuals to identify signs of dementia and understand how to help individuals suspected of having dementia to access screening assessment and services; and to generally increase the level of acceptance of individuals with dementia throughout the city. In short, a public awareness campaign should contribute significantly to creating a ‘memory loss friendly’ community in which those with dementia and their caregivers can thrive.

RECOMMENDATION 2-1. Public education should be expanded and enriched and should target those experiencing memory loss and those newly diagnosed with Alzheimer’s and related dementias, and their caregivers, as well as service providers, care managers, and health care professionals. Funding should be sought and obtained to enable the provision of this expanded public education.

Public education about memory loss services and resources should be expanded. This should also address the stigma connected to Alzheimer’s and related dementias. Community-based education centers, which may include neighborhood public libraries, should offer periodic presentations about memory-loss issues and serve to build better understanding of dementia, greater compassion, and an increased ability to identify people who may have mild cognitive impairment (MCI).

Nine key content areas were identified by the Education and Prevention Subcommittee that should be part of a comprehensive education and prevention effort. Following are these content areas with the corresponding recommendations.

<table>
<thead>
<tr>
<th>Education and Prevention: Content Areas &amp; Recommendations:</th>
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<tr>
<td>- <strong>Risk Reduction</strong>: Promote cognitive health and create a culture of “brain fitness” through mental stimulation, social engagement, physical exercise, and diet.</td>
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<tr>
<td>- <strong>Early Identification of Alzheimer’s and Related Dementias</strong>: Educate people about the signs of dementia, how they differ from normal aging, and when and where to seek a diagnosis.</td>
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<td>- <strong>What To Expect as the Disease Progresses</strong>: Offer diagnosed individuals, caregivers, and health care providers information about what to expect throughout the course of Alzheimer’s and related disorders, which will help with future planning.</td>
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<td>- <strong>Services and Resources</strong>: Ensure that caregivers are aware of and have access to community resources, training and support.</td>
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<tr>
<td>- <strong>Caregiver Wellness and Support</strong>: Help caregivers understand the stresses inherent in caring for a person with dementia and provide resources for self-care.</td>
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<tr>
<td>- <strong>Disease Management for Mild, Moderate, &amp; Advanced Dementia, Including End-of-Life Issues</strong>: Effective management of early to moderate dementia can slow the advance of cognitive impairment, reduce the impact of co-morbidity, and delay entrance into institutional care. Informed medical management of late stage and end-of-life co-morbidities will decrease unnecessary treatment and ease the burden and suffering of the person with dementia and caregiver at the end of life.</td>
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<tr>
<td>- <strong>Advanced Care Planning</strong>: Advance care planning can help foster greater patient and caregiver understanding of the patient’s medical condition, promote more patient-centered care, and ensure that a person’s preferences are honored at the end of life.</td>
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<tr>
<td>- <strong>Ethical Issues</strong>: Create an ethics review committee/group to consult on difficult ethical situations involving persons with dementia.</td>
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<tr>
<td>- <strong>Emergency Preparedness and Safety</strong>: Promote awareness of steps to take to prepare for an emergency and to address common dangerous behaviors prevalent in persons with dementia so as to avoid catastrophic outcomes.</td>
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Public education should be viewed expansively and could include feature films, works of art, and other expressions of gifts, talents, strengths and creativity of people with Early Memory Loss (EML). This low-cost strategy is designed to build more memory loss friendly, elder compassionate communities. A variety of community-based EML educational programs should be implemented throughout the city. These programs can serve as a point of entry to supportive services for people with EML and their caregivers.

Services for people with EML, MCI, and early stage dementia are in short supply. Also, people with EML/MCI often miss opportunities for referrals to services that delay the advance of their condition and/or prevent or treat co-morbid conditions. In addition, educational presentations are one avenue for raising the awareness of individuals who come into contact with people with dementia, who could perhaps better facilitate identification and ultimately improve timely access to treatment. Another component of the educational campaign could target individuals who frequently are in a position to identify people with dementia who have not accessed services. Postal workers, paramedics, police, fire, and transportation staff should be educated about the warning signs, behaviors and needs of people with EML/MCI, increasing their ability to better serve these people and to help them access the network of services and supports available.

Public education and training could also target persons with EML/MCI; people with Alzheimer’s and related dementias; family caregivers, other family members, interested friends and neighbors; professional paid caregivers – including home care workers, assisted living staff, nursing home staff; physicians, health care providers and allied professions; Adult Protective Services staff; nutrition programs and meal site staff, first responders; and other community-based service providers.

See Appendix III for a comprehensive presentation of the Education and Prevention Subcommittee recommendations for the nine key content areas for education and prevention activities throughout San Francisco. This appendix includes proposed curricula, the types of media to effectively promote the recommended educational efforts, and target populations.

**OBJECTIVE 3: Develop an informed and effective workforce for people with dementia.**

The health and social services workforce involved in the care of people with dementia must be well trained so workers have the skills and knowledge of best practices to provide the best quality of care in the roles and settings where they work. To ensure an informed and effective workforce, basic training and continuous professional and vocational development in dementia is essential.

Existing research demonstrates that cost savings in the care of people with Alzheimer’s are potentially large. Data show that interventions leading to improvements in memory and physical functioning or delaying the rate of decline could lead to cost savings for both formal and informal care.18 But knowledge of these interventions and how to make referrals to them is not common. Even primary care doctors working with patients over 75 years of age with cognitive impairments rarely refer them for anything other than pharmacological interventions. In one chart review of 240 managed care patients, researchers found so few references for non-pharmacological care that they

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chose not even to report on this data.\textsuperscript{19} Failures to refer people with dementia for community treatment and support are missed opportunities. If properly referred, people with dementia and their caregivers could access effective treatments and supports thereby improving the quality of their life, reducing the burden on the caregiver and reducing public expenditures. Expert Panel members confirmed these missed opportunities are also commonplace in San Francisco. Primary care doctors have an immense challenge in being current on guidelines in many areas. Referral for community care is inconsistent, and even identifying the correct pharmacological treatment is not guaranteed.

Recommendations under Objective 3 are designed to: (1) increase the knowledge of current standards and guidelines as well as the effectiveness of service providers; and (2) ensure closer alignment between common practices and known best practices and treatment guidelines.

\textbf{RECOMMENDATION 3-1. The most current guidelines and standards for dementia treatment and care should be identified and compiled for dissemination to professionals on a regular basis.}

Providing health and social service professionals, including community-based service providers and care managers, with the most current dementia care guidelines and standards that inform their care practices for appropriate screening, diagnosis, treatment, disease management, and late stage care, will help to improve the dignity and quality of care, and help to reduce stigmas.

Recommendation 14-1 calls for the creation of a \textit{Dementia Care Excellence Oversight Committee} that will oversee and monitor implementation of this \textit{Strategy}. Some of its most important functions must be to: (1) ensure that guidelines are compiled, maintained, and kept current; (2) see that they are broadly disseminated; and (3) work with program administrators to foster adherence to these guidelines. At first, adherence to guidelines and standards may need to be voluntary, perhaps encouraged through some form of recognition or awards for agencies that implement them effectively. Over time, some standards could be incorporated into city contracts for services provided, thereby institutionalizing practices recommended in guidelines. However, there would need to be safeguards to ensure that mandated practices are current and represent the best understanding of effective practice.

The intent of this recommendation is not to develop new guidelines and standards, but to work with existing resources already identified in our research, and to assemble a set of guidelines and standards that can be distributed throughout the service network. However, even assembling a set of guidelines and standards will be no easy task. Appendix VIII includes a list of initial questions for guiding this process and detailed references for model guidelines and standards that can be used.

\textbf{RECOMMENDATION 3-2. Training for professionals, including community-based service providers and care managers, should be expanded to facilitate the use of the most current guidelines and standards for dementia care. As part of this recommendation, DAAS should seek and obtain funding to enable the provision of this expanded training.}

If professionals, including community-based service providers and care managers, are to meet current dementia care guidelines and standards, expanded training will be needed to boost the capacity and capability of staff working at all levels of care. Training and information should be

provided to nurses, caregivers (paid and unpaid), care managers, primary care physicians, and Adult Protective Services. Also, expanded training should be provided for staff at assisted living facilities and nursing homes. Funding will be needed for this expanded training.

This training could either consist of or be reinforced by a reader-friendly monthly e-memo about recommended standards of practice, guidelines and community resources as well as standards for training of all personnel serving older adults with chronic conditions including Alzheimer’s and related dementias. The monthly e-memo should be disseminated to all service providers and caregivers listed above.

**RECOMMENDATION 3-3.** Targeted training for primary care physicians, hospitalists, and the medical staff of primary care health centers and clinics operated by the Department of Public Health, the San Francisco Community Clinic Consortium, UCSF, and Kaiser Permanente should be expanded related to medication prescriptions, diagnosis, end-of-life care, and managing difficult behaviors and critical crisis care issues.

Training designed specifically for physicians, hospitalists, and other medical staff is needed to ensure medical conditions are properly diagnosed, medications are correctly used, and over-treatment is not employed to extend life against the wishes of the patient and/or caregiver. Consistent knowledge of the effective use of pharmacological and non-pharmacological interventions must be part of the training.

Expert Panel members also spoke often of poor diagnoses, mistaken pharmacological prescriptions, and unnecessary life-extending procedures that could be avoided with greater and broader understanding of best practices.

Recommendations 3-1, 3-2, and 3-3 are not without significant institutional and practical challenges. Expert Panel members noted:

- It is difficult to mandate training for staff as this requires: (1) releasing staff from shifts and replacing them with other staff; or (2) scheduling training for odd duty hours and paying staff to participate. Even then, in many cases, mandating participation under these conditions could be difficult.

- While the concept of email updates on guidelines and standards makes sense for most staff, there are a plethora of such email updates and simply reviewing them is a challenge, let alone ensuring that the relevant information is at hand when needed.

- The ever-evolving nature of our understanding not just of dementia, but of its interplay with other conditions both behavioral and physical, make it challenging to ensure that guidelines are current and that those for whom the guidelines apply are using the most current recommended practices. Advances in technology may make it possible in the future to make such guidelines immediately available through Blackberries or other hand-held devices, enabling physicians to quickly search for the most current recommended interventions.

**RECOMMENDATION 3-4.** An electronic medical record (using a “patient dashboard”) should be researched and developed for the use of health and social service staff which will: (1) enable cross-system information sharing; and (2) improve service coordination.
For services to be coordinated effectively, service providers must have access to a patient medical record across sites and systems within San Francisco’s service delivery network. This record must capture current information from the standardized assessment (above), subsequent service use, and changes in medical, health and social conditions as the patient advances.

**OBJECTIVE 4: Expand capacity to deliver high-quality early diagnosis and intervention for all.**

People with dementia should have access to a pathway of care that delivers: a rapid and competent assessment; and an accurate diagnosis, sensitively communicated to the person with dementia and their caregivers. Diagnosis should be followed as needed with referral for treatment, care and support. There is abundant research supporting the benefit of early identification for people with cognitive impairment, but research on systems and strategies for early identification was difficult to find. It is estimated that only between one-third to one-half of people with cognitive impairment ever receive a formal diagnosis\(^{20}\). Often, cognitive impairment is not diagnosed until a person is admitted for an acute physical illness, but even then a cognitive impairment diagnosis and referral may be missed as health professionals focus upon the immediate medical crisis.\(^{21}\)

Early identification of cognitive impairment allows for care management to be initiated with the potential for reducing costs associated with pneumonia, chronic skin ulcers, infection, depression, behavioral disturbances, hip fracture, malnutrition, dehydration, intestinal obstruction, lacerations, sprains, hypothermia and burns.\(^{22}\) Early identification also reduces costs for hospitalization, delays nursing home placement, and permits advance planning.\(^{23}\) Finally, fiscal projections related to early identification and early introduction of treatments suggest that an average delay of onset of one year could reduce the number of people with cognitive impairment nationally by 210,000 patients, creating an annual projected savings of $10 billion\(^{24}\).

San Francisco has an extraordinary level of expertise when it comes to diagnosis of dementia. Unfortunately, this expertise is hamstrung by a number of factors outlined under Challenges in Section III.B and addressed with the following recommendations.

**RECOMMENDATION 4-1. Diagnosis of mild cognitive impairment (MCI) should be encouraged and facilitated with clearly established diagnostic criteria.**

Every person who now has Alzheimer's or a related dementia at one time had MCI. With proper diagnostic criteria already established, and with specialized medical care, a meaningful MCI diagnosis can be made and should be evaluated regularly. These individuals, while not yet demented, still require care and support. Importantly, MCI represents a window of opportunity to evaluate for and treat reversible causes of cognitive impairment before an individual develops dementia.

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\(^{21}\) Holmes, J., *Research School of Medicine*, University of Leeds (1999)  
There is emerging consensus that, as we gain understanding of this disease, we will be identifying and treating people much earlier in disease progression. Most new treatments will be more effective if evaluation is done very early and identified at MCI or earlier, possibly before significant symptoms are evident, and when the individual can most benefit at the highest level of functioning. People with MCI are in a transitional medical state and may very well benefit from support and services offered to people with early stage dementia.

**RECOMMENDATION 4-2.** A standardized screening tool for chronic conditions and illnesses, which encompasses cognitive function, mood, activities of daily living, and caregiver or family observations, should be selected or developed. This should be used by health care professionals (primary care physicians, physician assistants, nurses, nurse practitioners, social workers and clinics) and psychologists, to assess the need for a comprehensive evaluation for adults with memory complaints or cognitive change, possibly including referral to a specialist for thorough diagnosis.

A standardized screening tool should relate to a number of chronic conditions and illnesses. If it is not workable to develop a comprehensive tool, efforts should be made to incorporate dementia categories into other screening tools. If the use of either screening tool demonstrates the need for a more comprehensive evaluation, and a more thorough diagnosis, it must be effectively and precisely done. This screening tool should also be made available for use to psychologists.

Screening should be done in part to avoid stigmatized and inappropriate responses to people based on unfounded assumptions. Stigmas associated with this disease must be avoided when no diagnosis has been made, but assumptions about that person impact actions for care.

**RECOMMENDATION 4-3.** A range of clinical geriatric fellowships should be developed at UCSF for physicians, nurses, and social workers training in geriatric practice, with fellows committing to a number of years working in community health services (primary care health centers and clinics operated by the Department of Public Health and the San Francisco Community Clinic Consortium), performing assessments, and managing the care of people with Alzheimer’s and related dementias.

The beneficial impact of the use of a screening tool will be mitigated if an appointment for an assessment is difficult to obtain. There is an inadequate number of centers of excellence for diagnosis and management of dementia in San Francisco. At present, long wait lists await a person...
seeking an assessment. UCSF can become a strengthened center of excellence with additional funding to support clinical dementia care and to train fellows to provide diagnosis, treatment and management. Such a workforce development initiative would benefit from the passage of Senator Boxer’s workforce development legislation that would provide loan forgiveness as incentives. These and other financial incentives should be made available to recruit culturally diverse fellows that mirror the City’s demographics.

UCSF dementia care fellowships should be offered for the following: geriatrician medical specialty, geriatric psychiatrist, behavioral neurologist, geriatric nurse practitioner and geriatric social work. Geriatric fellowships could also be developed at San Francisco State University for geriatric case/care managers and at San Francisco Community College for geriatric registered nurses. The development of these fellowships will require grant support as well as lobbying at each institution.

Such fellowships, paired with the fiscal policy recommendation (below), would increase the supply of qualified geriatricians and dementia experts available to diagnose and manage the care of the growing number of people destined to develop dementia.

**RECOMMENDATION 4-4. Barriers and financial disincentives in medical care should be removed that deter physicians from providing geriatric assessments, diagnoses, and ongoing care by increasing reimbursement rates for these services.**

It will be necessary to remove financial disincentives for doctors to become geriatricians. At present, reimbursement is insufficient so, even with loan forgiveness and fellowship incentives, doctors are not likely to enter the geriatric field. Reimbursement for geriatric assessments and ongoing care are lower than reimbursements for delivery of other services, creating a disincentive to enter geriatric medicine and an ongoing financial loss for programs offering geriatric care.

Changes in reimbursement rates, fellowships and recruitment efforts to expand the number of geriatricians practicing in San Francisco, and effective utilization of a standardized screening tool, would certainly expand access to high quality early diagnoses. However, if program admission policies and financial disincentives await people receiving an MCI or dementia diagnosis, this will inhibit people from seeking an assessment.

Advocacy must be undertaken to remove barriers and financial disincentives that deter doctors from becoming geriatricians and providing needed geriatric assessments, diagnoses, and ongoing care.

**RECOMMENDATION 4-5. Barriers and financial disincentives should be removed that limit access to services that are based on a single diagnosis.**

Improving access to services for people with dementia will help to reduce discrimination and will encourage service providers to become more dementia friendly and capable. This is necessary because people with multiple chronic care issues, one of which is dementia, may also need other services such as mental health services, adult day services, or assisted living.

Policies need to be promoted that will increase access to these services based on: (1) an individual’s capacity to thrive in that service or setting; and (2) an individual’s not being excluded solely on the basis of a dementia diagnosis. Clinicians in “medical homes” (public clinics and health centers) should be encouraged to screen for a mental health diagnosis such as depression and other affective
disorders as well as to screen for dementia. Having a mental health condition as the primary diagnosis could increase access to mental health services whereas having a dementia as the primary diagnosis could exclude people from eligibility for mental health services. City departments could also include anti-discrimination language in city-funded programs.

Advocacy must be undertaken to remove barriers and financial disincentives that limit access to services based on a single diagnosis.

**OBJECTIVE 5: Ensure availability of high-quality, culturally responsive information for those diagnosed with dementia and for their caregivers.**

People with dementia and their caregivers should be provided with good-quality information on this illness and on services available, at diagnosis and throughout the disease stages.

**RECOMMENDATION 5-1. To enable easy access to quality information, people with cognitive impairment and dementia as well as their caregivers will benefit from the professionally staffed “central door” of San Francisco’s “no wrong door” approach.**

The DAAS Integrated Intake Unit is already in place to assist people seeking information about home and community-based services in the network. This Unit is the “central door” to access services. It coordinates Information and Referral to the following services: Home-Delivered Meals, Adult Protective Services, In-Home Supportive Services, and the Community Living Fund. Through this Unit, people seeking services and caregivers have access to comprehensive information about available resources without needing to make multiple calls to a variety of programs. The DAAS Integrated Intake Unit staff will be trained about the range of memory loss and dementia care services and supports available, and about the most appropriate locations where services can be obtained. The advantage of an Intake Unit staffed with experienced and well-trained, professionals is that it will be adept at not just responding to the specific request of the individual or caregiver, but to understand the possible constellation of other needs that may underlie the request for a specific service and be able to suggest other services the caller may not have known about.

In the “no wrong door” approach, all service providers should be able to link clients who have dementia with other services. Accordingly, in addition to the “central door”, there should be multiple additional contact locations that will be able to provide information and linkage to appropriate services, including memory loss, mild cognitive impairment (MCI), and dementia care and support. All service providers will be trained to be sensitive to the needs of people with cognitive impairment. San Francisco is a diverse city and people access services in different ways. With training and education recommended in this *Strategy*, still more service providers serving different racial, ethnic, and cultural communities will become familiar with early stages of cognitive impairment and aware of the most appropriate referral
locations where services can be obtained. Part of the training that these agencies will receive will be information about how to utilize the DAAS Integrated Intake Unit.

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<th>OBJECTIVE 6: Create expanded and easy access to care, support and advice following diagnosis.</th>
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**Advice and Support.** A dementia adviser should be available to facilitate easy access to appropriate care, support and advice for those diagnosed with dementia and for their caregivers. Also, groups should be available to provide ongoing peer support that can provide practical and emotional assistance, as well as help to reduce isolation.

**Care Coordination.** Significant international research indicates that care coordination or care management is a cost-effective intervention that can delay institutionalization and improve the quality of life for both the patient and the caregiver. Primary care physicians often do not make referrals for community-based care due to lack of sufficient information about resources.\(^{25}\) There is also research that indicates that embedding care managers into primary care settings can ease the burden on the physician and ensure better use of community resources.\(^{26}\) Most current US dementia research focuses on pharmacological intervention or a basic search for a cure, and less on precisely how coordination of service delivery is best implemented.\(^ {27}\) Nonetheless, there is a significant body of research indicating that different models for embedding care managers, or a team approach to service delivery, can have significant positive impacts upon the individual and caregiver, and there is some evidence that such a model can also reduce public expenditures. See Appendix I, Section 4.C. Care Coordination, on pages 23 to 28, in the Evidence Based Practice Summary, for more information about this issue. Over a half dozen models of coordinated care are reviewed.

Three recommendations related to this objective follow. Their implementation would help increase the degree to which people with dementia and their caregivers experience the network of services as coordinated around their needs rather than organized around institutional needs.

**RECOMMENDATION 6-1.** A team approach to dementia care and service delivery should be piloted, employing care managers with dementia expertise operating as the “single-point-of-contact” for people with dementia using primary care health centers and clinics operated by the Department of Public Health, the San Francisco Community Clinic Consortium, UCSF, and Kaiser Permanente. This will result in a better informed and coordinated delivery of services.

A team approach would require that care managers with dementia expertise be affiliated with or co-located in clinics where people with dementia receive primary care. Clinic patients and their social and health information would be shared among agencies responsible for the delivery of services


\(^{27}\) Bullock, R., Iliife, S. and Passmore, P., Can We Afford Not to have Integrated Dementia Services?, Age and Ageing, June 11, 2007.
Implementing a “single point of contact” method would result in each person with dementia and their caregiver being assigned to a care coordinator. This professional would be responsible for supporting the person and caregiver as they move through the stages of the disease. Immediately after diagnosis, the care manager would meet with the person and caregiver to begin treatment planning and to provide the caregiver with resources and information. In some models, this individual also consults with the primary care physician and other medical/behavioral professionals to ensure that treatment referrals are consistent with current guidelines. The care coordinator becomes the team’s resident expert in services and support for dementia care. Members of the Expert Panel noted that to embed care coordinators in every primary care clinic would not be practical in the current fiscal crisis. However, it would be feasible to pilot this team approach in one or more clinics in a collaborative effort between the Department of Aging and Adult Services and the Department of Public Health (DPH). This team approach is consistent with the DPH concept of a primary care “medical home” for each person covered by Medi-Cal.

**RECOMMENDATION 6-2.** Structured peer or volunteer support and learning networks should be developed for people with dementia and their caregivers, especially in early and mid stages. The establishment and maintenance of such networks will provide direct informal support delivered by trained volunteers. These networks can also provide practical and emotional support, reduce social isolation, and promote self-care.

While people with dementia are living in the community, it is usually the case that family members provide almost 75% of services and supports. But, as noted earlier, as many as 40% of San Francisco’s baby boomers have no family member living within 20 minutes of the City. For this reason, it is important that San Francisco explore models for providing informal care that do not rely upon family members.

This effort to create peer support and learning networks focusing on dementia could expand on other innovative programs to provide what older adults and adults with disabilities of all ages require to thrive. Three existing local models each rely on the development of a network of volunteers who provide a range of services and supports. These models include: (1) the Community Living Campaign, which is helping older adults and persons with disabilities of all ages through the formation of personal and social support networks; (2) San Francisco Village, which is a membership program that provides the social, service, and support benefits of a retirement community without having to give up one’s independence and own home or apartment; and (3) openhouse, which through community organizing, is fostering the development of intentional lesbian, gay, bisexual and transgender senior communities throughout San Francisco so that members can support one another as they age.

Expert Panel members pointed out that, while there is a need for an alternative to family caregiver support, individuals with dementia may require far greater levels and kinds of support than the populations served in the above models. Any replication or expansion of existing local models would require significant study and probably modifications.
OBJECTIVE 7: Implement a range of effective caregiver support strategies to better address the multiple needs of informal caregivers.

Family caregivers are the most important resource for people with dementia. Active work is needed to ensure that services and supports are available for them. Caregivers have a right to an assessment of their needs. They can best be supported if a comprehensive assessment is used to identify the supports they require to perform the vital role they play in the care of the person with dementia.

RECOMMENDATION 7-1. Immediately upon a diagnosis of dementia being made, a practice should be established where doctors and their staff refer caregivers as well as family members to supports, such as education, counseling, caregiver assessment, and services.

Service referrals should be provided once a person is diagnosed with cognitive impairment or dementia, so caregivers can have immediate access to ongoing resources. The California Guideline for Alzheimer's Disease Management calls for a referral to the Alzheimer's Association and the Caregiver Resource Center in the community to provide assistance to families with resources and supports. In addition to immediate referral to services, following up with the diagnosed person and caregiver is important to ensure that community services and pharmacological treatments are accessed. These resources should include: a comprehensive assessment of their needs as caregivers; structured counseling and education programs and a range of educational materials; and a follow-up call shortly after the diagnosis is received, when additional service referrals can be made.

According to caregiver interviews and Expert Panel comments, people given a diagnosis of dementia are currently told to come back to see the physician in a year. Resources and referrals are rarely provided to them or their caregivers at the time of diagnosis. As noted earlier, immediately after a diagnosis a window exists to involve the individual in treatment planning, to educate and support the caregiver, and to access pharmacological and community treatments that can significantly impact the trajectory of the disease. For all these reasons, a concerted effort should be made to ensure that support and information are provided to caregivers and that a comprehensive voluntary caregiver assessment is offered and encouraged.

RECOMMENDATION 7-2. Additional respite care services should be developed for people with Alzheimer's and related dementias. Increased respite care should be part of the supports (that include education, counseling, assessment, and services) for caregivers and family members. Funding should be sought for additional respite care.

Respite care is defined as in-home respite and overnight respite. Adult day services and other community-based services such as homecare can also provide respite. Homecare can be provided overnight. Surveys of families have indicated that it is considered most desirable for someone to come into the home to provide respite, as this is less disruptive for the individual with dementia.
There are not enough respite care services and resources to meet the needs of San Franciscans and funding available for respite is limited. In the absence of sufficient respite support, loved ones caring for the person with dementia are more likely to develop their own physical health and behavioral health conditions and become unable to sustain sufficient care support to maintain the loved one in the community.

OBJECTIVE 8: Improve the quality of hospital and nursing home care for people with dementia.

Throughout this Strategy are recommendations to reduce or delay the use of hospital or nursing home care. This should not be understood to infer that hospitals and nursing homes are not valuable services, but that they should be preserved for the most appropriate use. According to interviews with stakeholders and Expert Panel member comments, too often hospitals and nursing homes become the easiest placement option when available community services and supports are not assembled to enable the person to remain in the community. However, there are times when a hospital or nursing home is the only safe, secure and appropriate placement for a person with dementia. In these instances, it is vital that a consistent high quality of care be provided.

Improving the quality of hospital and nursing home care for people with dementia should be done by defining improved dementia care practices and quality of care standards, establishing care pathways, and identifying dementia care leadership

RECOMMENDATION 8-1. A meeting of acute care hospitals should be convened to review all existing care plans for patients with any type of dementia, identify best practices for the care of hospitalized adults with dementia, and implement best practices to improve their care.

This recommendation is based on the innovative work being done by the Acute Care for Elders (ACE) Unit at San Francisco General Hospital. Lessons derived from this recommended meeting could be used as a basis for training staff in other hospitals in best practice dementia care. If such a meeting were convened annually, it would be a natural venue for providing an update on new guidelines for high quality hospital care. The confidentiality of client records should be maintained.

RECOMMENDATION 8-2. Nursing home placement should not only be for the purpose of safety and containment of dementia related behaviors, but also for person-centered care with an array of services that address all of the needs of the person and not solely the diagnosis of dementia.

Nursing homes can be the most appropriate setting, and the safest and wisest choice, for some adults with advanced dementia, and for their caregivers. Many persons with late stage dementia may require 24-hour skilled nursing care. This is due to the progression of the disease and the often associated diminished impulse control leading to aggressive behavior, the lack of insight and subsequent refusal to accept care with bowel and bladder hygiene or assistance in walking, eating and bathing. Also, older adults often have coexisting medical conditions that require continued professional care.
Successful placement in a nursing home should not be viewed as a matter of an available bed, but of a qualitative placement as envisioned in the recommendations above. There should be consistent assignment of caregivers, with dementia-related training, and with an enriched activity program that would mitigate against a sole reliance on medications for behavior control. Nursing homes should contain dementia friendly environments, with green space, and areas for mobility, if appropriate. In San Francisco, Laguna Honda Hospital and the Jewish Home are best-practice providers of skilled nursing care, including advanced dementia care.

Standards for nursing home quality should be met as defined in the Alzheimer’s Association’s, “Recommendations for Assisted Living and Nursing Homes” and in the Federal Nursing Home Regulations. Training for staff in these quality standards should be provided.

**OBJECTIVE 9: Expand and improve the quality of community-based care for people with dementia.**

**RECOMMENDATION 9-1. An expanded range of community-based services should be developed for people in the early stages of cognitive impairment or Alzheimer’s and related dementias, based upon evidence-based practice and emerging research.**

To expand the range of community-based services, there should be therapeutic interventions including creative expression, intergenerational programs, and pet therapy, to be made explicit in the appropriate services and settings, and in the appropriate manner. The beneficial impact of such therapeutic interventions is demonstrated in research. Also, additional grocery and meal delivery services, transportation services, money management, and legal and financial planning services are needed for people with Alzheimer’s and related dementias, and their caregivers. These services will assist people to remain living in the community and help to relieve stress on caregivers.

Research also shows that cost savings in Alzheimer’s care are potentially large. Data show interventions that lead to improvements in memory and physical functioning or that delay the rate of decline could lead to cost savings for both formal and informal care.28 But research into many community-based interventions is still emerging and there are few that have been rigorously evaluated. Many are more accurately characterized as promising practices. The Oversight Committee for this Strategy should serve as a clearinghouse that reviews recent research and recommends specific practices found to be particularly effective.

Some supportive services do not require research to verify their efficacy. A range of in-home supports such as meal delivery, as well transportation and legal and financial planning clearly are needed. While they do not necessarily delaying progression of the condition, they are essential to the quality of life and for the effective planning for dementia’s advance.

**RECOMMENDATION 9-2. The full range of adult day services (Adult Day Health Care, Social Day Care, and Alzheimer’s Day Care Resource Centers), appropriate for people at different stages of the disease, should be expanded and improved. Day care programs and staff should be informed, trained, and capable of addressing the needs of individuals with cognitive impairment or Alzheimer’s and related dementias and their caregivers.**

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Given the increasing structure, consistency, support, and personal assistance required by a person with cognitive impairment, and the increased burden placed upon caregivers to provide the vast majority of this support, adult day care provides one of the best settings for the mid-stage individual living in the community. As compared with non-users of adult day care, caregivers of individuals with cognitive impairment using adult day care experience have been shown to have:

- Fewer difficult-to-manage behaviors and less time spent managing symptoms;\(^{29}\)
- Fewer hours managing memory difficulties and less burden, strain, and worry;\(^{30}\)
- Fewer recreational restrictions and conflicts between care giving and other responsibilities;\(^{31}\)
- A better relationship with the patient;\(^ {32}\) and
- Lower levels of depression, anger and perceived overload.\(^ {33}\)

To achieve maximum caregiver benefits, people with cognitive impairment should attend adult day services at least twice a week for an extended period of at least three months. Particularly when initiated early, sustained use of adult day care generates benefits for the participant, delaying nursing home placement\(^ {34}\) and attenuating the cognitive decline associated with institutionalization.\(^ {35}\)

Adult day care services play a critical role in delaying the advance of dementia, supporting the needs of the caregiver, and delaying nursing home placement. For this reason, preserving all existing adult day care resources is essential. This will help to meet the growing demand from the baby boomer population. Also, expanding that base is going to be crucial: a much larger number of affordable, accessible adult day care services (Adult Day Health Care, Social Day Care, and Alzheimer’s Day Care Resource Centers) should be available. All levels and forms of day care should have the ability to be sensitive to and respond to individuals with Alzheimer’s and related dementias.


\(^{32}\) Dziegielewski, S. F., & Ricks, J. L. (2000). Adult day programs for elderly who are mentally impaired and the measurement of caregiver satisfaction. Activities, Adaptation & Aging, 24, 51-64.


\(^{34}\) Ibid

Following are some specific recommendations for the preservation and expansion of adult day services in San Francisco:

a. The Adult Day Health Care (ADHC) facility at Laguna Honda Hospital closed in February 2009. The license is not being used and: (1) could be used by the Department of Public Health (DPH); or (2) made available to another organization to develop an ADHC center.

   NOTE: A license is not transferable, but an ADHC business can be sold. A new owner would need to do a “Change in Ownership”.

b. The fee to maintain this license should be paid by DPH annually until the license is used for another ADHC program.

   NOTE: The ADHC license was suspended by LHH effective March 20, 2009. The license can be placed in suspension for one year. LHH initially paid the license renewal fees through November 15, 2009. LHH then renewed the ADHC license again in October 2009 for another year - until March 19, 2010.

c. A new ADHC or exiting ADHC(s) should consider a relationship with a Federally Qualified Health Center, which could result in additional funding for operations.

d. Additional Adult Day Programs (Social Day) should be developed. This program works well with people who have dementia. It is private pay and not covered by Medi-Cal.

e. The number of Alzheimer’s Day Care Resource Centers (ADCRCs) should be increased. ADCRCs benefit caregivers, families, and neighborhoods, and help people to remain in the community. ADCRC is a designation that demonstrates expertise in dementia care. This is a specialty at ADHCs or Social Day Care Programs. Funding for the support of ADCRC status may need to be obtained from sources other than the State of California.

It is important to be aware that adult day health care programs are now under a state moratorium. However, social day programs are not. ADCRCs must be licensed as either a social day program or an ADHC. See Section VI, page 92, for the impact of the State budget on each of these programs.

RECOMMENDATION 9-3. Services and supports should be developed for people with cognitive impairment or Alzheimer’s and related dementias who have no family, or who do not have family members living in close proximity to San Francisco.

San Francisco has a high percentage of older adults who live alone, many with no family. Also, given evidence that in San Francisco up to 40% of people with cognitive impairment will not have a family member within twenty minute drive of San Francisco, care and support predicated upon daily involvement from family members will be unresponsive to a significant proportion of our population.

A pilot project should be established to develop support options to address the needs of both the “un-befriended” population with no family involved as well as those elderly with family in the region, but not close enough to provide daily support. A workgroup will be needed to explore the development of this pilot project and other strategies such as those suggested in Recommendation 6-2 on page 59. People with cognitive impairment, or Alzheimer’s and related dementias, who have no other available daily support, should be red-flagged for care management. Without it they will almost certainly require premature institutionalization.
RECOMMENDATION 9-4. A crisis intervention and assessment setting should be developed for the placement of people with cognitive impairment or Alzheimer's and related dementias who are no longer safe in their own environments and/or who have behavioral issues.

Input from the Expert Panel, supported by findings in research, points to behavioral crises as being a major cause for placement of people with dementia in nursing homes and hospitals. Some of these placements may be premature and could be avoided with the implementation of this recommendation. The crisis intervention and assessment setting would be a place where people with dementia could be assessed for: physical, cognitive and other impairments; for wandering and agitation; or for other challenging behavioral issues that need 24-hour care. This setting could also provide assessment for other appropriate care settings.

RECOMMENDATION 9-5. Advocacy for changes in the mental health system should be undertaken at the local and state level to eliminate the carve-out of mental health services for people with a primary diagnosis of dementia. San Francisco’s mental health system and medical/health care system should be encouraged to collaborate more effectively in serving clients with both dementia and mental illness, or those with Alzheimer’s who develop mental health related conditions.

People with a primary diagnosis of dementia cannot now be served by the mental health system. Dementia is a medical diagnosis, not a mental health diagnosis. At the present time, there must be a specific primary mental health diagnosis for a person to be served in the mental health system.

RECOMMENDATION 9-6. A plan should be developed to provide and fund services, particularly respite care, for people with Alzheimer’s and related dementias who are above Medi-Cal eligibility. The needs of these individuals, who are often unable to get the services they require, should be addressed.

People living just above the poverty line can be hit hard by dementia because they are not able to qualify for Medi-Cal, yet they can’t afford to pay for services out of pocket. Further, many of these individuals are either uninsured or under-insured. Existing models to serve this population include: the Community Living Fund (CLF) and a program through Community Behavioral Health Services that pays for “patch” services – e.g., paying board and care to avoid paying for hospitalization.

Given the high cost of living in San Francisco and the high cost of dementia supports, a number of approaches might be advanced to address the needs of this population:

- Expand eligibility for CLF from 300% to 400% of poverty.
- Consider the use of the ‘patch’ model for programs like adult day care, in-home supportive services, and other forms of respite;
- Develop the use of a sliding scale for services for people above Medi-Cal eligibility;
- Provide education and information about dementia related guidelines to all professionals and service providers not just those who serve low-income patients;
- Advocate for federal support for long term assisted living, adult day health care, and in home supportive services.

**OBJECTIVE 10: Improve the quality of services in residential care homes and expand the range of models of residential care for people with dementia.**

The quality of care for people with dementia can be improved in residential care homes by the use of exemplary practices and/or by the development of explicit leadership for dementia within the care homes. Improving dementia care practices and quality of care, establishing care pathways, and identifying dementia care leadership should be part of this effort. Training should be provided for the staff of care homes in following these care practices and quality of care standards.

Also, given the diminishing supply of nursing home beds and the increased demand for care in residential homes resulting from the advance of baby boomers, the role of residential care facilities in delaying entrance or avoiding nursing homes is an essential component of San Francisco’s Strategy.

It should be noted that residential care is not always synonymous with assisted living. The term residential care implies a licensed residential facility, while assisted living can mean a broad range of residential options including: (1) licensed residential care facilities; (2) residential care homes, which may or may not be licensed depending on how they are organized; (3) board and care homes, which are licensed; and (4) unlicensed residential settings where room and board is provided by the housing operator and care and supervision are provided by one or more other organizations.

Research shows that barriers exist to effective use of assisted living. An excellent study conducted by Hyde, Perez, and Forester, *Dementia and Assisted Living*[^36] highlights many of the challenges people with cognitive impairment face in entering and maintaining residence in assisted living facilities. Golant (2004) concluded that assisted living facilities were more likely to accept frail older persons when these people had less serious cognitive impairment and when they did not require ongoing supervision (e.g., did not wander; or did not have memory, judgment, or behavioral problems). He also indicated that less than 50% of the assisted living facilities would accept older persons if they had moderate to severe dementia.

Hyde’s study cites Hawes and colleagues (2003) who found that fewer than 45% of assisted living providers would retain a resident with severe dementia. Ball and associates (2004), in their study using qualitative methods in five assisted living facilities, found that that given the wish to serve the most frail residents and have an assisted living facility be their last home, there were many issues that had to be contended with, including impaired residents being ostracized and being moved to special dementia units. When care needs are very high, residents can experience neglect that calls into question their quality of life as they age in place.

Hyde concludes by noting that assisted living was developed specifically to be responsive to residents’ own definition of quality. The challenge will be to design assisted living facilities that respects that mission and honors the dignity of those whom assisted living seeks to serve; to find

meaningful and appropriate ways to ask questions of people with dementia; and to measure, with reasonable reliability and validity, their responses to care and treatments. Fortunately, the Research Summary provided in Appendix I, Section 4.K. Assisted Living Facilities & Residential Care Facilities for the Elderly, contains a full discussion of this research and models. See pages 48 to 52.

**RECOMMENDATION 10-1. A range of residential care settings should be developed for people who require both residential and nursing care services.**

There is a trend across the country and in San Francisco to reduce the number of skilled nursing beds that have provided custodial care for older adults, including people with Alzheimer’s disease and related dementias. The intent is to move people to other types of care. Residential care facilities are needed that can provide custodial care with 24-hour coverage. Step-down affordable residential care options will need to be developed throughout the city. However, without obtaining Medi-Cal waivers to provide funding for these new residential options, the burden on local financial support is increased. See Recommendations 12-3 and 12-5 for a full discussion of this funding issue.

A range of residential care settings should be developed for people who require both residential and nursing care services. This would include a range of affordable residential care options responsive to different stages of dementia and different behavioral conditions.

To fully implement this recommendation will require working with the State Department of Social Services (DSS), Community Care Licensing, to explore existing licensing categories and consider developing new licensing categories. Examples of existing residential care settings follow, each of which could be modified for dementia care:

- Residential Care Facilities for the Chronically Ill developed to address the needs of people with HIV/AIDS, which have a medical/nursing component.
- Adult Residential Facilities for Persons with Special Needs developed to address the needs of persons with developmental disabilities.
- The Green House model, which can be developed as a licensed residential care facility or as a licensed skilled nursing facility. This model provides smaller units that are residential in feeling, with more personalized care planning and greater autonomy for elders. Green Houses provide an environment in which residents receive nursing support and clinical care without this becoming the focus of their existence.
- Board and Care Homes, which are a smaller version of Residential Care Facilities for the Elderly.
- A local promising practice: DPH provides a patch to Residential Care Facilities For The Elderly and Adult Residential Care Facilities to cover the cost of housing and services for clients in the mental health system. The patch is above the SSI rate and is negotiated based on types of services provided.

**Potential locations for residential care settings:**

- San Francisco should explore using one or more of these examples to develop affordable residential care settings on the Laguna Honda Hospital (LHH) campus. LHH could employ an inter-disciplinary social-health model of care based on community reintegration and choice, which could provide rehabilitation, chronic care, dementia care, and end of life care. Having some step-down residential alternatives on the LHH campus for people who require custodial
care, including those with Alzheimer’s and related dementias, who do not require 24 hour skilled nursing care, would provide a greatly needed and hopefully less costly resource.

San Francisco should also explore using one or more of these examples to develop affordable residential care settings in under-served neighborhoods – specifically in Bayview Hunters Point. In particular, the Green House model should be explored and possibly developed so residential care settings would be available for people who require custodial care, including those with dementia, who want to remain living in the community.

DSS Community Care Licensing needs to have an explicit statement about dementia care services in its licensing categories and activities, which are tracked and monitored in its licensed facilities. If nursing services are not currently allowed by some residential care facility rules and regulations, these may need to be changed similar to the Residential Care Facilities for the Chronically Ill (RCFCI) regulations. Also, a mechanism to provide for nursing services will need to be established. One possibility is a contract with a home health agency. In regard to funding, every effort should be made to retain Medi-Cal funds for the services and support provided in these residential settings.

RECOMMENDATION 10-2. Residential care settings should be designed and operated not only to ensure individual safety and contain dementia-related behaviors, but also to offer person-centered care with an array of services that address the whole person.

Residential care settings will increasingly serve people with moderately severe dementia (mid-stage) or advanced cognitive decline (late-stage). Many of these people may require 24-hour skilled nursing care and/or 24-hour skilled personal care. While placement in a residential care facility can forestall nursing home placement, providing person-centered care and responding to the needs of people with mid-to late-stage dementia requires clarity about the capacity of each provider to address specific conditions related to these stages of dementia. To ensure the highest quality of care, the Oversight Committee should ensure the dissemination of standards for quality in residential care settings and encourage residential care facilities to meet them. To start, the recommendations for quality of care in facilities, found in the Alzheimer’s Association’s, “Recommendations for Assisted Living and Nursing Homes” should be used. Training for staff in these quality standards should be provided.

Ideally, a plan for dementia services in residential care settings should address quality issues to include: appropriate staffing levels and ratios per resident; more than required training in dementia; person-centered activities; and allowances for self-determination. At present, there are no low income or affordable residential care facilities that have a dementia focus in San Francisco.

OBJECTIVE 11: Improve access to end of life care for people with dementia.

People with dementia and their caregivers should have easy access to end of life care including hospice care. However, the requirement of a six-month terminal prognosis creates a major barrier to accessing these services. The uncertainty related to the final stage of dementia often results in people not being able to access hospice care at all. Loved ones are sometimes pressured to extend life with the use of feeding tubes and other extraordinary interventions while people with dementia are under hospital care.
RECOMMENDATION 11-1. Advocacy should be undertaken for changes in local, state and national policies to enable individuals with late stage Alzheimer's and related dementias to be able to more easily access hospice care. This will require establishing diagnostic criteria that are more in line with the progression of late stage dementia, allowing for the extension of time limits, and ensuring palliative care is available to people with dementia.

Hospice care is recommended for provision throughout Laguna Honda Hospital (LHH). Hospice care and the Medicare Hospice Benefit should be available to all terminally ill LHH patients, including those with Alzheimer's and related dementias, whether or not they reside in the Hospice Unit. Dementia patients receive care throughout LHH and are not currently admitted to that Unit.

NOTE: Hospice, a Medicare benefit and model of care that provides a constellation of support services at the end of life, is available in homes, skilled nursing facilities, and assisted living facilities (ALFs). Hospice care can be provided in ALFs as long as there is non-ambulatory status established for each ALF in which it is provided. The ALF must also apply for a waiver. It is up to the facility whether it can manage the care level and many do allow it if a bed is available.

The criteria for hospice care is so narrow that many people with dementia don't fit until they have approximately 3 to 5 days to live. Doctors are reluctant to give a 6-month terminal diagnosis for someone with dementia because physically they may live much longer and this is difficult to determine without a more predictable additional diagnosis (i.e., cancer). Recognizing that Alzheimer's and related dementias are a terminal condition with a less certain timeline to end of life, a change in hospice admission policies should be considered at the local, state, and national levels.

OBJECTIVE 12: Advocate for effective state and national support for the implementation of this Strategy.

As noted elsewhere, some of the recommendations in this Strategy can be implemented largely with local efforts and not require state or national reforms. However, many recommendations require policy or funding reforms, waivers or legislation. It will fall to the Dementia Care Excellence Oversight Committee to organize an ongoing advocacy role to implement these recommendations.

RECOMMENDATION 12-1. Education and advocacy for universal coverage for long-term supports and services should be undertaken so that this is part of national health care reform. Work to assure that Medicare and Medicaid regulations are coordinated to allow for the best possible patient care.

Following are specific areas where education and advocacy will be needed:

- Development of a comprehensive long term care benefit as part of a national health care benefit. Respite care, adult day health care, in home supportive services, and community-based long term care services should be included in this benefit.
- Changes in Medi-Cal that effect reimbursement levels for diagnosis, care management, assisted living, in-home supports and other vital services.
- Expansion of the scope of Medicare funding to include long term care. For example, changes should be sought in Medicare that would allow people in Medicare-funded assisted living programs to also attend Medicare-funded adult day care services – especially nursing, PT, OT, and speech therapy.
RECOMMENDATION 12-2. The City should advocate for legislation that would require the State Department of Health Care Services (DHCS) and State Department of Social Services (DSS) to develop expertise in dementia care.

Existing state licensing regulations do not adequately address the needs of people with dementia. State agencies such as DHCS and DSS dealing with facilities and services that will serve those with cognitive impairment need to have dementia care expertise to develop new licensing categories. To address this issue, the State DHCS and DSS should develop this expertise. Also, the State DSS Office of Community Care Licensing should hire a nurse who could facilitate the development of new or altered licensing categories for the range of affordable residential care options that will be serving people with Alzheimer’s and related dementias. These people will require custodial long term care, including both residential care and nursing care services.

RECOMMENDATION 12-3. The City should explore federal waivers for assisted living programs that will enable San Francisco to retain Medi-Cal funds for these services and manage them locally.

There are two waiver options that San Francisco could pursue to achieve this recommendation. The first is for the City to seek involvement in the California Assisted Living Waiver, which has been renewed. The second involves using the Home and Community-Based Services Waiver (based on AB 2968) being designed specifically for San Francisco. This waiver would provide for services covered by Medi-Cal in the affordable residential care facilities. Each of these options would retain Medi-Cal funds in San Francisco for community-based services in assisted living programs, including services for Alzheimer’s and related dementias.

RECOMMENDATION 12-4. An enhanced nursing home diversion services project should be considered. This project would be developed in collaboration with the California Department of Aging, funded by a grant from the federal Administration on Aging.

The enhanced nursing home diversion services project is an initiative of the Administration on Aging in cooperation with State Units on Aging and Area Agencies on Aging. It seeks to alleviate fiscal pressure on Medicaid and Medicare. The services would target individuals at the same level of clinical need as Medicaid waiver eligibility, but who have assets in excess of Medicaid financial eligibility, not to exceed an average of $25,000. The target for this project would be older adults and adults with disabilities, including people with Alzheimer’s and related dementias.

RECOMMENDATION 12-5. The feasibility of a managed chronic care demonstration project for older adults and adults with disabilities, including those with Alzheimer’s and related dementias, should be explored.

Such a demonstration project could create an actual system of chronic care for older adults with functional and cognitive impairments. It would retain Medi-Cal funds in San Francisco for community-based long-term services and supports, including services for Alzheimer's and related dementias. Examples of similar programs include: (1) Multi-Purpose Senior Services Program (MSSP), which San Francisco already has in place, operated by the Institute on Aging (IOA); and (2) the Program of All Inclusive Care for the Elderly (PACE), operated by On Lok and the IOA. This demonstration project would need to be more inclusive that the PACE program, however, and not limited to serving people who are eligible for or at risk of nursing home placement. It could be a
chronic care management model like PACE, but without the PACE program’s age and income restrictions.

This managed chronic care demonstration project could complement “Healthy San Francisco”, a city program that makes health care services accessible and affordable for uninsured residents under 65. Possibly, some of the PACE requirements and services could be unbundled so that they could be accessible to people within this system. For more details on the creation of a managed chronic care demonstration project, see Appendix IX.

**OBJECTIVE 13: Foster policies and practices that create a community sensitive to the needs of individuals with memory loss.**

People with memory loss, and Alzheimer’s and related dementias, are subject to stigma and discrimination in the community that arise largely out of ignorance and misunderstanding. This objective and the following recommendation seek ways to call San Francisco residents and their institutions to eliminate stigma and discrimination and replace it with compassion and understanding.

**RECOMMENDATION 13-1. Efforts should be undertaken to make San Francisco more accommodating of people experiencing forgetfulness and cognitive impairment. These efforts should be connected to the local, national, and international movements toward creating age and disability friendly communities.**

The efforts toward creating age and disability friendly communities will benefit people with memory loss and their caregivers. Partnerships should be sought with the San Francisco Public Library, the Planning Department, and the Department of Parks and Recreation.

The vision for age and disability friendly communities in San Francisco goes beyond providing what dementia services people need. It responds to a broader, more fundamental issue: what people require for a good life. This is especially true for people with early to mid-stage dementias, and may include: (1) the formation of personal and social support networks that promote the contributions of people with dementia, with the goal of strengthening our neighborhoods and communities; and (2) the creation of age- and disability-friendly communities that offer accessible and affordable housing, improved public safety, improved access to parks and recreation, and opportunities to be meaningfully engaged in the community.

Achieving this broader vision speaks to the larger issue of helping people with dementia and their caregivers not just to endure, but to thrive. Achieving this vision requires delivery of the highest quality services and supports, but it goes beyond that. It requires creating a community that has empathy and compassion and demonstrates these values in every nuance of daily life:
Where the mailman understands the person in a home or apartment is demented and that s/he will knock on the door, say hello, and pay attention to any signs of decline.

Where the single room occupancy hotel manager works cooperatively with a care manager and a resident with dementia to explore options for retaining housing and ensuring safety; and

Where a librarian recognizes a person with memory challenges whose symptoms are worsening and makes a call to the DAAS Integrated Intake Unit to see what help and support may be available.

Each of these examples illustrates how a more compassionate community could contribute to a greater quality of life for people whose cognitive capacities are diminishing. Advocacy and public education will provide San Francisco yet another opportunity to extend its long history of caring compassionately for those in vulnerable circumstances. Making San Francisco friendlier to people increasingly experiencing forgetfulness should be tied in to the national movement toward creating age and disability friendly communities.

**OBJECTIVE 14:** Facilitate and support an Oversight Committee responsible for implementing this Strategy, and advocating for improvement of prevention, education and services related to dementia.

**RECOMMENDATION 14-1.** A Dementia Care Excellence Oversight Committee should be established for: (1) overseeing the implementation of this Strategy and its recommendations; (2) monitoring the progress of workgroups, (3) monitoring the participation of partners; (4) undertaking advocacy efforts to influence state and national legislation; (4) overseeing the exploration and initiation of pilot projects and demonstration projects; (5) identifying guidelines and standards of care for all components of the network of services for individuals with dementia; and (6) fostering adherence to these standards by all appropriate service providers.

A standing Dementia Care Excellence Oversight Committee should be created that will be responsible for overseeing the implementation of this Strategy and its recommendations. It could also be the forum for considering emerging research and recommending changes to standards, approaches and strategies. It should provide updates periodically to the Long Term Care Coordinating Council. The Oversight Committee should have staffing from the Department of Aging and Adult Services and hold quarterly meetings. New workgroups, with staff support for each, will be required to ensure implementation of specific recommendations.
V. ACTION PLAN AND NEXT STEPS:

San Francisco’s response to the growing crisis in dementia care should be comparable to the City’s comprehensive and effective response to the AIDS epidemic back in the 1980s. To be successful, the implementation of this *Strategy for Excellence in Dementia Care* will require a unified, proactive, long term response. This effort should not be the responsibility of any single city department. Should this be the case, implementation will falter or fail. Instead, this effort will require the involvement of many city departments, non-profit agencies, social service agencies, health care providers, residential care and institutional care providers, and advocacy groups. Success will also require that ongoing staffing for the seven recommended workgroups is provided by several different city departments.

**Leadership required to advance this Strategy**

Visible leadership will be required to make this *Strategy* a reality. The overarching leadership and direction for its implementation across city departments should come from the Mayor’s Office. A *Dementia Care Excellence Oversight Committee*, whose members should be appointed by the Mayor, will oversee all implementation activities. The Department of Aging and Adult Services will take part of the leadership role. However, other city departments, agencies, and organizations will need to be actively involved and commit resources, staffing, advocacy, and time to this effort.

Other city departments, agencies, and organizations recommended for participation and leadership include: the Department of Public Health, University of California at San Francisco (UCSF), the Alzheimer’s Association of Northern California and Northern Nevada, Family Caregiver Alliance, Institute on Aging, San Francisco Medical Society, Sutter Health, Catholic HealthCare West, Brown & Toland Physicians Medical Group, Hill Physicians Medical Group, On Lok Lifeways, Kaiser Permanente’s national office in Oakland, and the Long-Term Care Coordinating Council. Expert consultation on specific issues will be required from members of the Expert Panel periodically for a limited time. For example, they may need to provide access to the UCSF Department of Medicine.

**Recommended workgroups required to implement this Strategy**

1. Training And Education
2. Guidelines And Standards
3. Additional Services And Settings
4. Medical Resources
5. Shared Electronic Medical Records System
6. Waivers, Pilot Projects, And Demonstration Projects
7. Advocacy

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**THE ACTION PLAN BEGINS ON THE FOLLOWING PAGE**

*NOTE: RECOMMENDATIONS ARE NOT REPEATED COMPLETELY IN THIS ACTION PLAN. INSTEAD, THEY ARE ABBREVIATED ON THE FOLLOWING SUMMARY AND DETAILED CHARTS, AND IN THE ACCOMPANYING NARRATIVE. THE NUMBERS OF EACH RECOMMENDATION CORRESPOND TO EACH FULLY STATED RECOMMENDATION FOUND IN SECTION IV. PLEASE REFER BACK TO THE PREVIOUS SECTION FOR THE SPECIFIC WORDING OF EACH FULLY STATED RECOMMENDATION TO OBTAIN ANY CLARIFICATION REQUIRED.*
# Action Plan - Summary

## Planning and Implementation Responsibilities

### PHASE ONE – PLANNING (November and December 2009)

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<td>Establish an ongoing Dementia Care Excellence Oversight Committee to oversee implementation of this Strategy and recommendations.</td>
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### PHASE ONE – IMPLEMENTATION (2010 to 2011)

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<tr>
<td>1-1</td>
<td>Integrate dementia care into San Francisco’s long-term care service delivery network.</td>
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<td>1-2</td>
<td>Train all agencies and programs to become dementia capable.</td>
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<td>2-1</td>
<td>Improve public awareness and understanding of dementia.</td>
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<td>3-1</td>
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<td>Train service providers and other professionals to implement current standards and guidelines.</td>
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### PHASE TWO – IMPLEMENTATION (2012 to 2015)

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Leadership Responsibility</th>
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<tbody>
<tr>
<td>3-4</td>
<td>Research and develop a medical record system enabling cross system information sharing.</td>
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<td>4-3</td>
<td>Create clinical geriatric fellowships at UCSF for physicians and other medical professionals.</td>
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<tr>
<td>6-1</td>
<td>Establish team approach to dementia care using care managers in health centers and clinics. This may be a pilot project.</td>
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<tr>
<td>6-2</td>
<td>Create structured peer support and learning networks for people with mild cognitive impairment and caregivers</td>
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<td>Immediately upon diagnosis, doctors and staff should refer caregivers to supports such as education, counseling, caregiver assessment, and services.</td>
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<td>Create additional respite care services for people with dementia as support for caregivers.</td>
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<td>Ensure nursing home quality standards are met to provide person-centered care and an array of dementia care services.</td>
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<td>Develop an expanded range of community-based services based on best practices.</td>
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<td>Expand and enhance range of adult day services and train staff to address cognitive impairment at all stages of the disease.</td>
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<td>9-3</td>
<td>Develop dementia services and supports for people who have no family or none close.</td>
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<td>9-5</td>
<td>Advocate for changes in mental health system to end carve-out from mental health services.</td>
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<td>9-6</td>
<td>Develop a plan to provide dementia services for people above Medi-Cal eligibility.</td>
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<tr>
<td>10-1</td>
<td>Develop a range of residential care settings for people who need residential and nursing services.</td>
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<td>Ensure residential care quality standards are met to provide person-centered care and an array of dementia care services in residential care facilities.</td>
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<td>Advocate to remove barriers for doctors to provide geriatric assessments, diagnoses and care by increasing reimbursement.</td>
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<td>Advocate to remove barriers for people that limit access to services based solely on diagnosis.</td>
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<td>Advocate to change policies so that people with late stage dementia can easily access hospice care.</td>
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<td>12-1</td>
<td>Advocate for universal coverage for long-term services and supports as part of national health care reform.</td>
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<td>Advocate for legislation for the California Department of Health Care Services and the California Department of Social Services to develop dementia expertise.</td>
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<td>Explore participation in the Assisted Living Waiver or the Home and Community-Based Services Waiver being designed for San Francisco in order to retain Medi-Cal funds.</td>
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<tr>
<td>12-4</td>
<td>Consider developing an enhanced nursing home diversion services project.</td>
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<tr>
<td>13-1</td>
<td>Undertake efforts to make San Francisco friendlier to people experiencing forgetfulness and memory loss.</td>
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**PHASE THREE – IMPLEMENTATION (2016 to 2020)**
SAN FRANCISCO'S STRATEGY FOR EXCELLENCE IN DEMENTIA CARE
ACTION PLAN: PHASE ONE - PLANNING

Recommendations that can be implemented in FIRST TWO MONTHS (November and December 2009)

Form an Alzheimer's/Dementia Expert Panel Planning Committee that will meet twice to review the recommendations & action plan*

Establish an ongoing Dementia Care Excellence Oversight Committee to oversee implementation of this strategy & recommendations**

**This oversight committee may include leadership from the public sector and the private sector. Membership may include: DAAS, DPH, LTCCC, UCSF, Alzheimer's Association, Family Caregiver Alliance, SF Medical Society, Sutter Health, Catholic Healthcare West, Kaiser Permanente

*This Planning Committee will consist of the Co-Chairs of the Expert Panel (Kathy Kelly and Jay Luxenberg), the four Subcommittee chairs (Ruth Gay, Patrick Fox, Cynthia Kauffman, Elizabeth Edgerly), and DAAS (Anne Hinton & Bill Haskell).
ACTION PLAN
PHASE ONE – PLANNING
TWO MONTHS (November - December 2009)

PHASE ONE – PLANNING will cover two months devoted to organizing a Dementia Care Excellence Oversight Committee. During this period, an Alzheimer’s/Dementia Expert Panel Planning Committee will oversee implementation of recommendation 14-1.

RECOMMENDATION 14-1. Establish an ongoing Dementia Care Excellence Oversight Committee to oversee implementation of this Strategy and recommendations.

The Planning Committee will meet twice to: (1) review and complete the action plan; (2) participate in organizing the Dementia Care Excellence Oversight Committee, and (3) plan for the transfer of responsibilities to it for the implementation of this Strategy. The Planning Committee will include:

- The two co-chairs from the Expert Panel: Kathy Kelly and Jay Luxenberg;
- The four chairs of the subcommittees: Ruth Gay, Patrick Fox, Cindy Kauffman, and Elizabeth Edgerly; and
- The Department of Aging and Adult Services: Anne Hinton and Bill Haskell.

Leadership Responsibility: Alzheimer’s/Dementia Expert Panel Planning Committee

Proposed Key Partners: The members of the Dementia Care Excellence Oversight Committee should be appointed by the Mayor. Co-chairs should be identified. Representatives from the following public and private sector agencies and organizations, among others, should be considered for membership:

- Department of Aging and Adult Services;
- Department of Public Health;
- University of California at San Francisco;
- Alzheimer’s Association of Northern California and Northern Nevada;
- Family Caregiver Alliance;
- San Francisco Medical Society;
- Institute on Aging;
- Sutter Health;
- Catholic Healthcare West;
- Brown & Toland Physicians Medical Group;
- Hill Physicians Medical Group;
- Kaiser Permanente;
- On Lok Lifeways;
- Long-Term Care Coordinating Council; and
- The Mayor’s Office

Recommended Workgroups:

<table>
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<tr>
<th>1. Training And Education</th>
<th>5. Shared Electronic Medical Records System</th>
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<tr>
<td>2. Guidelines And Standards</td>
<td>6. Waivers, Pilot Projects, &amp; Demonstration Projects</td>
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<tr>
<td>3. Additional Services And Settings</td>
<td>7. Advocacy</td>
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<tr>
<td>4. Medical Resources</td>
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</table>

Each workgroup will require the designation of a chair or co-chairs, and the identification of staff support.
SAN FRANCISCO'S STRATEGY FOR EXCELLENCE IN DEMENTIA CARE
ACTION PLAN: PHASE ONE - IMPLEMENTATION

Recommendations that can be implemented in
ONE TO TWO YEARS (2010-2011)

Integrate dementia care into long term care service delivery network

TrainDAAS Integrated Intake Unit staff to be experts in dementia resources & services

Train & educate primary care physicians, hospitalists, primary care & health clinic staff***

Facilitate diagnosis of mild cognitive impairment with established diagnostic criteria

Improve public & professional awareness, & understanding of dementia**

Train all agencies & programs to become dementia capable

Identify & promote current guidelines & standards to service providers & other professionals

Train service providers & other professionals to implement current guidelines & standards

Recommendation 1-1

Recommendation 2-1

Recommendation 1-2

Recommendation 3-1

Recommendation 3-2

Recommendation 3-3

Recommendation 4-1

**Public Education on:
1. Risk Reduction
2. Services & Resources
3. Early Identification
4. What to expect as the disease progresses
5. Disease management - mild, moderate, severe
6. Advanced Care Planning
7. Ethical Issues
8. Caregiver wellness & support
9. Emergency preparedness & safety

***Training in:
1. Medication prescriptions
2. Diagnosis
3. End of life care
4. Managing difficult behaviors
5. Critical care issues
ACTION PLAN
PHASE ONE – IMPLEMENTATION
ONE TO TWO YEARS (2010-2011)

PHASE ONE – IMPLEMENTATION will focus on implementing eight recommendations that do not require either a significant infusion of funding or major reforms. These recommendations focus on public education and targeted training to improve the capacity to implement best practices by implementing recommendations 1-1, 1-2, 2-1, 3-1, 3-2, 3-3, 4-1, and 5-1.

RECOMMENDATION 1-1. Integrate dementia care into San Francisco’s long term care service delivery network.

Leadership Responsibility: Dementia Care Excellence Oversight Committee
Proposed Key Partners: Department of Aging and Adult Services (DAAS), Department of Public Health (DPH), Family Caregiver Alliance, Alzheimer’s Association, Community-based service providers including senior centers, adult day care centers, social day centers, and institutional service providers, assisted living facilities, board and care facilities, Police Department, Fire Department

NOTE: This is a fundamental recommendation for the Expert Panel and will be achieved through the accomplishment of most or all of the other recommendations that follow.

RECOMMENDATION 1-2. Train all agencies and programs to become dementia capable.

Leadership Responsibility: Training and Education Workgroup
Proposed Key Partners: DAAS, DPH, Alzheimer’s Association, Family Caregiver Alliance, urgent care providers, first responders, emergency room staff.

RECOMMENDATION 2-1. Improve public awareness and understanding of dementia.

Leadership Responsibility: Training and Education Workgroup
Proposed Key Partners: DAAS, DPH, Family Caregiver Alliance, Alzheimer’s Association, San Francisco Public Library, Community based service providers including community centers, senior centers, adult day care centers, social day centers, primary care clinics, Mayor’s Office, Police Department, Fire Department

RECOMMENDATION 3-1. Identify and promote current guidelines and standards to service providers and other professionals.

Leadership Responsibility: Guidelines and Standards Workgroup
Proposed Key Partners: DAAS, DPH, Alzheimer’s Association, Family Caregiver Alliance, representation from state agencies, and local service provider groups.
RECOMMENDATION 3-2. Train service providers and other professionals to implement current standards and guidelines.

Leadership Responsibility: Training and Education Workgroup

Proposed Key Partners: Alzheimer’s Association, Family Caregiver Alliance, Institute on Aging, representation from state agencies and from local service provider groups.

RECOMMENDATION 3-3. Train and educate primary care physicians, hospitalists, primary care center staff and health clinic staff

Leadership Responsibility: Training and Education Workgroup

Proposed Key Partners: DPH, UCSF, Alzheimer’s Association, San Francisco Community Clinic Consortium, Laguna Honda Hospital, Kaiser Permanente, Catholic Healthcare West

RECOMMENDATION 4-1. Facilitate diagnosis of mild cognitive impairment with established diagnostic criteria.

Leadership Responsibility: Medical Resources Workgroup


RECOMMENDATION 5-1. Train DAAS Integrated Intake Unit staff to be experts in dementia resources and services.

Leadership Responsibility: Training and Education Workgroup

Proposed Key Partners: Alzheimer’s Association
SAN FRANCISCO'S STRATEGY FOR EXCELLENCE IN DEMENTIA CARE
ACTION PLAN: PHASE TWO - IMPLEMENTATION (CHART 1 of 3)

Recommendations that can be implemented in
THREE TO SIX YEARS (2012-2015)

- Research & develop an electronic medical record enabling cross-system information sharing
- Convene a meeting of acute care hospitals to review existing plans for dementia care & identify best practices***
- Convener additional respite care services for people with dementia as support for caregivers
- Upon diagnosis, doctors refer caregivers to education, counseling, caregiver assessment & services
- Create structured peer support & learning networks for people with mild cognitive impairment & caregivers
- Develop screening tool for chronic illness that includes issues related to dementia
- Create clinical geriatric fellowships at UCSF for physicians & other medical professionals*
- Establish team approach to dementia care using care managers in health centers & clinics**
- ** This would be a pilot project between DAAS & DPH
- Person with Dementia

*** This summit could expand on work being done by the ACE Unit at San Francisco General Hospital

* Geriatric fellowships to have a commitment to work in primary care clinics & health centers to provide dementia care & assess need for more comprehensive evaluations for adults with memory loss or cognitive change

** This would be a pilot project between DAAS & DPH
ACTION PLAN
PHASE TWO – IMPLEMENTATION (FOR CHART 1 OF 3)
THREE TO SIX YEARS (2012-2015)

PHASE TWO-1 IMPLEMENTATION focuses upon building the network’s infrastructure and capacity to deliver integrated services. To achieve this purpose, the Oversight Committee will advance Recommendations 3-4, 4-2, 4-3, 6-1, 6-2, 7-1, 7-2, and 8-1.

Recommendation 3-4. Research and develop a medical record system enabling cross system information sharing.

Leadership Responsibility: Shared Electronic Medical Records System Workgroup

Proposed Key Partners: DAAS, DPH, UCSF, City and County of San Francisco, and information technology partners such as Google or Microsoft, San Francisco Community Clinic Consortium, Kaiser Permanente, Catholic Healthcare West, Sutter Health, Institute on Aging, Kindred Nursing and Rehabilitation Centers, and various local service providers, San Mateo County’s medical records

RECOMMENDATION 4-2. Develop screening tool for chronic illness that includes issues related to dementia.

Leadership Responsibility: Medical Resources Workgroup

Proposed Key Partners: DAAS, DPH, UCSF, Institute on Aging, Kaiser Permanente, Catholic Healthcare West, Sutter Health, San Francisco Medical Society, San Francisco Community Clinic Consortium

RECOMMENDATION 4-3. Create clinical geriatric fellowships at UCSF for physicians and other medical professionals.

Leadership Responsibility: Medical Resources Workgroup

Proposed Key Partners: DAAS, UCSF, Institute on Aging

RECOMMENDATION 6-1. Establish team approach to dementia care using care managers in health centers and clinics. This may be a pilot project.

Leadership Responsibility: Waivers, Pilot Projects, and Demonstration Projects Workgroup

Proposed Key Partners: San Francisco Community Clinic Consortium, UCSF, and Kaiser Permanente, San Francisco General Hospital
**RECOMMENDATION 6-2.** Create structured peer support and learning networks for people with mild cognitive impairment and caregivers.

**Leadership Responsibility:** Additional Services and Settings Workgroup

**Proposed Key Partners:** DAAS, Community Living Campaign, San Francisco Village, openhouse

**RECOMMENDATION 7-1.** Immediately upon diagnosis, doctors and their staff should refer caregivers to supports such as education, counseling, caregiver assessment, and services

**Leadership Responsibility:** Medical Resources Workgroup

**Proposed Key Partners:** Kaiser Permanente, Hill Physicians Medical Group, Brown & Toland Physicians Medical Group, Family Caregiver Alliance, Alzheimer’s Association, On Lok, and Institute on Aging.

**RECOMMENDATION 7-2.** Create additional respite care services for people with dementia as support for caregivers.

**Leadership Responsibility:** Additional Services and Settings Workgroup

**Proposed Key Partners:** DAAS, DPH, Family Caregiver Alliance, Alzheimer’s Association, adult day care and adult day health care providers, & in-home supportive services programs.

**RECOMMENDATION 8-1.** Convene a meeting of acute care hospitals to review existing plans for dementia care and identify best practices.

**Leadership Responsibility:** Medical Resources Workgroup

**Proposed Key Partners:** DAAS, DPH, San Francisco General Hospital ACE Unit, local hospitals, especially emergency rooms and urgent care settings, UCSF, Institute on Aging.
SAN FRANCISCO’S STRATEGY FOR EXCELLENCE IN DEMENTIA CARE
ACTION PLAN: PHASE TWO - IMPLEMENTATION (CHART 2 of 3)

Recommendations that can be implemented in THREE TO SIX YEARS (2012-2015)

Ensure nursing home quality standards are met to provide person-centered care & an array of dementia care services*

Expand & enhance range of adult day services & train staff to address cognitive impairment**

Advocate for changes in mental health system to end carve-out of dementia from mental health services

Develop a range of residential care settings for people who need residential & nursing services****

Develop dementia services & supports for people who have no family - or none close***

Ensure residential care facility quality standards are met to provide person-centered care & an array of dementia care services*****

Develop dementia services & supports for people above Medi-Cal eligibility

Develop an expanded range of community-based services based on best-practices

Recommendation 8-2

Recommendation 9-1

Recommendation 9-2

Recommendation 9-3

Recommendation 10-1

Recommendation 10-2

Recommendation 9-4

Recommendation 9-5

Recommendation 9-6

Person with Dementia

* Standards of quality should be met as defined in "Recommendations for Assisted Living & Nursing Homes" by the Alzheimer’s Association

**The full range of adult day services includes: (1) Adult Day Health Care, (2) Social Day Care, & (3) Alzheimer’s Day Care Resource Centers

***This will be developed as a pilot project

**** This will require working with the California Department of Social Services’ Office of Community Care Licensing to explore existing licensing categories and consider new licensing categories.

***** Standards of quality should be met as defined in “Recommendations for Assisted Living & Nursing Homes” by the Alzheimer’s Association
PHASE TWO – IMPLEMENTATION (FOR CHART 2 OF 3)
THREE TO SIX YEARS (2012-2015)

PHASE TWO-2 IMPLEMENTATION continues work developing and implementing standards and advancing a pilot demonstration project while expanding the range of services available to individuals with dementia and their caregivers. Phase II-2 would focus on implementation of Recommendations 8-2, 9-1, 9-2, 9-3, 9-5, 9-6, 10-1, and 10-2.

**RECOMMENDATION 8-2. Ensure nursing home quality standards are met to provide person-centered care and an array of dementia care services.**

**Leadership Responsibility:** Dementia Care Excellence Oversight Committee

**Proposed Key Partners:** Long Term Care Ombudsman, Laguna Honda Hospital, Alzheimer’s Association, & other nursing home providers, California Association of Nursing Home Reform

**RECOMMENDATION 9-1. Develop an expanded range of community-based services based on best practices.**

**Leadership Responsibility:** Additional Services and Settings Workgroup

**Proposed Key Partners:** DAAS, DPH, Alzheimer’s Association, Family Caregiver Alliance, Long-Term Care Coordinating Council, community based-service providers, including adult day health care, social day care, & Alzheimer’s Day Care Resource Centers, On Lok Lifeways.

**RECOMMENDATION 9-2. Expand and enhance range of adult day services and train staff to address cognitive impairment at all stages of the disease.**

**Leadership Responsibility:** Additional Services and Settings Workgroup

**Proposed Key Partners:** DAAS, DPH, Alzheimer’s Association, Family Caregiver Alliance, Long-Term Care Coordinating Council, community based service providers, including Adult Day Health Care, Social Day Care, and Alzheimer’s Day Care Resource Centers, & San Francisco Adult Day Services Network.

**RECOMMENDATION 9-3. Develop dementia services and supports for people who have no family or none close.**

**Leadership Responsibility:** Additional Services and Settings Workgroup

**Proposed Key Partners:** DAAS, DPH, Family Caregiver Alliance, Alzheimer’s Association, In Home Supportive Services Registry Board, & New Leaf Services and other community-based agencies that provide services or other forms of home-based support (e.g. meals, transportation).
**RECOMMENDATION 9-5.** Advocate for changes in mental health system to end carve-out from mental health services.

**Leadership Responsibility:** Advocacy Workgroup

**Proposed Key Partners:** DAAS, DPH Community Behavioral Health Services, Alzheimer’s Association, Family Caregiver Alliance, San Francisco Mental Health Association, & mental health providers.

**RECOMMENDATION 9-6.** Develop a plan to provide dementia services for people above Medi-Cal eligibility.

**Leadership Responsibility:** Additional Services and Settings Workgroup

**Proposed Key Partners:** DAAS, DPH, Controller’s Office, Alzheimer’s Association, Family Caregiver Alliance, Long-Term Care Coordinating Council, community-based service providers, including adult day health care, social day care, and Alzheimer’s Day Care Resource Centers.

**RECOMMENDATION 10-1.** Develop a range of residential care settings for people who need residential and nursing services.

**Leadership Responsibility:** Additional Services and Settings Workgroup

**Proposed Key Partners:** DAAS, DPH, San Francisco Planning Department, San Francisco Redevelopment Agency, Mayor’s Office of Housing, California Department of Social Services, Laguna Honda Hospital, Long Term Care Coordinating Council.

**RECOMMENDATION 10-2.** Ensure residential care quality standards are met to provide person-centered care and an array of dementia care services in residential care facilities.

**Leadership Responsibility:** Dementia Care Excellence Oversight Committee

**Proposed Key Partners:** DAAS, Alzheimer’s Association, Family Caregiver Alliance, UCSF, Institute on Aging, Laguna Honda Hospital, Long Term Care Ombudsman, California Alliance of Residential Care Providers, California Assisted Living Association, and residential care facilities, California Association of Nursing Home Reform.
SAN FRANCISCO'S STRATEGY FOR EXCELLENCE IN DEMENTIA CARE
ACTION PLAN: PHASE TWO - IMPLEMENTATION (CHART 3 OF 3)

Recommendations that can be implemented in THREE TO SIX YEARS (2012-2015)

- Advocate to change policies so that people with late stage dementia can easily access hospice care
- Advocate for legislation for California DHS & DSS to develop expertise in dementia*
- Undertake efforts to make San Francisco friendlier to people experiencing forgetfulness & memory loss
- Consider developing an enhanced nursing home diversion services project
- Explore participation in Assisted Living Waiver or HCBS Waiver to retain Medi-Cal funds
- Advocate for universal coverage for long term services & supports as part of national health care reform
- Advocate for removing barriers for doctors to provide geriatric assessments, diagnoses & care by increasing reimbursement
- Advocate to remove barriers for people that limit access to services based solely on diagnosis.
- Advocate to remove barriers for people with late stage dementia can easily access hospice care
- *The State DSS, Office of Community Care Licensing, should hire a nurse to facilitate development of new licensing categories for new residential care options
ACTION PLAN
PHASE TWO – IMPLEMENTATION (FOR CHART 3 OF 3)
THREE TO SIX YEARS (2012-2015)

PHASE TWO-3 IMPLEMENTATION addresses recommendations 4-4, 4-5, 11-1, 12-1, 12-2, 12-3, 12-4, 13-1. Most of these recommendations focus on either advocacy to remove fiscal and/or programmatic barriers to access to services and supports, an improved, more accepting community culture for people with memory issues, and to demonstrate new approaches to services that require waivers or other regulatory changes.

RECOMMENDATION 4-4. Advocate to remove barriers for doctors to provide geriatric assessments, diagnoses and care by increasing reimbursement.

Leadership Responsibility: Advocacy Workgroup

Proposed Key Partners: DAAS, DPH, Alzheimer’s Association, UCSF, Institute on Aging, physician groups, & local hospitals

RECOMMENDATION 4-5. Advocate to remove barriers for people that limit access to services based solely on diagnosis.

Leadership Responsibility: Advocacy Workgroup

Proposed Key Partners: DAAS, DPH, Community Behavioral Health Services, Alzheimer’s Association

RECOMMENDATION 11-1. Advocate to change policies so that people with late stage dementia can easily access hospice care.

Leadership Responsibility: Advocacy Workgroup

Proposed Key Partners: DAAS, DPH, Laguna Honda Hospital, Institute on Aging, Alzheimer’s Association, local hospitals, other nursing homes, hospice programs

RECOMMENDATION 12-1. Advocate for universal coverage for long term services and supports as part of national health care reform.

Leadership Responsibility: Advocacy Workgroup

Proposed Key Partners: Alzheimer’s Association of Northern California and Northern Nevada, Family Caregiver Alliance
RECOMMENDATION 12-2. Advocate for legislation for the California Department of Health Services (DHS) and the California Department of Social Services (DSS) to develop dementia expertise.

Leadership Responsibility: Advocacy Workgroup

Proposed Key Partners: DAAS, Mayor’s Office, DPH, Alzheimer’s Association, Family Caregiver Alliance

RECOMMENDATION 12-3. Explore participation in the Assisted Living Waiver or the Home and Community Based Services (HCBS) Waiver being designed for San Francisco in order to retain Medi-Cal funds.

Leadership Responsibility: Waivers, Pilot Projects, and Demonstration Projects Workgroup

Proposed Key Partners: DPH, Long-Term Care Coordinating Council, & assisted living providers

RECOMMENDATION 12-4. Consider developing an enhanced nursing home diversion services project.

Leadership Responsibility: Waivers, Pilot Projects, and Demonstration Projects Workgroup

Proposed Key Partners: DAAS, DPH, Institute on Aging, State Department of Aging, Laguna Honda, Alzheimer’s Association, Family Caregiver Alliance, On Lok Lifeways

RECOMMENDATION 13-1. Undertake efforts to make San Francisco friendlier to people experiencing forgetfulness and memory loss.

Leadership Responsibility: Additional Services and Settings Workgroup

Proposed Key Partners: DAAS, DPH, Alzheimer’s Association, Family Caregiver Alliance, community-based agencies, San Francisco Public Library, San Francisco Community Clinic Consortium, Board of Supervisors, Mayor’s Office, San Francisco Planning Department.
Explore the feasibility of a managed chronic care demonstration project for older adults & adults with disabilities, including people with dementia, to retain Medi-Cal funds.

Develop a crisis intervention & assessment setting for people with dementia who are not safe in their own environments, or who have behavioral issues.

Recommendation 12-5

Recommendation 9-4
ACTION PLAN
PHASE THREE – IMPLEMENTATION
SEVEN To 11 YEARS (2016-2020)

PHASE THREE – IMPLEMENTATION covers the period from 2016-2020 and focuses upon implementation of two recommendations: Recommendation 9-4 and Recommendation 12-5, both of which involve developing new approaches to the delivery of services that will require waivers and or changes in regulations.

**RECOMMENDATION 9-4. Develop a crisis intervention and assessment setting for people with dementia who are not safe in their own environments, or who have behavioral issues.**

**Leadership Responsibility:** Additional Services and Settings Workgroup

**Proposed Key Partners:** DAAS, DPH, Laguna Honda Hospital, Institute on Aging, Alzheimer’s Association, Family Caregiver Alliance, Police Department, Adult Protective Services Forensic Center

**RECOMMENDATION 12-5. Explore the feasibility of a managed chronic care demonstration project for older adults and adults with disabilities, including people with dementia, to retain Medi-Cal funds.**

**Leadership Responsibility:** Waivers, Pilot Projects, and Demonstration Projects. Workgroup

**Proposed Key Partners:** DAAS, DPH, Long Term Care Coordinating Council, UCSF, Laguna Honda Hospital, Institute on Aging, Alzheimer’s Association, Family Caregiver Alliance, & local community-based service providers, On Lok
VI. IMPACT OF 2009-10 STATE BUDGET ON SAN FRANCISCO’S EXPERT PANEL RECOMMENDATIONS: DECEMBER 15, 2009

The impact on services under-funded or eliminated during the State’s severe economic downturn cannot be understated. The State of California, in particular, has struggled with budget shortages of a magnitude that could not have been predicted. In the face of balancing a budget that required deep cuts in education and services, the impact on families dealing with Alzheimer’s disease and related dementias are particularly cruel. In California, the final budget included $4 billion in health and human service program cuts. The actual impact is closer to $6-8 billion when the loss of federal matching funds is accounted for.

- It is a myth that the federal stimulus money will enable the health and social service infrastructure to continue, as asserted by the Governor.
- The administration is looking to private organizations to mitigate the funding gaps.
- The Governor’s predicted mid-year budget cuts, slated for release January 2010 are expected to potentially further reduce or even eliminate the remaining fragile services that have already been slashed to the bare edge of service delivery. This will require active and capable advocacy efforts to preserve and protect these remaining fractured programs for the future.

Implementation of budget cuts for people with Alzheimer’s disease and related dementias are ongoing, but some key and severe budget shortfalls are in the following programs:

- Caregiver Resource Centers (CRC) were cut 70% throughout California. In San Francisco, the loss of state caregiver support funding may impact the Bay Area Caregiver Resource Center significantly. Staff reductions, a halt in respite funding, and reductions in services are in process at this time.

- Alzheimer’s Day Care Resource Center funding (ADCRC) was eliminated, with the State encouraging the Area Agencies on Aging (AAA) to consider using Older Americans Act money to fund these specialized Alzheimer’s Day Care programs. An interesting challenge is that the Adult Day programs that received this special funding stream, will still be required to operate to their licensing requirements. Many ADCRCs have indicated they want to continue to operate under the name because of the business identify they have in their local communities, but are scrambling to consider how to fund their quality of adult day care.

- California Alzheimer’s Disease Centers (CADCs) were cut by 50%. The California Department of Public Health has reduced each Center’s grant from $526,500 to $281,800 but is also continuing to fund the Evaluation and Data Center at UCSF at $282,000. Most of the CADCs also have other sources of funding, such as for research. Each Center will be impacted in different ways, and all will continue to operate with varying impact on delivery. Most hard hit in this program are these Centers’ outreach to diverse communities, testing and diagnostic abilities for people with cultural and language needs other than English.

- The diminished In-Home Supportive Services (IHSS) budget will reduce or eliminate services to individuals with the lowest need. The criteria that was included in the budget language was intended to guide development of a plan of care, not to deny services. It is
estimated 36,179 recipients statewide will be dropped, and of great concern are those individuals who are in the moderate stages of Alzheimer’s who may need supervision and ongoing minimal support to dress, eat and manage their daily lives, but will no longer meet criteria for such services. These changes were due to go into effect September 1, 2009 but the State has delayed implementation because the details are still being worked out.

Several legal actions are currently underway, which may impact to some degree on the budget reductions

- The federal district court in Oakland has issued an injunction to halt the implementation of the three-day cap in Adult Day Health Care (ADHC) services.

- The federal district court in San Francisco on August 20th turned down a request for a temporary injunction of the elimination of nine Medi-Cal optional benefits for adults, including dental, podiatry, optical, incontinence creams and washes. The benefits were eliminated July 1, 2009. A state court previously denied the request.

- The February budget reduced In-Home Supportive Services (IHSS) wages from $12.10/hour to $10.10/hour. A lawsuit was filed in US District Court and the wage cut was halted in June. The State has appealed.

- An injunction is currently in place to protect those currently receiving IHSS services from being cut due to changes in eligibility criteria.

In any case, the well considered and staged recommendations of the San Francisco Expert Panel cannot roll out without considering these daunting budget implications. In the face of these difficult times and fear of even more impact, it may be that the Alzheimer’s/Dementia Expert Panel recommendations provide an opportunity for the City and County of San Francisco to build an infrastructure from the scaffolding of these fallen or damaged structures into a city that is Alzheimer’s and dementia “capable”. Several considerations provide opportunity:

- Early diagnosis and identification is a theme throughout this document. However, the Panel’s PHASE ONE recommendations focus primarily on creating a “dementia friendly” community through increased public awareness, education and training, and professional education and training for all service providers as well as identification and promotion of standards and guidelines. This effort should include looking at ways to build a network of services that implements these recommendations, even as they promote awareness of and best practices with an Alzheimer’s/dementia population.

- While we cannot predict whether the severe budget impact will continue for many years, the PHASE TWO recommendations – which would begin implementation in years 3-6 – have a focus on advocating for universal coverage for people living in the community as part of Health Care Reform, advocating for building dementia expertise, and especially removing barriers that limit access to services. Moving in this direction will appropriately help position the City and County of San Francisco to further develop the structure and integrated network of private and public services.

- It is impossible to ignore the impact of the current and ongoing budget cuts on Alzheimer’s/dementia care programs and services. The PHASE THREE recommendations will take into account the changes of previous years and will need to move forward based on where the service delivery is at that point.
The implementation of the Expert Panel recommendations must essentially consider how to weave the current and remaining texture of service delivery into the hopes and dreams that are present in the Panels’ short term, middle and long term recommendations for the future of San Francisco, so that we can realize San Francisco’s Strategy for Excellence in Dementia Care.
VII. CONCLUSION

Conclusion

There is no cure for dementia on the immediate horizon. A wave of baby boomers is approaching the age where Alzheimer’s and related dementias will begin to emerge. There will be a crisis in dementia care and San Francisco must respond. The Alzheimer’s/Dementia Expert Panel spent months deliberating on research, local data, and input from caregivers and other stakeholders. The recommendations provided in this report are the product of that focused and intensive work. San Francisco must act with urgency, move forward to implement these recommendations, and realize our vision of care for people with dementia so that they can live in dignity and thrive.
San Francisco’s Strategy For Excellence In Dementia Care

Research, recommendations, and an action plan to address the growing crisis in dementia care, and an economic analysis of that care.

Part Two of Two

APPENDICES:
- Evidence Based Practice & Emerging Research
- Inventory of Dementia Services & Supports
- Education & Prevention - Recommendations Detail
- Finance Detail
- Inventory of Plans in Other Jurisdictions
- California Guideline for Disease Management
- Additional Standards and Guidelines
- Additional Strategies
- Key Informant Interviews
- Bibliography
- Challenges in San Francisco: Caregiver Issues

By Alzheimer’s/Dementia Expert Panel
For Department of Aging and Adult Services

December 2009
## APPENDICES

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Appendix I: Evidence Based Practice & Emerging Research

1. OVERVIEW

The Best Practice summary that follows was developed by the Evidence-Based Practice and Emerging Research Subcommittee and the Research Team. This summary was based on an evaluation of over 160 documents, many of which were identified by the Alzheimer’s/Dementia Care Expert Panel. A priority was given to documents published in 2003 or later. Research was reviewed from England, Scotland, Sweden, Australia, New Zealand, Korea, Canada, and the United States. The scope of the review included an examination of evidence-based approaches to:

- Each component of care for those with cognitive impairment, e.g. diagnosis, pharmacological treatment, caregiver support, including education and prevention; and
- How other public health and social welfare challenges have been addressed through the implementation of a ‘system of care’ approach that integrates and coordinates services and supports; and
- Dementia-focused capitated systems such as those in Canada, Australia, England and Scotland, as well as locally developed closed systems like On Lok’s PACE model.

Among one of the more interesting discoveries in conducting the research was meeting Esther. “Esther” was invented by a team of physicians, nurses, and other providers who joined together to improve patient flow and coordination of care for elderly patients within a six-municipality region in Sweden. "Esther" is not a real patient, but her persona as a gray-haired, ailing, but competent elderly Swedish woman with a chronic condition and occasional acute needs has inspired impressive improvements in how patients flow through a complex network of providers and care settings. The Esther Project is essentially predicated upon the premise that system changes are best designed by adopting the perspective of the patient, Esther. While not focused upon patients with cognitive impairment, Esther is organized around creating a system of care that is responsive to the needs of frail, chronically ill older adults.

The Esther Project team has become one of two international teams participating in the Pursuing Perfection initiative. This program, launched by The Robert Wood Johnson Foundation (RWJF), is designed to help physician organizations and hospitals dramatically improve patient outcomes by pursuing perfection in all their major care processes. The Institute for Healthcare Improvement serves as the National Program Office for this RWJF initiative. During the three-year project, the Esther Team was able to achieve the following improvements:

- Hospital admissions fell from approximately 9,300 in 1998 to 7,300 in 2003.
- Hospital days for heart failure patients decreased from approximately 3,500 in 1998 to 2,500 in 2000.
- Waiting times for referral appointments with neurologists decreased from 85 days in 2000 to 14 days in 2003.
- Waiting times for referral appointments with gastroenterologists fell from 48 days in 2000 to 14 days in 2003.

Beyond these gains, through an exhaustive number of interviews with patients, nurses, doctors and caregivers, it achieved a sensitive understanding of life as Esther lives it. The Esther Project grew
from a need that many US health systems share: to improve the way patients flow through the system of care by strengthening coordination and communication among providers. The url below provides a link to the Esther home page and the cover article provides compelling evidence of the benefits of planning from a patient-centered perspective.


2. **SYSTEMS: HOW DO THE BEST SYSTEMS OF CARE FUNCTION?**

Currently, San Francisco does not offer a seamless system of services for the care of individuals with dementia and faces organizational, fiscal and regulatory barriers to operating in such a manner. Instead, San Francisco has an open network of public and private non-profit as well as for-profit service providers that together offer a range of dementia care services. These are provided within San Francisco’s larger long term care service delivery network.

Nonetheless, the intent of the Expert Panel was that the planning process should identify ways in which dementia care services could be delivered in a more comprehensive, coordinated and integrated manner so that the client experience is seamless with well-coordinated transitions in care and well-coordinated linkages to all services and supports. Panelists suggested that what should be considered is the integration of care for cognitive impairment into the larger framework of health, social services, and housing. This is because the broader health, social services, and housing context is so intertwined with effectively addressing the quality of life of individuals with cognitive impairment. To fully address the needs of individuals with cognitive impairment requires delivering as comprehensive an array of services, as seamlessly as possible. To achieve this purpose, there is much to learn from how:

- Other countries have operated systems to serve individuals with cognitive impairment;
- Closed systems of care for cognitive impairment have been developed in the United States;
- Systems have been developed in the United States to address other populations.

**Systems of Care including Health and Social Services**

Regardless of cross-national differences in the delivery of long-term care, countries confront similar challenges, including fragmented services, disjointed care, less-than-optimal quality, system inefficiencies and difficult-to-control costs. Integrated or whole-system strategies are becoming increasingly important to address these shortcomings through the seamless provision of health and social care.\(^1\) The effective treatment of cognitive impairment requires a broad array of services delivered by professionals, paraprofessionals, and informal caregivers, in the home, community and in health care and assisted living environs. This care involves medical, mental health, housing and financial systems support.\(^2\) The effort to improve the effectiveness of this multi-faceted challenge has led to “investigation of whole system approaches to improve the manner in which sectors, institutions, providers and services work in tandem as a long-term care enterprise.”\(^3\)

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At the core of a systems approach, is an integrated approach to care that Kodner defines as “a discrete set of techniques and organizational models designed to create connectivity, alignment, and collaboration within and between the cure and care sectors at the funding, administrative and provider levels.” According to Leutz, integrated care comes in three varieties: 1) **Linkages**, where health and social service providers still operate in silos while attempting to collaborate and coordinate across systems; 2) **Coordination**, which involves the ‘rebalancing’ of systems with the design of purposeful bridges to integrate silos, share information and improve coordination; and 3) **full integration**, which results in fully shared fiscal and service responsibility, global management and unified service delivery. San Francisco operates somewhere in between delivery of linked and coordinated services.

There is a growing body of research that describes whole system models, particularly those that are prototypes that are nested under one roof in an integrated health and social care system. These studies indicate that a ‘whole systems’ approach to support to individuals with cognitive impairment improves consumer outcomes, reduces stress on caregivers, and reduces public expenditures. The thirty nations that comprise the Organization of Economic Co-Operation and Development (OECD) have recently promoted policies of deinstitutionalization and community-based care for the elderly. These policies respond to common cost pressures associated with population aging, and the challenge of providing improved care for the elderly. They aim to substitute less costly services for institutional care, to improve patient satisfaction and decrease public expenses.

Johri, Beland and Bergman took a comparative cross-national approach to identify common features of an effective system of integrated care, and to examine the potential of such models to positively affect both the care of the elderly, and the cost to public finances. They conducted a systematic review of recent demonstration projects testing innovative models of care for the elderly in OECD countries. Projects included aimed to create comprehensive integration of acute and long-term care services, and were evaluated using a comparison group. For each project, Johri, Beland and Bergman reported on available results on rates of hospitalization, long term care institutionalization, utilization and costs, impact on process of care, and health outcomes. In addition, the following common features of an effective integrated system of care were identified:

- A single entry point;
- Case management, geriatric assessment and a multidisciplinary team; and
- Use of financial incentives to promote utilization of lower levels of care.

Johri, Beland and Bergman concluded community-based care can impact favorably on rates of institutionalization and cost of care. They also concluded that comprehensive approaches to program restructuring are necessary, as cost-effectiveness depends on characteristics of the system of care.

Senin, Cherubini, Mecocci studied the management of frail elderly subjects, using a "comprehensive geriatric assessment", as well as a model of long-term care developed in Italy. This approach was shown to reduce the risk of hospitalization and nursing home admission, with a parallel decrease in expenses and an improvement in the patient's quality of life. The effectiveness of the long-term care system depended on: 1) the availability of all the services that are necessary for the frail elderly, both in the hospital and in the community; 2) the presence of a coordinating team, the comprehensive geriatric assessment team, which develops and implements the individualized treatment plans,

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4 Ibid.
5 Ibid
identifies the most appropriate setting for each patient and verifies the outcomes of the interventions; 3) the use of common comprehensive geriatric assessment instruments in all the settings; and 4) the gerontological and geriatric education and training of all the health care and social professionals. The study suggests that the ‘whole system’ approach extends beyond service delivery and includes the use of a common language, instruments and tools, systematic reflection on patient outcomes to verify the most effective interventions, and a professional education system that supports whole system approaches and the use of effective, research-based practices.

Three models will be examined of whole systems approaches to care for individuals with cognitive impairment: 1) PACE; 2) SIPA; and 3) PRISMA.

Program of All-inclusive Care for the Elderly (PACE)

Established in 1971 and expanded with federal demonstration funding from 1987-1997, PACE has operated as a fully integrated system that provides acute and long-term care services coordinated by and organized around an adult day health center. Adapted by On Lok, and based upon the British day hospital approach to care, PACE offers adult day health center services integrated with geriatric primary care health, social and respite services, woven together by a case management system. The goal of the program is to maintain frail older individuals in the community for as long as possible. The program targets individuals who are eligible for Medicare and Medicaid. PACE emphasizes the role of informal caregivers and incorporates linkages with limited supportive housing resources.

PACE is a provider under Medicare and a state option under Medicaid. As of January 2005, there were 36 PACE programs in 18 states serving over 10,500 people with the average age of participants of 80 years, with 49% having been diagnosed with dementia. Elements of integration include:

- **Financing.** Pooled Medicare and Medicaid revenues along with total control over all program expenditures in a fully capitated system;
- **Service delivery.** Services are delivered staff of an adult health care center or through contracts for specialty medical services, acute hospitalization, and nursing home care;
- **Multidisciplinary case management.** Responsible for comprehensive assessment, service provision, care coordination, and clinical monitoring;
- **Focus on prevention.** Emphasis upon consolidated service delivery, system efficiencies; and risk-based capitation.

The US Health Care Financing Administration financed a qualitative evaluation conducted by Kane et al and a quantitative evaluation conducted ABt Associates. Kane et al and Zimmerman et al found the PACE model to be an effective integration mechanism. Researchers emphasized the highly personalized service delivery and high client satisfaction. Participation in PACE was associated with a decrease in hospital use, reduced institutionalization, balanced with substantial increases in utilization of outpatient medical care as well as home-based support.

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evaluations found that PACE is a successful, cost-effective model for managing and maintaining elderly individuals in the community.

Kodner et al also found that key features to the PACE model limit the scalability (scalability is the terminology used in the research) of the model. Specifically, without the assistance and cooperation of the federal and state governments, substantial capital and start-up costs in the millions of dollars are difficult to generate privately and to obtain necessary state waivers, a sponsoring organization must also secure letters of credit, reinsurance, and other required financial documents. Secondly, many elderly do not elect to participate if they are not comfortable with the adult day care setting. Finally, the small size of each program site, serving around 300 clients, makes replication contingent upon multiple adult day care center sites to serve as the hub of the system.

The John A. Hartford Foundation has been a sponsor of the PACE model, providing over $3.5 million in start-up funding to support the National PACE Association, for technical assistance to local communities interested in creating PACE model programs and assisting in accessing requisite start-up funding. It identified a range of options for financing start-up including tax-exempt bonds, foundation investments, and equity transfer from sponsoring health systems.

**System of Services Integrated for Person who are Aging (SIPA)**

Developed at McGill University/Universite de Montreal Research Group is a community-based, primary-care led, case managed health care system for the frail elderly. Operating at two Canadian centers of local community services (CLCS), from June 1999-March 2001 SIPA served 160 clients at each site. As with PACE, the majority of services were delivered at the CLCS with specialty medical services, hospitalization and nursing home services provided under contract. Key features included:

- **Multidisciplinary team** comprised of therapists, home care workers, pharmacists, nutritionists, a personal physician, with a nurse or social worker serving as the care coordinator;
- **Commitment to Evidence-based Geriatric techniques** including multidisciplinary clinical protocols, intensive home care, 24-hour on-call responsibility are all organized around reducing inappropriate institutionalization and maintain community living;
- **Simulated prepaid capitation system** that was never fully implemented, but nonetheless retained a flexible use of funds and close scrutiny of costs of care.

SIPA is the only North American integrated whole system model to be evaluated through a randomized control trial. Beland reported the program was highly effective in increasing access to community-based health and social services and reduced hospitalizations by 50%\(^1\). While SIPA reduced length and cost of emergency room stays, increased the likelihood of returning home after an emergency room stay, and reduced the cost and length of institutionalization, these savings were offset by the increase in the cost of community-based care. Moreover, there were no differences in health outcomes or total costs between experimental and control groups. As a result of the mixed results, the Quebec government discontinued the program while considering how to incorporate elements of the model.\(^2\)

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**PRISMA (Canada)**

The PRISMA model is composed of six main integrating elements:

- *Inter- and intra-organizational coordination* provided by a joint governing board on the governance level and a service coordination committee on the managerial level;
- *Single-point-of-entry mechanism* allowing access to all covered healthcare and social services;
- *Clinical care management* through a team of case managers who work with both physicians, providers, and family members;
- *Common assessment instruments, clinical charts, and care plan*
- *Capitated financial structure*
- *Integrated information system* including computerized tools, automated clinical records and patient utilization data.

A three-year quasi-experimental study was undertaken with measurements taken at 12 month intervals\(^{13}\) that found a declining trend in institutional care, improved functional autonomy with more frail patients for two years and had a positive effect on caregiver burden. However, the intervention failed to alter use of services or impact mortality.

**General Findings about Whole System Care**

Leutz found that integration must be customized to local conditions and Hudson et al found that success depends to a significant degree upon local leadership forging local partnerships rather than through top-down structural reforms. These two factors make generalizing about replication of models very difficult. Kodner identified four key factors that contributed to successful implementation of whole system models:

- *Umbrella organizational structures* that facilitate integration of services at the administrative, managerial and service provision levels;
- *Multidisciplinary case management* with a single point of contact that facilitates care planning and evaluation;
- *Organized provider networks* bound by standardized assessment, referral and service agreements that provide a seamless and uniform service experience;
- *Financial incentives or structures* that promote the utilization of prevention strategies and interventions that foster efficiency and lower levels of care.

**San Mateo County, San Mateo, CA**

This project is a Program Enhancement of a project funded by a FY2004 AoA Integrated Care Management grant. Utilizing two years of federal demonstration funding, San Mateo County Aging and Adult Services established the Integrated Information Project, a component of the effort to achieve a fully capitated Medicare/Medicaid long-term care system. The Integrated Information Project involves implementation of a uniform assessment tool using a single automated case management system for all members of the target population entering home and community-based long-term care services in the county. No evaluation data on this demonstration has been identified.

Conclusion

Taken together, the components and qualities of an effective whole system approach include:

- Oversight body that incorporates administration, management, line staff and caregivers that carefully review utilization data, satisfaction surveys, financial data, and current research;
- Integrated financial system or shared financial risks and incentives;
- Automated data system with electronic patient records and shared information across service sites;
- Emphasis upon the use of evidence based practice to inform use of effective strategies that maintain individuals at ever lower levels of care and within the community;
- System wide adherence to ‘guidelines’ that outline recommended interventions and protocols;
- Use of common assessment tools and referral criteria;
- Strong education and support for caregivers;
- Seamless referral strategies for treatment for co-morbid conditions and during transitions between home care, institutional care, hospitalization, and nursing care with adult day health care programs at the hub of the system of services; and
- Case management or care coordination creating a single point of contact and consistent assistance in navigating the varied services and supports required.

Achieving a fully coordinated, integrated and whole system approach for the delivery of health and social services in San Francisco would require significant start-up investments, the support and encouragement of the state and federal government, and a significant investment in system-wide planning. As even a mid-term goal, this may be asking more than a financially strapped public and private sector can bear. However, given the new administration’s interest in bold investments to stimulate the economy, at least conceptualizing how to incorporate features of effective systems into San Francisco’s open network of care may be a worthwhile activity. At worst, it provides a map of the most effective and efficient means of coordinating care, reducing stress on caregivers, and improving the quality of life of individuals with cognitive impairments.

3. EDUCATION & PREVENTION: WHAT WORKS?

This section describes the ways in which education and prevention strategies can reduce the impact of dementia upon people with dementia, on their caregivers, and on the public. Since there is no viable intervention that can actually prevent dementia, risk-reduction strategies are presented here that can delay progression and suppress the negative impact of some symptoms. But dementia is inexorable and there is no pharmacological or non-pharmacological treatments that can fully prevent progression, only moderate it somewhat. In this context, prevention involves implementation of key interventions proven to delay progression and help individuals remain in lower cost, less restrictive environments for as long as possible. Where education and prevention come together is that for ‘prevention’ or risk reduction strategies to achieve their maximum benefit, they must be implemented on a timely basis. For that to occur, primary care doctors, nurses, attendants, and caregivers must be aware of indicators of specific symptoms and they must know the correct intervention.
Effective ‘prevention’ strategies are identified in most every section of this report. However, accompanying the description of each one is invariably research showing that these research-based strategies are under-utilized. What is needed is an effective means of educating providers and caregivers so that the right knowledge is both available and utilized at precisely the right moment. As described below, current education and training approaches are not achieving the intended results: primary care, emergency room doctors and other healthcare staff do not have consistent, current knowledge of resources and treatment alternatives and consistently miss opportunities for early identification, diagnosis and referral. While there are excellent inventories and guidelines outlining what works, this information simply is not considered consistently at the moments when the information is most needed. This section concludes with reference to Section IV.C. as in the research on care coordination may lie solutions that could facilitate access to the most important information at the most timely moments.

**The Importance of Prevention or Risk Reduction Strategies**

The World Health Organization (WHO) identifies three successive stages of prevention:

- **Primary prevention.** This stage of prevention covers all activities designed to ‘reduce’ the instances of an illness in a population and thus to reduce, as far as possible, the risk of new cases appearing. In relation to dementia, currently there is no treatment or intervention that has been proven to prevent onset of dementia.

- **Secondary prevention.** This covers activities aimed at reducing the prevalence of an illness in a population and thus to reduce its duration. Except in relation to a small number of reversible forms of dementia generally caused by other treatable co-morbid conditions, there is no treatment or intervention that can reverse or reduce the duration of dementia.

- **Tertiary prevention.** This aims to reduce the incidence of chronic incapacity or recurrences in a population, and thus to reduce the functional consequences of an illness, i.e. therapy, various rehabilitation techniques and intervention designed to assist the patient to return to educational, family, professional, social and cultural life. Here, too, there is no treatment that can restore functioning and assist a person with dementia to a prior level of functioning.

There are currently no proven measures or treatments that prevent dementia and the causative factors are considered too complex to make general population screening possible. Further, while there is a substantial body of research that suggest the onset and progression of dementia and other forms of cognitive impairment can be delayed, there is no cure.

Therefore, in this report, prevention is more accurately described as **risk reduction strategies** that slow progression of the disease, effectively treat or prevent co-morbid conditions, improve patient quality of life, ease caregiver burden and reduce reliance on high-end assisted living, hospitals and skilled nursing facilities. In this regard, subsequent sections of this report identify numerous treatments and interventions that have been demonstrated to delay progression and alleviate symptoms that left unchecked result in institutionalization.

While they do not meet the classic definition of a prevention strategy, nonetheless, the effective, broad and consistent implementation of these practices can reduce patient suffering, caregiver stress, and public costs.

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In respect of Alzheimer’s disease alone (given that Alzheimer’s accounts for 59% of all cases of dementia), Access Economics estimates\textsuperscript{15} that, if from 2005 the average onset of Alzheimer’s could be delayed by:

- 5 months, there would be a 5% reduction in new cases each year. This would result in 3.5% fewer cases by 2020 (4,583) and 4.8% fewer cases by 2040 (18,970).
- 5 years, there would be a 50% reduction in new cases each year. This would result in 35.2% fewer cases by 2020 (46,568) and 48.5% fewer cases by 2040 (96,690).

In 2004, assuming that Alzheimer’s disease costs some 59% of the cost of all dementias, and allowing for increased prevalence due to demographic aging and cost increases of 2.5% per annum between 2002 and 2004, the cost of Alzheimer’s disease in Australia is estimated by Access Economics to be $3.6 billion.

On the basis of their modeling, Access Economics has presented cumulative savings scenarios. If the average onset of Alzheimer’s disease was reduced by 5 months from 2005, then by 2020 cumulative savings of $1.3 billion would be realized and by 2040, $6.6 billion. If the average onset of Alzheimer’s disease was reduced by 5 years from 2005, then by 2020 cumulative savings of $13.5 billion would be realized and by 2040, $67.5 billion. The savings in terms of human suffering are immeasurable.

To achieve these savings, it is imperative to identify dementia early. Changes in memory can be detected up to 10 years before dementia is diagnosed\textsuperscript{16}. Research has revealed some of the factors that increase the risk of dementia. Modifying these factors may prevent or delay the onset of dementia. Greater understanding of the neurodegenerative processes involved in dementia has opened avenues for the development of new treatments. An important discovery is that vascular disease plays a large role not only in vascular dementia, but also in Alzheimer’s disease\textsuperscript{17}. There are a multitude of ways that cardiovascular risk factors interact with Alzheimer’s disease. Diabetes increase the risk threefold for Alzheimer’s disease possibly by diminishing the ability to clear Alzheimer’s disease related proteins and ischemic injury to the brain lowers the threshold for the expression of a dementia associated with Alzheimer’s disease pathology.

Risk factors for vascular disease include high blood pressure, cholesterol and homocysteine, diabetes, smoking and obesity. These risk factors in midlife and beyond have been linked to decline in cognition and risk of dementia. Diet influences risk of dementia. Foods or supplements containing antioxidants or omega-3 fatty acids have been found to be protective but consumption of foods high in total and saturated fat and cholesterol increase risk. Activity levels also moderate dementia risk. Higher levels of leisure, physical and mentally stimulating activity in elderly people are associated with lower rates of dementia. This is consistent with the protective effect of formal education over and above socioeconomic status. Public health intervention for modifiable risk factors can prevent or delay dementia onset at the population level. For example, a randomized controlled study of hypertension treatment reduced the risk of dementia by 55% after 4 years.

Among the conditions that are associated with reduced risk of dementia or delayed onset:

- Hypertension treatment for subjects with high blood pressure;
- Normal midlife blood pressure;
- Normal midlife cholesterol;
- Weekly fish or seafood consumption;

\textsuperscript{16} Ibid
\textsuperscript{17} Ibid
Moderate wine consumption (8 to 14 drinks per week)
Use of Vitamin E and C supplements;
Highest quintile of dietary Vitamin E intake;
High leisure activity;
High physical activity
Frequent cognitive exercise (top 10%); and
More than two years of non-steroidal anti-inflammatory drug users.

Many of the above have small correlations with reduced incidences of dementia and it should not be understood to suggest that keeping fit and eating well can prevent dementia, only that such behaviors can lead to a reduced prevalence in some forms of mostly vascular-related dementias across a large population.

In addition to there being opportunities for delaying the onset of dementia, there has been substantial improvement in clinical diagnosis of the different dementias. Earlier diagnosis provides benefits for both the person with dementia and the person’s family through treatment, support and planning. This will become more important as disease-modifying treatments become available. As the following section suggests, beginning with diagnosis and extending through all stages of treatment, the gap between what we know and what we do has significant impact upon the quality of care, patient quality of life, caregiver burden and public and private costs for care.

**Missed Opportunities: When Knowledge is not Translated into Practice**

To understand the critical importance of ensuring that education and training efforts translate into common practice, brief references are made to sections of this report. Each one provides evidence of the availability of knowledge, best practice, community resources, treatments and interventions each of which have improved the quality of care, reduced patient suffering, delayed functional decline, eased caregiver burden and most often reduced public expenditures. Yet, research shows the knowledge of these options has not consistently translated into common practice. In short, the knowledge available is not at the fingertips of those responsible for making critical decisions about patient care and caregiver support.

It is important not to interpret the following summary of Section 4. SERVICES & SUPPORTS, starting on page 19, as an indictment of medical practice as relates to dementia. It is simply the case that much more is known about caring for people with dementia than health professionals can possibly have at their fingertips and, with rare exceptions, no systems are in place to address this systemic weakness.

- Sections 4. A and B describe the billions of dollars in cost savings that could result from earlier identification and referral of dementia and the failure to diagnose and treat co-morbid conditions effectively. People with dementia in early stages manifest symptoms that while subtle and similar to normal memory loss, nonetheless are detectable and then diagnosable if the correct diagnostic tools are utilized. Yet, half of all cognitive impairments are never formally diagnosed. Failure to identify and diagnose dementia in early stages represents a missed opportunity for care planning, early pharmacological and non-pharmacological interventions, and education of caregivers, which collectively can significantly slow progression and reduce the burden of caregiving. Expert panelists noted the impact of missed diagnoses where individuals with mild to moderate cognitive impairment present at emergency rooms or primary care clinics and despite being seriously disoriented, obtain only treatment for physical ailments without addressing disorientation. But too often primary care doctors, emergency technicians or doctors, nurses, or caregivers overlook the symptoms and fail to seek or prescribe tests to obtain a diagnosis.
• Section 4. C describes the benefit of non-pharmacological interventions available in the community, while noting that out of absence of information about these resources, most often primary care doctors prescribe drugs, but do not make referrals to community resources. Partners in Dementia Care, a New York state partnerships with the Veterans Administration demonstrated that pairing primary care doctors with care coordinators who were current on all the available interventions and community resources and could assist the caregiver in getting trained and educated, resulted in significant reductions in stress on the caregiver, reduced instances of depression, and improved quality of care.

• Section 4. D describes the devastating effect of incorrect prescriptions for medications to control behaviors or depression, the negative impact of primary doctors selecting the wrong cholinesterase inhibitors for the specific stage of cognitive impairment. In Expert Panel meetings, expert panelists described this as being commonplace and gave examples of the crippling effects of drug interactions or prescription of drugs for depression that significantly accelerated functional decline.

• Section 4. E describes the availability of numerous interventions that reduce costs, improve or slow the loss of memory, manage behaviors, and maintain physical functioning. Yet one study of 240 dementia patients revealed that a chart review found absolutely no evidence of referral for anything other than pharmacological treatment. Caregivers were not sent to education programs, exercise, nutrition, and adult day care programs were not suggested, and patients were not referred to memory exercise programs and other community-based resources that can slow the progression of functional decline. The potential benefit of sensitivity to environmental factors is also described that can reduce patient stress and alleviate other behavioral symptoms, e.g. adjustments in lighting to treat sleep disorders. Yet, too often environmental modifications are not evident in residential programs or recommended for patients still living at home.

• Section 4. F describes the tremendous benefit to the patient and the significant reduction in public expenditures that result from individuals remaining in the home as long as possible. One study projected that simply delaying by one month entry into skilled nursing facilities would result in savings of $1.2 billion annually. Here caregiver education is of tremendous importance and the failure of health professionals to refer caregivers to resources like the Family Caregiver Alliance or the Alzheimer’s Association results in caregivers lacking an understanding of how to modify their home environment, provide effective home support, modify behaviors and being familiar with alternative treatment options and community resources, or just understanding the condition and its progression so that care planning can be made in advance. Yet, far too often referral to these sources does not occur, first because the diagnosis does not occur as early as possible and second because primary care doctors do not systematically make these referrals.

• Section 4. G describes co-morbid conditions and how they can be identified and treated. Here again, it is too often a story of missed opportunities. Expert Panelists commented about how common it is for co-morbid conditions to be misdiagnosed or mistreated, particularly in relation to behavioral conditions. Here the consequences of prescribing the wrong medication can lead to significant and unnecessary complications. Many behavioral problems can be addressed with environmental modifications. Since behavioral problems are one of the most common reasons that caregivers ultimately place their loved ones in assisted living programs, being adept at balancing pharmacological and environmental modifications can significantly reduce reliance on more restrictive levels of care.

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• Sections 4. H and I describe how adult day health care, social day care centers and Alzheimer’s Day Care Resource Centers can significantly slow the progression of cognitive decline while also easing the burden placed upon caregivers, particularly in early and mid stages of cognitive impairment. Unfortunately, primary care physicians do not routinely refer patients and caregivers to these resources.

• Section 4. J describes a summary of strategies for supporting caregivers with one large study indicating that caregiver education and referral to community resources can lead to improved outcomes for both the caregiver and patient. Indeed in no less than 19 studies psycho-educational programs have been shown to be one of the most effective interventions with the broadest impact upon caregivers and patients. As noted above, however, too often caregivers are not referred to resources that will provide the beneficial education, training and community resources: another missed opportunity.

• Section 4. K describes various kinds of assisted living or Residential Care Facilities for the Elderly (RCFE) and the extent to which regulations proscribe wholly insufficient levels of training for staff in these programs. The failure to adequately train staff in RCFEs often results in patients being referred to skilled nursing facilities before this would be necessary if staff had been better trained to address patient needs, particularly in relation to behavioral problems.

• Section 4. L describes skilled nursing facilities and their care for individuals in mid to late stages of dementia. San Francisco is blessed with two extraordinary such facilities (Laguna Honda Hospital and the Jewish Home). However, as in other jurisdictions, the failure of the network of services and supports to identify and implement effective risk reduction strategies leads to increasing numbers of individuals being discharged from assisted living facilities sooner that would have otherwise been the case. The result is the demand for skilled nursing facilities far outstrips the supply, a situation that will only worsen significantly as San Francisco’s baby boomer generation ages.

• Finally, Section 4. M describes a discussion of end-of-life and hospice care. Here unlike elsewhere, the real problem is applying too much of what is known to intervene and extend life with medical interventions (feeding tubes, etc.). Extending the life of individuals with advanced dementia may only extend suffering and create more stress on loved ones who struggle with the moral implications of making the difficult decision to cease efforts to extend life.

In all instances cited above, it is not the lack of information in the literature about the benefits of specific interventions and strategies. It is the failure of that information to be translated into common practice that results in preventable human suffering, caregiver burden and public costs. Each of the above examples represent missed opportunities to implement effective strategies that either reduce symptoms, slow the advance of the condition, and/or improve the capacity of caregivers to support the individual with a cognitive impairment. The problem is not with individual doctors, other health professionals, or individual hospitals that are indifferent to the need to what is best for patients. The problem is systemic: with too much information that changes frequently, there is no system for ensuring that those responsible for patient care and caregiver support, have the information they need, when they need it. In the absence of such a system, the story of the crisis in dementia care will be a litany of missed opportunities, unnecessary human suffering, and avoidable public expenditures.

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**Education Strategies**

Education strategies have the potential for significantly improving the quality of care for individuals with cognitive impairment, improving their quality of life, reducing the amount of time spent in more expensive, more restrictive settings, and lowering the burden on caregivers. In part, this is due to current knowledge of best or most effective practices as identified in the literature and in a variety of ‘guidelines’ developed in the United States and internationally. Current research and guidelines point to specific practices, treatments, and interventions that if employed could significantly improve the quality of care for those with cognitive impairment. However, research shows that to a very significant degree, practitioners in a variety of settings do not implement recommended practices with any degree of consistency. Put simply, the gap between what is known and what is done is quite large, and the impact of that gap can be very significant in terms of human suffering and public costs.

In the subsection on Prevention above, references are made to the missed opportunities resulting from this gap between what is known and what is done. The key individuals who are able to bridge this gap are doctors and other health care staff who treat individuals with cognitive impairment, and their caregivers, and an array of individuals who have routine contact with individuals with impairments such as social services staff and residential services staff. As noted above, the solution lies in each of these individuals having the right information at the right moment.

**Primary care and emergency room physicians**

Physicians have the functional role of identifying, diagnosing and treating individuals with a cognitive impairment. With primary care and emergency room doctors, missed opportunities result from a combination of factors:

- Less than ideal level of training in medical school in the identification and treatment of dementia;
- The vast number of conditions, symptoms and ailments about which a doctor should be current;
- Lack of time to keep current with a variety of emerging promising practices; and
- Lack of time to carefully observe and question elderly patients to identify signs of memory loss.

Most primary care physicians do not access websites for disease-specific information unless they are specifically looking for something related to a current case. Primary care physicians have too many possible areas about which they should know to routinely look for emerging trends in every condition that is prevalent among elder patients. As a result, they tend to use free or fee-based subscription services that email journal articles or updates. For example, with Amedeo.com doctors can identify the areas where they would like information and a daily list of articles would be provided. However this free service requires the doctor to then scan a long list of journals and seek out the information amidst a dizzying number of options.

UCSF offers its doctors a similar but, more user-friendly service. “Up to Date” provides periodic summaries of current research with links to articles. This is a more accessible and time-efficient means of getting information as it doesn’t just present doctors with a list of relevant journals, but rather introduces each resource with narrative identifying its relevance. A doctor could scan the
email and identify issues and research relevant to his or her current practice/patients. But “Up to Date” still requires a busy doctor to pour over a lengthy email and as s/he finds something of interest, then to print out an article. When you consider the number of medical issues for which it would be advisable for a primary care doctor to be current, it is no wonder that it doesn’t happen with consistency. It is also not surprising that these same doctors rely more heavily on pharmacological interventions as they receive a regular stream of reader-friendly, easily digestible information from pharmaceutical corporations with ‘research’ demonstrating the efficacy of their products. Unfortunately, this leads to an over-reliance upon pharmacological interventions and a corresponding under-utilization of effective non-pharmacological interventions.

There are other resources that could be used to inform and improve the practice of the entire network of services and supports for individuals with dementia. Guidelines have been developed in Europe and the United States with some being narrowly focused upon one aspect of care and others covering the full spectrum of the cognitive impairments. Among the excellent resources containing the most current and effective practice recommendations:

Guidelines and Protocols for Cognitive Impairment in the Elderly – Recognition, Diagnosis and Management (January 2008). This guideline focuses on protocols for identification, diagnosis and management of early stages of cognitive impairment. It is but one of dozens of examples that could have been cited. It contains very specific recommendations for identifying individuals with cognitive impairment and then confirming the specific condition with diagnostic tools.

Guideline for Alzheimer’s Disease Management, Final Report. California Department of Public Health and Alzheimer’s Association. Providing perhaps the most current analysis of evidence-based practice in assessment, diagnosis, treatment, and community-based care, these guidelines provide detailed recommendations based upon research for virtually every aspect of treatment and care for individuals with dementia. It is an excellent resource. As with other resources, however, it is incumbent upon the health professional to seek it out or to have it accessible at the moment that a diagnosis, prescription, or referral must be made.

Tools for the Early Identification, Assessment, and Treatment for People with Alzheimer’s Disease and Dementia. Another publication by the Alzheimer’s Association that provides specific tools for identifying and assessing dementia.

Dementia Care Practice: Recommendations for Assisted Living Residences and Nursing Homes, Alzheimer’s Association Campaign for Quality Residential Care. As with the Final Report above, this guideline provides comprehensive and specific guidelines related to all aspects of operations in assisted living and skilled nursing facilities.

Dementia Care Practice: Recommendations for Assisted Living Residences and Nursing Homes, End of Life Care. This guideline extends the recommendations in the guideline above with recommendations for end-of-life care.

The point of the above references is to underscore the degree to which information is accessible related to virtually every aspect of the identification, treatment and support for people with cognitive impairment and their caregivers. An effective information delivery system can ensure that the best information is available to health professionals at the moment when that information is needed.
Training for other Health Professions

Certified Nursing Assistant Training: The “WHAT HAS HAPPENED TO ME” dementia specific training program has been developed in order to expand training of the Certified Nursing Assistant (CNA), the front line care giver, in how to understand and care successfully for the resident with dementia.

The Dementia Training Standards Act of 2001, AB 1347, Chapter 389, Statutes of 2001, focuses on the CNA staff caring for residents in California Skilled Nursing and Intermediate Care facilities. The Act requires a 2 (two) hour initial Dementia specific training component to be incorporated into each facility’s orientation program and to provide an additional mandatory 5 hours in-service training per year for CNAs.

The “WHAT HAS HAPPENED TO ME” dementia program discusses the complex scope of dementia, different disorders that can cause dementia and allows the CNA to identify different forms of Dementia, behavioral problems associated with Dementia and how to provide daily care in a compassionate and dignified manner. The Alzheimer Association also has a range of caregiver resources and training options. For example, it provides a multimedia, online training program appropriate to all staff in assisted living programs. The CARES Program is divided into six modules, each one approximately one hour in length. The training includes segments on:

- Introduction to an Effective Care Team
- Introduction to Dementia
- Understanding Resident Behavior as Communication
- Making a Connection with the Resident
- Eating Well
- Recognizing Pain

In this context, the challenge is to find ways to ensure that physicians responsible for caring for the elderly are able to easily access the most recent guidelines related to diagnostic and treatment protocols. Again, these resources are easily accessible. The challenge is developing a framework in which primary care doctors, other health care personnel, emergency medical technicians, emergency room doctors and caregivers are able to access this information at the right moment.

Caregivers

Research shows that caregivers who have been educated or trained experience far less stress and those for whom they care tend to remain at home and out of expensive residential programs. An informed caregiver is able to advocate for the correct pharmacological prescription, environmental modification, exercise regimen, or other community resource. An informed caregiver can be a critical factor in ensuring that a patient receives the most appropriate treatments at the most appropriate time. In short, an informed caregiver can serve to avoid many missed opportunities and prevent many mistakes simply by questioning physicians, presenting alternatives, and insisting upon adherence to guidelines and best practice. Fortunately, there are good and reasonably accessible resources for providing caregivers with the information needed to advocate effectively. Unfortunately, this requires that caregivers devote a significant amount of time, not just for caring for their loved one, but researching how best to do so.

Among the best resources for caregivers are guidelines, educational materials and training most significantly from the Family Caregiver Alliance and the Alzheimer’s Association. All of these resources are accessible via the websites of each organization.
Family Caregiver Alliance. The Family Caregiver Alliance website has a wide variety of tools, assessments, articles, guidelines on how to handle a wide range of legal, treatment, housing, and support issues. These support materials are well organized by topic, easily sortable, and were developed explicitly to support caregivers. It is an excellent resource.

http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=368

At this site is an online database, Family Caregiving: Emerging Practices & Tools for Professionals, that houses an inventory of well-indexed practices and tools relevant to issues faced by family caregivers and organized into:

- Education and Training;
- Selected Evidence-Based Interventions;
- Focusing on the Caregiver;
- Daily Care;

This database is designed to bridge the research-to-practice gap and ensure professionals working with families have access to meaningful and quality programs and services. It will assist researchers, program administrators, and practitioners identify successful and innovative programs, and provide an understanding of what makes these programs successful. The aim of this repository is to:

- highlight fresh ideas from emerging practices;
- promote adoption of practices informed by research;
- foster innovation;

Family Caregiving: Emerging Practices & Tools for Professionals is the first step towards the creation of an Innovations Clearinghouse on Family Caregiving of cutting edge programs and policies in caregiving and aging. This online Clearinghouse will evolve to include evidence-based practices, advocacy efforts and public policies that offer meaningful solutions, strengthen the caregiving voice and support families in their caregiving role. It will also provide dynamic educational opportunities and online communities of a national scope for professionals. For now, it provides a model framework for maintaining an inventory of current practice that is easy to use and provides valuable information to caregivers.

Alzheimer’s Association Savvy Caregiver Training. The six-week Savvy Caregiver Training Program, which the chapter last year began to offer, is that opportunity.” Based on research by experts, the Alzheimer’s Association Savvy Caregiving series tackles caregiving as a set of learnable skills, centered around the twin goals of taking care of oneself while helping the care-receiver maintain a state of contented involvement in activities. Caregivers learn to step back, to become a skilled observer, to understand their family member through the Alzheimer’s lens, and to strategize and take control of the evolving situation. Participants report an increased sense of mastery over their caregiving role.

The Memory and Aging Center at UCSF: The Memory and Aging Center hosts an award winning website with state of the art information for caregivers and professionals on the major neurodegenerative conditions. It offers special emphasis on non-Alzheimer’s disease dementias including frontotemporal dementia and prion disorders. The website offers videos linked to YouTube that describe the clinical features of neurodegenerative conditions, and has extensive caregiver advice.
Powerful Tools for Caregivers Online Mather LifeWays Institute on Aging. Another resource for caregivers is based on the Chronic Disease Self-Management Program at Stanford University. Powerful Tools for Caregivers Online is a six-week, online educational course that will help the caregiver:

- manage the common stresses associated with caring for a relative or friend with a chronic medical condition
- design effective action-planning tools and time management as a caregiver
- communicate more effectively with friends, family, health care providers, and coworkers
- find resources
- cope with emotions such as guilt and depression

The recurrent theme of this section is that a gap exists between what is known and what is done and the seeming inability to bridge this gap. The research points to a number of possible strategies to help narrow this gap.

Final Considerations

Team-Based, Coordinated Care. A variety of team-based, care coordination programs and demonstrations integrated care coordinators, case managers and care advocates whose function it was to be the team expert as to the most appropriate treatments and supports. A primary care physician has dozens of conditions, diseases, and symptoms to consider in caring for the elderly. By taking a coordinated team approach, it allows multiple perspectives and multiple resources to be focused upon the needs of the patient. Section IV.C. describes a number of these models, most all of which demonstrated significantly improved patient and caregiver outcomes.

Quality Assurance Systems. One feature that distinguishes a network from a system is the reliance upon system-wide quality assurance practices. One of the goals of the Alzheimer's Association's Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes is to “incorporate the practice recommendations into quality assurance systems.”

Extremely limited fiscal resources may be available to address our health and human needs. This is a disease that is projected to increase exponentially in prevalence potentially financially compromising the health system, leaving hundreds of patients in late stages with literally nowhere to go. At the same time, research from throughout the world points to a large number of strategies and interventions – beginning with identifying cognitive impairment at the earliest possible moment – that can slow the progression of cognitive impairment thereby significantly delaying entry into the most restrictive care settings that are in greatest demand. Given that we face a potentially catastrophic landscape by 2020, much depends upon developing a framework that incorporates the best of what we know from the research.

4. SERVICES & SUPPORTS

The summary of research in relation to services and supports is organized into 14 subsections with each subsection focused upon a particular component of care for individuals with cognitive impairments. Each subsection begins with a review of the literature, followed by identification of specific models or exemplary practices, as available.
While over 140 documents were reviewed, several sources were utilized extensively and warrant acknowledgment, including:


**Practice parameter: management of dementia (an evidence-based review). Report of the Quality Standards Subcommittee of the American Academy of Neurology.** According to the guideline developer, this guideline has been reviewed and is still considered to be current as of October 2003. This review involved new literature searches of electronic databases followed by expert committee review of new evidence that has emerged since the original publication date. This review identified over 2500 studies, 380 of which met the criteria for inclusion in the meta-analysis. Practices then were rated: Standard (highest evidence of benefit), Guideline (moderate level of documented benefit) and Practice Option (where there was significant uncertainty of benefit).


Guideline 86 is a national clinical guideline from Scotland with evidence-based recommendations for diagnosis, pharmacological and non-pharmacological treatments, and services for patients and caregivers.

http://www.sign.ac.uk/guidelines/published/support/guideline86/index.html

**Improving Services and Support for People with Dementia, National Audit Office, July 2007**

This document is a very current and exhaustive summary of the literature relating to services and supports for caregivers of individuals with cognitive impairments.


This document is a nearly 500-page review of the Australian system’s national demonstration project. The document includes both literature citations, reviews of randomized clinical trials, and evaluations of outcomes on four short-term case management-caregiver education demonstrations and four long-term case management models.


4A. **IDENTIFICATION AND REFERRAL:** Multiple points in emergency services, primary care, and community-based services where individuals with early stage cognitive impairments can be identified and referred to the right place in a sensitive way.

There is a significant amount of research available in relation to most of the components of care for individuals with cognitive impairments, particularly as relates to treatment of mid to late stages of the disease, however, while there is also abundant research supporting the benefit to early
identification of individuals with cognitive impairments, research on systems and strategies for early identification were difficult to find. As a result there is a significant diagnosis gap with only between one-third to one-half of people with cognitive impairments ever receiving a formal diagnosis. Often cognitive impairments are not diagnosed until a person is admitted for an acute physical illness, but often even here a cognitive impairment diagnosis and referral may be missed.

Early identification of cognitive impairment allows for care management to be initiated with the potential for reducing costs associated with pneumonia, chronic skin ulcers, infection, depression, behavioral disturbances, hip fracture, malnutrition, dehydration, intestinal obstruction, lacerations, sprains, hypothermia and burns. What’s more, early identification reduces costs for hospitalization, delays nursing home placement, and permits advance planning. Finally, fiscal projections related to early identification and the early introduction of treatments that can delay onset of cognitive impairments suggest that an average delay of onset of one year would reduce the number of patients with cognitive impairments by 210,000, creating an annual projected savings of $10 billion.

As noted in Section 4.E., there are numerous interventions that can lead to improvements in memory and physical care, can delay the onset of cognitive impairments and reduce the cost of formal and informal care. For these interventions to have effect and to maximize potential cost savings, individuals with cognitive impairments must be identified early and referred effectively to those programs that deliver these interventions.

People with symptoms associated with the possible onset of cognitive impairments often do not present to their primary care physician because of fear and the stigma associated with a diagnosis of cognitive impairment. The attitudes of the physician to the disease can also hamper diagnosis, with many holding the view that little can be done. The British National Audit Office report on improving services and support for people with cognitive impairments suggests that memory assessment services can help to break down barriers and reduce stigma by:

- being called ‘memory’ services rather than ‘mental health’ or ‘old age psychiatry’ services
- improving communication
- moving away from intimidating psychiatric or other hospital settings to a primary care environment.

Developed in England and recommended by the National Institute for Health and Clinical Excellence and the Social Care Institute for Excellence, memory services are a multidisciplinary team focusing on early detection, assessment and treatment of cognitive impairment. This is a single point of referral for all cases suspected of cognitive impairment. Memory services like the Croydon Memory Services can provide a cost-effective way of significantly increasing the number of people seen for early diagnosis and treatment.

Clues to cognitive impairments may be subtle and nonspecific, however, symptoms often are stimulated by physical or emotional crisis. As such, emergency rooms, emergency medical

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22 Holmes, J., Research School of Medicine, University of Leeds (1999)
technicians, fire and police services are often in position to recognize cognitive impairments and refer individuals appropriately. Postal workers, clergy members, bankers, family members and friends are others who are likely to observe behaviors that could lead to a referral for an evaluation. The Alzheimer’s Association publication entitled *Ten Warning Signs of Alzheimer’s Disease* is an excellent tool to sensitize individuals to identify cognitive impairment. However, we could not find models offering widespread training of those outside of the primary care system.

In addition to the *Ten Warning Signs*, the Alzheimer’s Association has also developed a family questionnaire for the purposes of obtaining information from family members about behaviors that could indicate cognitive impairment.

As noted in Section 4.B. below, the challenge is not the absence of screening and diagnostic assessment tools that are effective once a person has been identified exhibiting behaviors suggestive of cognitive impairment, but the absence of models for training individuals to be more sensitive to these behaviors and to understand the importance of early detection and referral for services. The solution to this dilemma may lie in the review of education and prevention literature and the identification of a training program targeting individuals who come into contact with individuals during the very early stages of cognitive impairments.

The Michigan Dementia Plan outlines a plan for training community “gatekeepers” to be better able to identify and refer individuals with cognitive impairments, identifying postal workers, clergy, and emergency services providers as being in a position to identify persons with cognitive impairments, however, researchers were unable to identify an evaluation of the implementation of this strategy.

### 4 B. ASSESSMENT & DIAGNOSIS - EARLY SCREENING:

*Assessment of daily functioning, cognitive status, co-morbid medical conditions, behavioral symptoms, medications, living arrangements, transportation, caregiver resources, recreation/activities and future planning issues, and a need for palliative and/or end-of-life planning.*

The literature contains a wide range of standardized assessment tools designed to assess daily functioning, cognitive status, and co-morbid medical conditions, as well as to assess living environment and caregiver capacity. Early, accurate functional assessment facilitates implementation of strategies that maximize patient independence and can delay cognitive impairment’s advance. Barthel Indices assess a patient’s capacity for self-care and independent living,\(^{28}\) and can be administered either directly to the patient or to caregivers.\(^{29}\) These early functional assessments provide primary care physicians and caregivers with a baseline of functionality that can be used to measure patient decline.

Cognitive status should be assessed and reassessed periodically (most recommend every 6 months) to identify sudden changes and to monitor the possible harmful effects of environment and medication. The Mini-Mental State Exam (MMSE)\(^{30}\) is the most commonly used tool for cognitive assessment even with the assertion that it is too much influenced by education and language on performance.\(^{31}\) The MMSE is not sensitive to the early stages of cognitive impairment and is particularly weak at capturing cognitive symptoms associated with non-Alzheimer’s disease dementias. Further, the MMSE is a proprietary tool with added administrative costs that may cause providers to utilize other tools that have been demonstrated to be valid and reliable. Distinguishing

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the different forms of cognitive impairment can be achieved through the use of neuropsychological testing, particularly in the early stages of cognitive impairment.\textsuperscript{32}

Since upwards of 25\% of patients with cognitive impairments suffer from co-morbid physical conditions,\textsuperscript{33} it is important that functional assessments also include physical, psychological, and socio-economic domains. Structured interviews with a caregiver and patient can be used to obtain a medical history and to assess current physical condition. The assessment should include a review of all medications both prescribed and non-prescribed and reassessments every six months should be conducted to identify rapid cognitive decline, as this can be a result of wide variety of reversible co-morbid conditions.

Eighty percent of patients with cognitive impairments experience behavioral symptoms and 50\% experience depression. Since symptoms associated with behavioral conditions can be among the most challenging for caregivers, they often precipitate institutionalization.\textsuperscript{34} As a result, behavioral assessments should be conducted, as appropriate. The sudden onset of behavioral symptoms should also trigger other assessments as sudden onset can result from pain, medication, infection or cardiopulmonary disease. Effective communication between the caregiver and physician about decline in cognition and functioning is essential in managing depression as a decline in functioning without a commensurate decline in cognition often precedes the first episode of depression.\textsuperscript{35}

In addition to monitoring changes in the patients cognitive, behavioral, and physical conditions, it is also important to assess the patient’s living environment as this form of assessment could identify functioning capacity in a familiar setting, as well as the need for environmental supports to maximize safety. Safety concerns relate to three main areas: 1) falls, which is the leading cause of injury and death among elder adults; 2) wandering; and 3) driving. The use of a home safety checklist, such as the one developed by the Alzheimer’s Association, can assist the primary care physician and caregiver in assessing these safety concerns.

Individuals with cognitive impairments are at particularly high risk of personal neglect, caregiver neglect and abuse. Whenever three of the following seven risk factors are present, an assessment or investigation should also be conducted to identify abuse or neglect. Indeed, the presence of only one or two risk factors, may suggest the need for intervention or investigation. Risk factors include:

- Problems with short-term memory
- Psychiatric diagnosis
- Alcohol abuse
- Difficulty interacting with others
- Self-reported conflict with family members or friends
- Feelings of loneliness
- Inadequate or unreliable support system\textsuperscript{36}

4. C. CARE COORDINATION: Treatment planning and service coordination to ensure integration of medical, medication, environmental assessment and modifications, social, financial, caregiver, and support needs and ongoing monitoring of need for reassessment every six months.

Care for people with cognitive impairment is a test of how well health and social services and other partners work together. There is significant level of international research indicating that care

\textsuperscript{33} Maslow, Selstad, & Denman, 2002
coordination or care management is a cost-effective intervention that can delay institutionalization and improve the quality of life for both the patient and the caregiver. Primary care physicians often do not make referrals for community-based care due to lack of sufficient information about resources. There is also research that indicates that embedding case managers into primary care settings can ease the burden on the physician and ensure better use of community resources. But with most US research focusing upon pharmacological intervention or a basic search for a cure, far less has focused on how this coordination of service delivery is best implemented. While there has been some research done on isolated, non-pharmacological treatments and supports, there is little US research on the benefit of care coordination, case management or the integration of services specifically in relation to individuals with cognitive impairments. Far more research on coordination of care has been done in England, Scotland, Canada, and Australia, however these coordinated care practices operate in health systems that are vastly different from San Francisco, limiting the relevance or applicability of this research. US studies on care coordination summarized below provide some evidence of the effectiveness of care coordination on both patient and caregiver outcomes.

**Improving care for individuals with cognitive impairments through community linkages: A multi-site demonstration project**. The purpose of the multi-site project was to develop and implement a model for care for individuals with cognitive impairments that improved linkages of caregivers to community services. Key components of the model included a single point of informational contact, provider education, case-finding, caregiver education and support, internal linkages, and linkages with community services. The model was implemented at six medical centers. Outcome measures included caregiver, provider, and community agency satisfaction. Caregivers reported high satisfaction with information provided to them about community resources. Primary care providers reported that services for individuals with cognitive impairments had improved from one year earlier. Community agencies reported high satisfaction with the dementia program. Caregivers identified the “single point of contact” as the single greatest factor contributing to their support. Unfortunately, the absence of a control group limits the scope of these findings.

**Partners in Dementia Care (PDC)** was an innovative partnership of the U.S. Department of Veterans Affairs (VA) health care network in upstate New York (VISN 2) and four Alzheimer’s Association chapters in the same area. From 1997-2003, these organizations worked together to improve care and outcomes for veterans with Alzheimer’s disease and other cognitive impairments and their family caregivers. The model of care used in the PDC project was intended to address four problems that are common in VA and non-VA health care settings: 1) under-identification of possible cognitive impairment, 2) lack of adequate diagnostic assessments, 3) lack of coordination between medical care and community services, and 4) lack of information and support for family caregivers. The model includes procedures and tools for early identification, assessment, care management, and family caregiver information and support.

PDC placed strong emphasis on training and conducted a wide array of formal and informal training activities throughout the project. A new VA position, Dementia Care Coordinator (DCC), was

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created for PDC, and one DCC was placed in each of VISN 2’s five medical centers. The DCCs performed many functions related to planning, training, enrollment and assessment of veterans and their families, and ongoing care coordination within VA and between VA and chapters. The DCCs also functioned as a resource and team leader for the many VA physicians, nurses, and other staff who participated in PDC at each medical center.

PDC identified, enrolled, and served more than 550 veterans and 500 family caregivers. An extensive evaluation conducted by an independent research team focused primarily on the feasibility of the intervention and its impact on veterans and their families. Evaluation findings show many positive outcomes. VA and chapter staff members were enthusiastic about the model, the training, and the VA/Chapter partnership. They agreed on average that PDC improved quality of care and outcomes for veterans and families, increased their own ability to provide care, and gave them confidence that services needed by veterans diagnosed with cognitive impairment were available. Almost all veterans who enrolled in PDC received the recommended diagnostic assessment, and more than half of the families chose to use chapter services. Veterans and caregivers who participated in the telephone interviews reported on average that they had received enough information or help with important areas of care, including treatment options, family concerns, daily living tasks, and legal and financial issues. Veterans and caregivers who used chapter services were more likely to say they had enough information or help with these areas of care. Those who said they had enough information or help with particular areas of care were more likely to be satisfied and less likely to have symptoms of depression and other negative psychosocial outcomes.

Use of VA health care services changed very little between the 6 months before enrollment in PDC and 6 months after enrollment. Use of chapter services was associated with a higher likelihood that the veteran would have a VA primary care visit and, for veterans with mild memory impairment, a larger number of primary care visits. For veterans with moderate to severe memory impairment, use of chapter services was associated with a lower likelihood of having a specialty physician visit. In addition to these findings, PDC data indicate many findings and associations that did not reach statistical significance but suggest important areas for future research.

The findings from PDC are encouraging. With funding from the Robert Wood Johnson Foundation, the PDC project team used these findings and learning from implementation in VISN 2 to refine the project model. The resulting best practice model is now ready for implementation in other VA health care systems and rigorous testing with a treatment/control group research design.

Conclusions about the impact of PDC on the use and cost of VA health care services for veterans with dementia must await the results of this research. Some PDC procedures were clearly feasible and well accepted. These procedures could be incorporated in quality improvement projects in VA health care settings. They include: the early identification procedures and tools; involvement of non-physician providers, including all clinic staff, in identifying people with possible dementia who need a diagnostic assessment; and the VA/Chapter partnership, including the consent process that allows chapters to initiate contact with families rather than waiting for families to call the chapter.

Anecdotal reports and previous research findings suggest some physicians are reluctant to identify and diagnose dementia because they believe the condition is hopeless and there is “nothing to do” for the person or family. Although not provable with the existing data, it is likely the VA/Chapter partnership in PDC and the availability of information and support for veterans who received a diagnosis of dementia and their families increased physician willingness to make these diagnoses.
The Integrated Care Management Grant Program. The Administration on Aging (AoA) Integrated Care Management grant program is designed to identify and support innovations in aging services that involve the use of partnerships with managed care organizations or Medicare Modernization Act Demonstrations and/or the creation and use of capitated financing arrangements that improve older people’s access to social and preventive services. This program is part of a strategic effort AoA has undertaken to strengthen the role of community aging services programs in promoting a more balanced and integrated system of health and long-term care for older people.

Projects include either program enhancements that build on existing approaches or new models that support the design and/or implementation of new approaches in managed care. Grantees include Area Agencies on Aging (AAAs) and Community Aging Services Providers (CASPs). A broad mix of partnerships between area agencies on aging, community organizations, managed care organizations, universities, and health care providers are represented in the programs. Ten grants were awarded to the following organizations in FY2005, one of which is operating in San Mateo County. Researchers were unable to identify any evaluation of these projects, but would expect that evaluations of these programs will be available soon.

Effectiveness of Collaborative Care for Older Adults With Alzheimer's Disease in Primary Care. Researchers assert that this study was the first randomized clinical trial testing the effectiveness of treatment guidelines for Alzheimer’s disease as delivered through a collaborative care model. Further, researchers assert that this is the first trial in this area that integrates these recommendations within primary care. This setting is important because it represents the care site where most older adults receive their medical care, including those with cognitive impairment, and primary care physicians frequently prescribe psychoactive medications to these older adults. This setting is also important because it represents the logical target for any initiatives to improve the early identification and treatment of dementia or precursor conditions. The primary care practices targeted in the current study serve a medically-indigent, mixed-race population with multiple co-morbid conditions. These patient groups have been understudied in previous treatment trials of Alzheimer’s disease and these patients have fewer personal resources, including family caregivers.

A randomized controlled trial was conducted in Indianapolis primary care settings that compared outcomes for two groups, one afforded “augmented usual care” and the other to receive “care management services.” The experiment was conducted over a 12-month period with improved outcomes for the care management group both at 12 months and at 18 months, six months after care management services was discontinued.

There were 2 care managers, each of whom was an advanced practice nurse, with 1 based at each of the 2 large primary care practices. The care manager saw caregivers and patients in the primary care clinic bimonthly initially and then contacts were lengthened to monthly for a period of 1 year. At each contact with the care manager, caregivers completed the Memory and Behavior Problems Checklist to assess current symptoms and stressors. Based on the caregiver’s responses, individualized recommendations were made regarding how to manage a patient’s behavioral symptoms.

The primary care physician and the care manager were supported through two additional mechanisms. First, the care manager had weekly meetings with a support team comprised of a geriatrician, geriatric psychiatrist, and a psychologist who reviewed the care of new and active patients and monitored adherence to the standard protocols. Second, the care manager was supported by a Web-based longitudinal tracking system that managed the schedule for patient contacts, tracked the patient’s progress and current treatments, and provided an instrument for communicating the patient’s and caregiver’s current clinical status to the entire care team. All intervention patients and their caregivers also were invited to participate in voluntary group sessions. During these sessions, caregivers were taken to a support session led by a social psychologist that focused on caregiver stress. Patients were taken to a nearby room for a group chair-based exercise class led by a health psychologist and the care manager.44

To assess outcomes, a telephone interview was repeated at 6, 12, and 18 months. The interview included 3 standardized instruments developed by the Alzheimer's Disease Cooperative Study investigators45: the Neuropsychiatric Inventory (NPI),46 activities of daily living,47 and health care resource use.48 Intervention patients experienced significant improvements in total NPI scores compared with patients who received augmented usual care. Lower NPI scores reflect fewer behavioral symptoms. Although the intervention was discontinued at 12 months, significant improvements in NPI scores continued at the 18-month assessment. Caregivers experienced significant improvements in caregiver stress at 12 months but not at 18 months as measured by the caregiver NPI. Lower scores on the caregiver NPI reflect fewer symptoms of stress related to the patient’s behavioral and psychological symptoms of dementia.

Medicare Alzheimer’s Disease Demonstration. The Medicare Alzheimer’s Disease Demonstration was conducted to determine the effects of increased access to community-based care on client and caregiver outcomes. While there is significant evidence of increased client and caregiver satisfaction with home/community-based care, it is unclear whether these programs will result in lower public expenditures and in at least one study, there was limited evidence of reduction of depression and burden on caregivers.49 These findings point to the lack of certainty in terms of the value of case management and increased access to care, as in this demonstration, patients with case management accessed more services and patients and caregivers had higher levels of satisfaction with services, yet only modest benefit to caregivers was found. The study did not examine impact upon patient outcomes.

Several international studies were reviewed in relation to projects studying the effects of coordination of care. Two are summarized below.

**Manchester Intensive Case Management for Dementia.** This quasi experimental study was designed to evaluate a model of intensive case management for people with dementia based in a community-based mental health service for older people. Individuals in one community team setting received case management and were compared with those in a similar team without such a service. Forty-three matched pairs were identified. Eligible older people and their caregivers were interviewed at intake and again at 6 and 12 months. The impact of the scheme upon placement occurred in the second year at the end of which 51% of the experimental group remained at home compared with 33% of the comparison group. For the experimental group significant improvements in the social contacts of older people were noted; a decrease in the stress of their caregivers was observed, together with a reduction in their input to the care of the client; and there were significant improvements on ratings of overall need reduction, aspects of daily living and level of risk.

**The National Evaluation of the Aged Care Innovative Pool Dementia Pilot: Final Report., Australian Institute of Health and Welfare, 2006.** This study examined the impact of four short-term case management and caregiver training pilots and four long-term case management models. The study provides convincing evidence of the efficacy of both models with significant improvement in daily functioning, lower levels of stress among caregivers, and delayed entry into institutional care.

The studies cited provide convincing evidence of the efficacy of coordinated service delivery. There are far too many models of care coordination to summarize and the health system context in which care coordination is delivered further complicates adoption of models from other countries.

**4. D. PHARMACOLOGICAL INTERVENTION & MEDICATION MANAGEMENT:**

As a person’s disease progresses, close monitoring of medications for cognitive impairment (cholinesterase inhibitors, NMDA antagonist and other medications for cognitive impairment) and medications related to co-morbid conditions.

**Pharmacological Interventions**

While there is no cure for dementia, there is some evidence that there are some treatments that can help with the symptoms. Drug treatments are one element. There are scores of drugs that have been used in treatment of cognitive impairment and co-morbid conditions associated with cognitive impairment. It is outside the scope of this summary to provide a description of all of them. Below is a brief summary of those drug treatments for which there is evidence of their positive impact as demonstrated in randomized controlled studies. Even here, there is much debate about the possible debilitating side effects of these drugs.

This review does not go into depth regarding the relative effectiveness of each drug at different stages of cognitive impairment and for different forms of dementia. It is important to note that pharmacological research advances very quickly as it is one area where there is significant investment in research. As such, the understanding of the delicate interaction of pharmacological treatments changes quickly. So, while it is important to capture current best practices, it is more important to realize it is vital that, as this information changes, the most current and recommended treatment protocols for each form of dementia and for each stage of the disease be made available to primary care physicians. A challenge to providing the most effective care to individuals with cognitive impairment is the need to increase the capacity of primary care physicians to utilize the most current pharmacological treatments and to effectively refer patients for non-pharmacological services and supports that can slow cognitive decline. Indeed, it has been noted (below), that very often the use of the wrong pharmacological treatments can exacerbate symptoms and accelerate decline, particularly in relation to the use of pharmacology to control or manage behavioral symptoms.
Currently there are four commonly used FDA-approved medications for Alzheimer’s disease (AD). Each has been shown to be effective at different stages of Alzheimer’s Dementia. Evidence exists that the acetylcholinesterase inhibitors, donepezil, rivastigmine and galantamine may have beneficial effects at all stages of dementia (mild, moderate and severe), whereas the NMDA receptor antagonist, memantine is most effective in moderate-severe AD. Furthermore, combinations of an acetylcholinesterase inhibitor and memantine may offer benefits over use of either drug alone. Finally, some evidence exists that cholinesterase inhibitors may offer modest benefits to individuals at the earliest stages of AD, what is sometimes referred to as mild cognitive impairment, particularly those with genetic risk factors for progression to dementia such as the ApoE4 allele.

It should also be recognized that a variety of new diagnostic tools and treatments that have the potential to alter or modify the progression of the underlying AD are progressing through human clinical trials and may soon be available for routine clinical use. Diagnostic tools such as measurement of AD-related protein levels in the spinal fluid and blood, as well as new types of brain scans that can detect accumulation of AD-related amyloid protein may eventually help to improve specificity of an AD diagnosis and possibly even identify individuals at earlier, pre-dementia stages of disease when treatments and other interventions are most likely to be effective.

**Cholinesterase inhibitors:** Drugs known as cholinesterase inhibitors help some people with cognitive impairment become less forgetful and confused, though they cannot stop the disease from eventually worsening. In 2006, the National Institute of Health in England advised that cholinesterase inhibitors are cost-effective in moderate Alzheimer’s disease and in the United States the use of cholinesterase inhibitors is recommended at all stages of dementia.

Several second-generation cholinesterase inhibitors including donepezil, rivastigmine and galantamine have been introduced. At the case control study level, there is support for long term use of cholinesterase inhibitors to delay institutionalization.\(^{50}\) The cost of additional community services is not taken into account in this study, but savings in the cost of caring for patients in institutions may be substantial.

- **Donepezil.** A systematic review of the use of donepezil in people with vascular dementia demonstrated some benefit to patients with mild to moderate dementia examined over a six month period.\(^{100}\) There is a large body of consistent evidence indicating the effectiveness of donepezil in reducing psychiatric symptoms and a limited number of behavioral problems in patients with mild to severe dementia.\(^{51, 52}\)

- **Galantamine** is effective for the maintenance of cognition in people with mild to moderate Alzheimer’s disease.\(^{53}\) There is evidence of some cognitive benefit to patients with mixed Alzheimer’s disease and cerebrovascular disease.\(^{54}\) Higher doses of galantamine are more

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effective than lower doses, although there is no added benefit of doses in excess of 24 mg per day.\textsuperscript{55} Slow dose escalation appears to improve tolerability to the drug.\textsuperscript{56} One study suggests that the greatest benefit is achieved in patients with moderate dementia with an MMSE score of less than 18.\textsuperscript{57}

- **Rivastigmine.** In people with mild to moderately severe Alzheimer’s disease, rivastigmine treatment showed significant benefits in cognitive and global function.\textsuperscript{58-61} Like Galantamine, rivastigmine is approved by the FDA for mild to moderate dementia. None of the cholinesterase inhibitors are approved for mild cognitive impairment.

- **N-methyl-D-aspartate (NMDA) antagonist memantine.** People in mid or late stage dementia should be prescribed NMDA. In two randomized trials\textsuperscript{62} NMDA was tested against a placebo with 900 mild to moderate level dementia patients. In a pooled analysis of the data, subgroups were examined. In a first analysis, patients were stratified by severity of dementia (measured by the MMSE total scores at baseline). In this analysis, memantine was superior to placebo in all subgroups, but the magnitude of effect was more pronounced in the more severely demented patients.

In these trials, Memantine at a dose of 10 mg b.i.d. was safe and well tolerated with a frequency of dropouts due to adverse events that was close to placebo. Memantine is approved for the treatment of severe dementia, but not mild dementia.

**Pharmacological Interventions for Behavior Management**

When non-pharmacological treatments are not effective in reducing agitation or other behavioral symptoms, psychotropic medications may be used with caution and require close monitoring due to potential interaction with other medications and side effects.\textsuperscript{60} While medication may reduce symptoms, rarely will they eliminate them. Indeed, with the exception of atypical anti-psychotics, there is little evidence of the efficacy of medication in relieving behavioral symptoms and significant evidence of possible deleterious side effects.\textsuperscript{61}

**Medication Management**

Inappropriate management of medications is a significant cause of co-morbidity and mortality in adults, particularly for adults with dementia.\textsuperscript{62} As a result, patients and caregivers should bring all medications, prescribed and not, as well as all herbal and other nutritional supplements for every medical appointment. To identify the need for altering medication treatments, it is recommended that the primary care physician ask questions about each medication, such as:

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\textsuperscript{59} International Psychogeriatrics (2003), 15:207-213 Cambridge University Press


□ Is this medication achieving its purpose?
□ Is this medication causing an adverse effect that is annoying or severe enough to warrant discontinuation?
□ Is this medication interacting with other medications in a dangerous way?
□ Is this medication necessary?
□ Can the dose of the medication be decreased?
□ Can use of this medication be safely discontinued?

Some types of medications should be avoided among Alzheimer’s patients, especially those that cause increased confusion, e.g. sedative-hypnotics and barbiturates, particularly in those patients who are using acetylcholinesterase inhibitor agent.63

4. E. NON-PHARMACOLOGICAL APPROACHES AND SUPPORTS. Especially in early stages, introduction and support for different home-based environmental modifications, task simplification, and appropriate activities that may delay advances in the disease. While many of these approaches have not undergone rigorous evaluation, they represent a promising, but not yet proven range of interventions.

There are numerous studies demonstrating the efficacy of non-pharmacological approaches. Data implies that cost savings in the care of people with Alzheimer’s are potentially large. Data show that interventions that lead to improvements in memory and physical functioning or that delay the rate of decline could lead to cost savings for both formal and informal care.64

Unfortunately, knowledge of these treatments and how to make referral to them is not common. Even primary care doctors working with identified patients with cognitive impairments over 75 years of age rarely refer their patients for anything other than pharmacological interventions. Indeed in one chart review of 240 managed care patients, researchers found so few references for non-pharmacological care that they chose not even to report on this data.65

Given the potential benefits in costs and patient/caregiver outcomes derived from these non-pharmacological treatments and indications that primary care physicians do not routinely refer patients for these interventions, the need for training for physicians about these benefits is clear. There is also research that the availability of knowledgeable case managers in the primary care setting can ease the burden on the physician and ensure follow-through on the part of the family.66

A summary of a variety of non-pharmacological approaches follows.

**Cognitive Stimulation.** Cognitive stimulation may occur informally through recreational activities or formally through:

- A program of memory provoking, problem-solving, and conversational fluency activities;
- The space retrieval method; and
- Face name training.

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Formal cognitive stimulation produced a positive clinical impact on cognitive function in people with cognitive impairment. Although memory of specific pieces of information improved, it did not produce general benefits to memory function.67

**Behavior Management.** Before recommending any pharmacological treatments or non-pharmacological interventions for behavior management, it is important to assess for co-morbid physical conditions that could be the root cause of the behavior.

The term “behavior management”, is used to reflect structured, systematically applied and normally time-limited interventions usually carried out by caregivers or care home staff under the supervision of a professional with expertise in this area. Four randomized clinical trials reported behavior management as an intervention for patients living in a variety of residential settings, although how these relate to level of severity of dementia in individuals is not clear.68 69 70 71 Each of the studies reported behavioral interventions with different levels of complexity. Evidence suggests that reduction of repetitive verbalizations, management of aggression and management of eating behaviors in people with dementia have a positive effect on behavior and well-being.72

There is evidence to support the use of behavioral management to reduce depression in people with dementia living in the community with a caregiver. Evidence also suggests that provided the intervention is tailored to the individual that behavioral management is also effective in reducing inappropriate behaviors across a number of settings.73

**Psychological Support.** Although it may be difficult for those with moderate to later stage dementia to benefit from therapy, due to memory and language impairments, there is clear evidence suggesting that those experiencing mild cognitive impairment or early stage dementia benefit from individual or group psychotherapy. For example, depression in people with dementia receiving behavioral therapy either involving pleasant events or problem solving was compared to that in control groups. Depression was improved for up to six months after both interventions. In addition, supportive therapy appears to be an important part of the coping process for those individuals in the early stages of dementia. Therapy with those with memory impairments may require some adaptations (such as providing more written information, slower presentation of information) but can be beneficial.74

**Changes in Environment.** Residential unit design, such as corridor configuration, can influence restlessness, anxiety and disorientation in institutionalized people with dementia.75 Given that people with dementia experience increasing memory impairment and cognitive decline it is important to

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71 ibid
have an environment that aids orientation. A descriptive systematic review of the design of environments for people with dementia including cohort, quasi-experimental and longitudinal studies, cross-sectional surveys and one-off case studies showed that changes in environment can have a positive impact on associated symptoms of dementia.\textsuperscript{76} Findings from the studies are impaired by the absence of comparison groups, comparison between non-equivalent groups and small sample size. The studies examined:

- Environmental comparisons
- Design features
- Environmental services and policies
- Problem behaviors in people with dementia in different physical environments.

The most common outcome measures were impact on problem behaviors, on ADLs and on cognitive and social function. Physical environment interventions including simple modifications such as signage and homelike environments resulted in positive outcomes in patients’ ADLs, behavior, and orientation. Small-scale group living also had a positive therapeutic impact. Measures which should be considered when planning an environment for people with dementia include:

- Incorporating small size units
- Separating non-cognitively impaired residents from people with cognitive impairment
- Offering respite care as a complement to home care
- Relocating residents, when necessary, in intact units rather than individually incorporating non-institutional design throughout the facility and in dining rooms
- In particular, moderating levels of stimulation, incorporating higher light levels, using covers over fire exit bars and door knobs to reduce unwanted exiting
- Incorporating outdoor areas with therapeutic design features
- Considering making toilets more visible to potentially reduce incontinence
- Eliminating factors that increase stress when bathing.

**Physical Exercise.** A well-conducted meta-analysis showed that in people aged over 65 with cognitive impairment and dementia, exercise was associated with statistically significant positive outcomes.\textsuperscript{77} The quality of the study was limited by small sample size and the absence of blinding.

Evidence from patients in residential care suggests that a combination of conversation and exercise on a structured basis may reduce deterioration in mobility in people with cognitive impairment but there is no evidence to support the use of either intervention in isolation. Overall the clinical impact of physical activities on core or associated symptoms of cognitive impairment is minimal.\textsuperscript{78}

### 4. F. \textsc{Various Independent Living, In-Home Support and Supplemental Services}

Includes money management, food / meal delivery, transportation assistance and other services to address needs as identified by the person with cognitive impairment and their family caregiver.

\textsuperscript{76} Day K, Carreon D, Stump C. The therapeutic design of environments for people with dementia: a review of the empirical research [see comment]. Gerontologist 2000;40(4):397-416.


The importance of effective independent living, in-home support and supplemental services can’t be overstated, as even a one-month average delay in institutionalization is projected to result in savings of $1.2 billion annually.\textsuperscript{79} For an individual living with cognitive impairment to remain at home, a wide variety of independent living, supplemental services and in-home supports are essential. Historically, caregivers most often provide these supports. San Francisco has a disproportionate number of adults approaching ages at risk of cognitive impairment who do not have family members in the City or nearby. In this context, it is essential that San Francisco identify models to provide these forms of supports without relying upon family caregivers. Unfortunately, very little research could be found on evidence-based practices in relation to most of these forms of support.

**Meal Delivery.** Inadequate food and fluid intake can result in malnutrition, dehydration, skin breakdown, delirium, and increased morbidity and mortality.\textsuperscript{80} As a result, the provision of routine delivery of nutritious meals is a key component of in-home support. This is particularly the case as cognitive impairment advances and people lose their ability to maintain their diet and even more important for patients being discharged from a hospital. In the hospital, patients with dementia are more likely than other older patients to lose self-care abilities, including self-feeding, and are much less likely to regain these abilities after discharge.\textsuperscript{81} Consequently providing interventions that are tailored to the patients’ cognitive and related communication abilities can dramatically impact both immediate as well as long-term health and function.

Simple delivery of nutritious meals may not guarantee increased nutritional intake as patients’ cognitive functioning declines. In an interesting presentation given at the Alzheimer’s Australia NSW Dementia Symposium 2006, Les MacDonald from Meals on Wheels outlined some of the challenges of ensuring that its service responds to home-bound individuals with cognitive impairment. He described the dual need for drivers to spend more time with individuals with cognitive impairment even providing supervised environments for clients while eating. However the need to spend more time with clients is balanced by the demand to maintain a delivery schedule to ensure the maintenance of food temperature. He pointed to Meals on Wheels reforms that resulted in training for those who deliver meals in identifying individuals with cognitive impairment and in recognizing signs of malnutrition. Meals on Wheels also has developed ‘snack packs’ of nutritious snacks that can be consumed when the client desires. Even with the most responsive food delivery system, as individuals experience progressive decline in their cognitive functioning, additional support will be required to ensure that meals are consumed and consumed according to a routine.

**Transportation.** When an individual is diagnosed with dementia, one of the first concerns of families and caregivers relates to transportation. A diagnosis may not mean a person can no longer drive safely. In the early stages of cognitive impairment, some but not all people may still possess skills for safe driving. Most cognitive impairment, however, is progressive; symptoms such as memory loss, visual-spatial disorientation, and decreased cognitive function will worsen over time. A person’s driving skills will decrease and, eventually, they will have to stop driving. Many people associate driving with self-reliance and freedom; the loss of driving privileges is likely to be upsetting. Some people, recognizing the risks, will limit or stop driving on their own. Others may be unable to assess their own skills and may insist on driving even when it is no longer safe. Families and caregivers may have to intervene when an individual’s symptoms pose too great a traffic risk.

\textsuperscript{79} Leon, Cheng, and Neumann, 1998.
Because the progression of cognitive impairment varies from person to person, it is difficult to know at what point an individual can no longer drive safely, but primary care physicians are required to report a dementia diagnosis to the Department of Motor Vehicles (DMV). Upon notification, the DMV will conduct an assessment of client medical records, personal interviews and other information to determine if a person should continue to drive.

The inability to drive may limit access to community-based resources, participating in recreation, and completing simple chores like shopping. The availability of public transportation and assisted transportation systems becomes critical for people with limited caregiver support. Eldercare Locator at (800) 677-1116, a nationwide directory assistance service, is designed to help older persons and caregivers locate local support resources, including transportation, for aging Americans.

Money Management. A team of doctors from the University of Alabama, Birmingham, developed a 25-minute test that physicians can use to determine the competence of patients with cognitive impairments to handle financial affairs. The test, described as the first designed specifically to evaluate financial capabilities, was introduced by Dr. Daniel C. Marson at the 2006 International Conference on Alzheimer's Disease and Related Disorders in Madrid, Spain. "Impairment and eventual loss of financial abilities are an important and often devastating consequence of Alzheimer's disease and related cognitive impairment," Marson said. "As the disease progresses, patients lose arithmetic and other basic money management skills, and the ability to make both complex and simple financial decisions. The test examines eight areas of financial activity: basic monetary skills, conceptual knowledge, cash transactions, checkbook management, bank statement management, judgment, bill payment and knowledge of personal assets and/or estate arrangements. In an aging population, physicians increasingly are asked to evaluate the financial competence of patients, Marson said, and the test will give families and courts guidance in doing this. The doctors administered the test to 248 people - 69 healthy older adults with no memory problems; 54 patients with mild cognitive impairment, known as MCI; 98 patients with mild Alzheimer's; and 27 patients with moderate Alzheimer's. They were judged by physicians as capable, marginally capable or incapable in each of the test's eight areas, then graded on overall financial capacity. The study found that 94 percent of normal older adults were capable based on their judgments, as compared to 84 percent for patients with mild cognitive impairment, 26 percent for mild Alzheimer's patients and 1.5 percent for moderate Alzheimer's patients.

"The findings suggest financial capacity first becomes mildly impaired in MCI, and then rapidly deteriorates in the mild and moderate stages of Alzheimer's," Marson said. "He said the team recommends people diagnosed with MCI, along with their families, become engaged in financial and estate planning in anticipation of developing Alzheimer's and rapid loss of financial competence.

Legal Counsel. There are many legal considerations that are increasingly relevant at mid and late stages as cognitive decline robs the person of the ability to make sound decisions. Via the California Due Process in Competence Act, a set of standards has been codified to guide the courts in determining competence in different contexts. A diagnosis of cognitive impairment is not sufficient to prove incompetence and doctors are often called upon to perform competency assessments to respond to court requirements, for example prior to establishing a conservatorship. Planning for the inevitable loss of competency is a sensitive issue and the primary care doctor may need to raise it more than once before the person and/or caregiver take action. During early stage Alzheimer's it is critical to obtain input and direction from the person diagnosed as to how end-of-life treatment should be handled and this should be codified in an advance directive. The Guideline for Alzheimer's Disease Management, 2008, has detailed, step-by-step guidance for addressing the issue of competency.
**In Home Supports.** In order to maintain a person with dementia at home, a range of independent living, in-home supports and supplemental services are necessary, particularly for those with limited or no caregiver support. In-home support is vital to delaying institutionalization. One qualitative study reported caregivers needing to coordinate home supports from over a dozen providers with different schedules, points of contacts, and services.

In California, the primary source of in-home support assistance is through the Department of Aging, In Home Support Services (IHSS) program. The IHSS program provides personal care and domestic services to aged, blind or disabled individuals in their own homes. The purpose of the program is to allow people to live safely at home rather than in costly and less desirable out-of-home facilities. IHSS is an entitlement program; federal and state laws mandate the program’s existence. While IHSS regulations determine the range of services, it is the consumer who drives the program. In San Francisco, two modes exist: (1) the independent provider mode, provided through the IHSS Public Authority, in which the consumer hires a family member or relative who is trained to provide IHSS services; and (2) the contract mode, provided through the IHSS Consortium, in which IHSS services are provided by trained homecare workers.

IHSS is unique among programs in California’s long-term care service delivery system in the types of services it provides. This is because IHSS employs a social model rather than a medical model. Services are determined by a social worker assessment rather than medical criteria. The social model focuses on activities of daily living and the IHSS consumer’s ability to function in his or her own home. The medical model assesses clients on medical deficits.

The challenges facing IHSS are best viewed in the context of California’s changing demographics. As the population ages and individuals become less able to care for themselves, there will be an increasing demand for personal assistance services. Against California’s demographic backdrop are the multiple challenges that are expected to result from the Olmstead decision of the Supreme Court and the passage of Assembly Bill (AB) 1682, both of which occurred in 1999. These two events have the potential to increase the number of IHSS consumers statewide, with an associated increase in program operating costs. In addition, further caseload growth is expected with the aging population.

**Medicaid Home & Community-Based Services (HCBS) 1915 – C Waiver.** HCBS waivers allow people eligible for nursing home care to receive care and support in the community and remain at home. This is a potential benefit for people with dementia. In a study conducted in Indiana from 2001 to 2005, researchers studied the relative use of emergency room and other primary care services of nursing home residents with dementia and a cohort of nursing home eligible people who used a HCBS waiver to receive long-term support in the home. Results from the study showed, that while people living at home used a significantly higher level of inpatient services, their overall cost of care was significantly lower than among those living in nursing homes.82

AB 2968 requires the California Department of Health Care Services (DHCS) to write a HCBS waiver application specifically for San Francisco, to fund wraparound services to support the elderly and people with disabilities in residential settings. As of December 2009, a draft of the HCBS waiver application had been completed for San Francisco by DCHS and shared with CMS informally.

Once the informal review is completed, a formal submission of the application will be made. The eligibility criteria is Medi-Cal eligible adults age 22 and higher who:

1) are at Nursing Facility B level of care;
2) either a) reside in a nursing facility or b) are being diverted from a nursing facility;

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3) have a recent history (past 30 days) of behavioral problems and/or substance abuse use;
4) are capable of residing in a licensed board and care community-based setting or in supportive housing with waiver services; and
5) require daily oversight and assistance, including intermittent RN or LVN services.

People with dementia are also included in this waiver. This target population was raised at the Stakeholders’ Meeting in July 2009, and DPH and the State responded this would be the case.

The Living at Home/Block Nurse Program Model\(^3\) is the product of over 20 years of work with elders, their caregivers, home nursing and senior-serving organizations, and supporters in the community. It is a citizen-action model, based on the conviction that local volunteer governed entities can and do serve the needs of local people best, as opposed to top-down corporate or agency models. Community ownership and operations limited to a small geographic area guarantee highly focused efficiencies and flexible, non-bureaucratic effectiveness in helping elders. By receiving in-home social support and health care, elders are enabled to stay in their homes for extended periods of time, preserving their quality of life and retaining their community networks, while at the same time avoiding expensive nursing home costs.

The principle of neighbors helping neighbors is central; where consent, caring and mutual respect form the trust basis for all relationships. Use of expensive acute services, like an emergency room visit, is reduced while older people remain healthy longer, continue to live at home, participate in their communities, and receive assistance as needed from family members and neighbors. Ultimately, this support system helps avoid caregiver burnout and premature institutionalization.

This model is very cost-effective. Given current costs of acute medical care and nursing home stays, a typical rural community Program's annual budget can be more than recovered by helping just two elders avoid or delay using the expensive institutional services for a year. Higher costs in many urban settings may mean a doubling of the above numbers, but current Programs in all locations are saving taxpayers several times the cost of their operations.

This model's unique attributes stem from the fact that the leadership, planning and implementation are done by people living in the community. While unable to identify independent evaluation of this program model, in the context of San Francisco’s dire need to identify models that promise to provide patient support akin to that provided typically by family, Living at Home is worth considering.

Whether delivered by IHSS, other in-home support providers, or by caregivers, in addition to those described above, the types of support needed depends on what the individual requires, but the range of services most often needed includes:

- Light cleaning duties
- Preparing a light meal
- Assisting with laundry
- Providing caregivers with a short break
- Providing a day, evening and night sitting service
- Assistance on hospital discharge
- Shopping
- Collecting pensions/prescriptions
- Assistance to attend appointments

\(^{3}\) http://www.elderberry.org/model.asp
Research cited elsewhere points to the importance of coordination of services and simplification of routines. As the disease progresses, the importance of simple access to in-home supports becomes more important. *Given the high proportion of ‘un-befriended’ aged adults without a family caregiver in the vicinity, it is vitally important that San Francisco explore alternatives to family care support in order to prevent these un-befriended adults overtaxing the scarce supply of affordable beds in assisted living and skilled nursing facilities.*

### 4. G. IDENTIFICATION AND TREATMENT OF CO-MORBID CONDITIONS:
Integration of primary care and services for individuals with cognitive impairments to ensure effective, prompt identification and treatment of co-morbid conditions.

Medical and behavioral co-morbid conditions are very common among individuals with cognitive impairment and benefit from early identification, treatment and close monitoring. As cognitive impairment advances, self-monitoring of medications and maintenance of healthy routines becomes more difficult, increasing the need for caregiver support and primary care physician monitoring.

Considering the disease's prevalence and the absence of effective treatments, it is not surprising that much research focuses on this condition. While the importance of disease research is recognized, there is much debate about whether people with Alzheimer's and related dementias should be permitted to participate in clinical trials and under what conditions. Discussions have focused on the appropriate risk-benefit ratio of Alzheimer's disease trials and the types of consent (subject, proxy, or advance directive) that are acceptable. The debates over the ethical conduct of research centers on determining the appropriate balance between protecting a vulnerable population from the potential risks of research while allowing subjects to participate in trials that could lead to personal medical benefit, as well as medical benefit for the population as a whole.

Research on people with Alzheimer's and related dementias have been almost exclusively concerned with studies of treatments for the disease. Although this is an important starting point, more attention should be given to the inclusion of people with Alzheimer's disease in research on co-morbid medical conditions. As a result, we do not know as much as might be expected about treatment for co-morbid conditions among individuals with dementia. It has been shown that the treatment of co-morbid medical conditions such as cardiovascular disease, infection, pulmonary disease, renal insufficiency, arthritis, and diminution of vision and hearing can improve functionality and cognition in persons with Alzheimer's disease.84

**Co-Morbid Medical Conditions**

Regardless of the condition, routine reassessment requires that the primary care physician85:

- Review treatment of existing co-morbid conditions, including dosages of medications;
- Evaluate acute changes; and
- Expect unreported problems.

A discussion of the diagnosis of co-morbid behavioral conditions is in Section 4.B. Many of the non-pharmacological treatments identified in Section 4.E. are helpful in managing behavioral symptoms.

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Auditory and visual impairments are common among people with dementia and can affect patient performance on other assessments of cognitive functioning. Further, there is evidence that unaddressed sensory impairments can accelerate cognitive decline.\textsuperscript{86} As a result, ensuring that prescriptions for glasses and hearing aids are current and that they are being used appropriately is very important.

Pain is a co-morbid condition and is positively associated with increased use of health services. Indeed, in a Veteran’s Center study conducted by Kunik et al, self-reported pain was associated with having an inpatient medical admission. People who reported their overall level of pain in the previous week as "very bad" were almost seven times as likely to have an inpatient medical stay in the next year as those who reported no pain. On the basis of the findings of this study, it seems possible that targeting pain for clinical intervention would reduce use of health care services by patients with dementia. Previous research has shown that pain is highly prevalent among people with dementia, yet pain is not often systematically addressed and is frequently under-diagnosed and under-treated by health care teams. Although research has validated the assessment of pain among people with mild to moderate impairment, limited support exists for accurately assessing pain among people with severe cognitive impairment. With deficits in language leading to limited capacity for self-report, people with dementia have been noted to manifest symptoms of pain through behaviors that overlap widely with those indicative of other conditions, such as aggression. These behaviors can affect well-being of the person, the caregiver and health service use.

Although pain among nonverbal people with dementia is poorly understood, research in this area may shed significant light on issues of behavioral and psychiatric disturbances in this population. Subsequently, the cause or causes of these difficulties could be appropriately addressed by health care professionals, which would probably have an impact on these patients’ quality of life and future use of health care services.\textsuperscript{87}

Infection. Patients with dementia respond to subtle insults with delirium, a highly morbid condition characterized by confusion, agitation apathy and motor symptoms including falls, muscle jerks and sometimes seizure. Infections, particularly urinary or pulmonary can precipitate delirium in the elderly and lack of recognition often leads to hospitalization or even death. Recognizing that infection can lead to worsening of symptoms is important. Recognizing infections can be difficult in patients who cannot communicate.\textsuperscript{88}

Dental Care. Even before diagnosis, people with cognitive impairments have especially high risk of tooth decay which increases severity of cognitive decline.\textsuperscript{89} Poor oral hygiene can also have a negative effect on overall health, nutritional intake, behavioral symptoms, social interactions and quality of life.\textsuperscript{90}

Malnutrition. Inadequate food and fluid intake can result in malnutrition, dehydration, skin breakdown, delirium, and increased morbidity and mortality.\textsuperscript{91} A number of environmental

\begin{thebibliography}{99}
\bibitem{87} Mark E. Kunik, M.D., M.P.H., Jeffrey A. Cully, Ph.D., A. Lynn Snow, Ph.D., Julie Soucek, Ph.D., Greer Sullivan, M.D., M.S.P.H and Carol M. Ashton, M.D., M.P.H. Treatable Comorbid Conditions and Use of VA Health Care Services Among Patients With Dementia, Psychiatric Services, 56:70-75, January 2005
\bibitem{91} Amella, E.J. (2004). Feeding and hydration issues for older adults with dementia. In M. Mezey, E. Capezuti, & T. Fulmer
\end{thebibliography}
modifications can increase food intake, including provision of favorite foods, playing music while eating, and providing verbal reinforcement and prompts. The use of feed tubes is not recommended, as discussed in Section 4.N.

**Falls.** Injuries from falls are very common among individuals with cognitive impairments. The provision of environmental modifications can reduce injuries of this type. Hallways with guardrails, low-back chairs, non-slip carpet or bath mats and creation of safe, contained areas for wandering all contribute to patient safety. A significant amount of research has been conducted in relation to the prevention of falls, most of it pointing to the need for very customized solutions that respond to individual situations. Common interventions that have not proven to reduce hip fractures or falls that cause them include: exercise, tai chi, hip pads, and many forms of staff training. As cognitive impairment advances the onus of responsibility shifts to the staff and staff compliance with guidelines is a critical factor.92

**Sleep Disorders.** Sleep disorders are common for people with cognitive impairment. Pharmacological interventions should be tried when other non-pharmacological treatments have failed. A combination of “sleep hygiene” education for caregivers and daily walking for people with dementia reduced sleep disturbances for those with mid-stage dementia.93 Sleep hygiene include:

- Sleeping area free of distractions;
- Naps should be limited and short;
- Increased exercise and activity in morning and early afternoon;
- Patients should be dressed during the daytime; and
- Caffeine and nicotine should be avoided and nighttime fluids and diuretics should be restricted.

There is recent evidence that the mere participation in adult day care by itself can improve nighttime sleep.94 Even warm milk and tryptophan, a tepid bath, or light snack high in carbohydrate can be helpful.95

Pharmacological treatments for sleep disorders should be tried only after non-pharmacological treatments have been tried and failed, and even then medications should be used only with great caution as their efficacy has not been demonstrated and the risks and side effects inherent in their use is considerable, particularly if the underlying cause of the sleep disorder is related to depression.96

**Co-Morbid Behavioral Conditions**

It is important to note that many individuals with dementia may have pre-existing behavioral health conditions that may or may not have been identified before a diagnosis of cognitive impairment. Regardless of whether behavioral symptoms preceded a diagnosis of cognitive impairment, behavioral symptoms may pose a greater challenge than cognitive decline for patients with dementia.

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92 Tilly, J., & Reed, P. I. Falls, Wandering, and Physical Restraints: Interventions for Residents with Dementia in Assisted Living and Nursing Homes, Alzheimer’s Association 2006.
96 Ibid.
and their caregivers. The nature and frequency of psychotic symptoms varies over the course of illness, but in most patients, these symptoms occur more often in the later stages of disease. Management of psychosis requires a comprehensive non-pharmacologic and pharmacologic approach, including an accurate assessment of symptoms, awareness of the environment in which they occur, and identification of precipitants and how they affect patients and their caregivers. Non-pharmacologic interventions include counseling the caregiver about the non-intentional nature of the psychotic features and offering coping strategies. Approaches for the patient involve behavior modification; appropriate use of sensory intervention; environmental safety; and maintenance of routines such as providing meals, exercise, and sleep on a consistent basis. Pharmacologic treatments should be governed by a "start low, go slow" philosophy; a mono-sequential approach is recommended, in which a single agent is titrated until the targeted behavior is reduced, side effects become intolerable, or the maximal dosage is achieved. Atypical anti-psychotics have the greatest effectiveness and are best tolerated. Second-line medications include typical anti-psychotics for short-term therapy; and, less often, anticonvulsants, acetylcholinesterase inhibitors, antidepressants, and anxiolytics. Goals of treatment should include symptom reduction and preservation of quality of life.

**Depression.** Depression affects 50% of people with dementia with the nature of the depression changing with the severity of the disease. Symptoms of dysphoria are associated with early stage of cognitive impairment and agitation, apathy and motor slowing more typical of later stages. With a third of individuals with cognitive impairments suffering from depression experiencing fear, suspicion and delusions, the primary care physician must recognize symptoms that underline depression. Many of the non-pharmacological treatments identified in IV.E. have proven effective in treating depression among those with cognitive impairment including increasing participation in pleasant experiences, especially when done with the caregiver. Recreation and adult day care participation are also shown to reduce depression. In one recent study, persons with early stage cognitive impairment who participated in recreational activities designed to stimulate cognitive, physical and psychosocial well-being were significantly less depressed at both 6- and 12-month follow-ups than peers who did not participate. More on identification of depression is in Section IV.B and on the prevention and treatment of depression in Section 4.E. and 4.D.

**Substance Abuse.** Conditions that cause cognitive and functional impairment are not mutually exclusive; hence the question of whether the dementia is comorbid with another condition, such as delirium, depression, or substance abuse, or a medical condition, such as tumor or infection, must be addressed. Often, treatment of the coexisting condition can reduce the degree of impairment and improve the quality of life. Dementia may also have multiple etiologies. For example, substance abuse can contribute to dementia of other etiologies as well as cause dementia in their own right, eg, dementia due to substance-induced persisting dementia. Because an older individual may present with a complex history and multiple medical comorbidities, it is important to diagnose the patient, not the disease.

**Agitation.** A frequent symptom experienced by individuals with cognitive impairments, anxiety is complex both in diagnosis and treatment. Treatments include modification of the environment, interpersonal strategies, and the use of physical or chemical restraint, however research has demonstrated that the use of restraints is not recommended as it has been found to increase

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mortality.\textsuperscript{99} If reassurance does not allay symptoms, patients may respond favorably to short-acting anxiolytics, such as oxasepam or lorazepam, although each may have significant adverse effects and are rarely effective as a long-term therapy.\textsuperscript{100}

**Psychosis.** Psychotic features of dementia include hallucinations (usually visual), delusions, and delusional misidentifications. Hallucinations are false sensory perceptions that are not simply distortions or misinterpretations. They usually are not frightening and therefore may not require treatment. Delusions are unshakable beliefs that are out of context with a person's social and cultural background. Delusional misidentification may result from a combined decline in visual function and cognition.\textsuperscript{2} For example, patients may suspect that their family members are impostors (i.e., Capgras' syndrome), believe that strangers are living in their home, or fail to recognize their own reflection in a mirror.

In studies of patients with Alzheimer's disease, three psychotic features were present in 15 to 75 percent of patients. Delusional misidentifications are thought to occur in at least 30 percent of patients with dementia.

The above list of co-morbid conditions is far from complete, but represents the major conditions found in individuals with dementia and other forms of cognitive impairment.

\textbf{4. H. ADULT DAY HEALTH CARE (ADHC) & SOCIAL DAY CARE CENTERS}

Particularly valuable for those in early and mid-stage dementia is the availability of daily recreation, socialization and stimulation in day care centers designed to accommodate dementia. It is important to distinguish between ADHCs and social model day care centers. Many individuals with early stage cognitive impairment/dementia do not require participation in an ADHC and can generate significant benefit from a social day care center. Indeed for those in early stages of cognitive impairment, participation in ADHCs can be startling as ADHCs serve only individuals who are eligible for skilled nursing facilities and thus the participants tend to be at mid-stages of dementia. Unfortunately, there is a financial incentive to over-utilize the more expensive adult day health care programs as they are eligible for MediCal reimbursement while social model day care centers are not. Furthermore, MediCal regulations prevent families from ‘double-dipping’ meaning that if a family utilizes an Adult Day Health Care program, it may not use Medi-Cal to reimburse in-home support. This puts families in the difficult position of either having to choose between the two or to seek placement in an assisted living facility.

**Social Model Day Care & Early Memory Loss Programs.** An emerging trend is the development of social model day care centers that integrate a memory loss program. Brookdale Foundation has been promoting the development of these specialized Early Memory Loss Program, a community-based, social model, day service program that provides dementia-specific group activities for participants and respite from caregiving tasks for family caregivers. Programs are open a \textit{minimum} of one day a week for at least four hours per session, offering people with Alzheimer/dementia and other memory disorders regularly scheduled opportunities for socialization and group activities in a supportive environment.

At least one paid professional staff member and a core of trained volunteers, students and program assistants, provide staffing for sites. In addition, programs offer access to other services for

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participants and their families, such as individual counseling for caregivers, information and referral to other health and social services, and support group meetings for family members.

**Adult Day Health Care (ADHC).** Given the increasing structure, consistency, support, and personal assistance required by a person with cognitive impairment and the increased burden placed upon caregivers to provide the vast majority of this support, adult day health care is one of the best settings for the mid-stage individual living in the community. As compared with non-users of adult day care, caregivers of individuals with cognitive impairments using adult day care experienced:

- Fewer difficult-to-manage care recipient behaviors and less time spent managing these symptoms;\(^{101}\)
- Fewer hours managing memory difficulties and less burden, strain, and worry;\(^{102}\)
- Fewer recreational restrictions and conflicts between caregiving and other responsibilities;\(^{103}\)
- A better relationship with the patient;\(^{104}\) and
- Lower levels of depression, anger and perceived overload.\(^{105}\)

To achieve maximum caregiver benefits, it is recommended that individuals with cognitive impairments attend adult day services at least twice a week for an extended period of at least three months. Particularly when initiated early, sustained use of adult day care generates benefits for the patient, as well, delaying nursing home placement\(^{106}\) and attenuating the cognitive decline associated with institutionalization.\(^{107}\)

Attendance in adult day care can increase access to many of the non-pharmacological treatments identified in IV.E. (above). The moratorium on adult day health centers ends in 2010. The Expert Panel may want to consider recommending expansion of ADHC and social day care centers in this report.

**4. I. ALZHEIMER'S DAY CARE RESOURCE CENTERS (ADCRC):** ADCRCs provide care specifically for people with Alzheimer's disease or other cognitive impairments, and support and education for caregivers and the community.

The benefits of participation in adult day care programs for caregivers and people with dementia is described in Section 4.H., above. However, people with dementia advance in the disease it becomes increasingly important that their environment, routine of activities, and treatments be customized to their condition. Adult day care and social day care centers, while increasingly sensitive to the needs of individuals with cognitive impairments, staffing, activities, staff training and the environment are not consistently structured to be responsive to individuals with cognitive impairment. Alzheimer's


\(^{104}\) Dziegielewski, S. F., & Ricks, J. L. (2000). Adult day programs for elderly who are mentally impaired and the measurement of caregiversatisfaction. Activities, Adaptation & Aging, 24, 51-64.


\(^{106}\) Ibid

Day Care Resource Centers (ADCRC) provide a positive experience and care for persons with Alzheimer's disease and other cognitive impairment with a program explicitly designed to respond to the needs of individuals with cognitive impairments and their caregivers.

The primary purpose of the ADCRCs are to: prevent premature or inappropriate institutional placement of persons with moderate to severe levels of impairment due to cognitive impairment; provide support and respite for caregivers; serve as models of the optimum type and level of day care services that are needed by persons with cognitive impairment; make training opportunities available to professionals and other persons providing care and treatment for this population; and increase public awareness and knowledge about Alzheimer's disease and related disorders.

The centers provide services that support the physical and psychosocial needs of persons with Alzheimer's disease or related cognitive impairment. Individual care plans are developed for each program participant with activities scheduled in accordance with these plans. The overall objective is to keep the participants as healthy and active as possible by helping them maintain their highest level of functioning and to improve the quality of their lives while providing respite to caregivers. Persons who have been diagnosed as having Alzheimer's disease or other cognitive impairment are eligible to participate, without regard to age or financial resources. Targeted are those persons having moderate to severe levels of care needs and behavioral problems which make it difficult for them to participate in other care programs.

Participants are requested to share in the cost of care through fees based on the cost of services and a sliding fee scale that is specific to each site. Approximately one-third of the sites are administered under Adult Day Health Care licensure and certification, permitting them to accept Medi-Cal eligible persons.

While researchers were unable to identify any outcome evaluations or clinical trials of ADCRCs, that they deliver the kinds of evidence-based non-pharmacological treatments and supports as described in Section 4.E. and in a physical environment explicitly tailored to the needs of individuals with cognitive impairments, it is reasonable to assume their achieving at least the level of benefit found in research on involvement in adult day care settings.

4. J. CAREGIVER EDUCATION, SUPPORT & RESPITE: Assessment and support for caregivers, including respite.

While estimates vary, especially during early and mid-stages of cognitive impairment, caregivers provide the vast majority of support for people with dementia. Over half of all individuals with cognitive impairments live in home settings and 87% of individuals with cognitive impairments are cared for primarily by family members with the three-quarters of caregivers being women. There is widespread evidence to support the use of comprehensive caregiver support in reducing institutionalization. In one study, 65% of the intervention group was living at home after 30 months compared to 26% in the control group.

In a Finnish study the median time of residing in the community following a program of systematic comprehensive support by a nurse or dementia family care coordinator was 647 days in the intervention group and 396 days in the control group.\(^\text{112}\)

Unfortunately, benefit to the person with cognitive impairment comes at considerable cost to the caregiver. There is considerable research that caregivers are at extreme risk of developing physical and behavior morbidity, including cardiovascular disease, depressions, stress and anxiety.\(^\text{113}\) However, other research suggests that caregiver assessment, education and referral for community resources can lead to improved outcomes for both the caregiver and person who has dementia.\(^\text{114}\)

The starting point for caregiver education and support is to assess caregivers to determine their capacity to provide the level of support required by the person with cognitive impairment. This should cover:

- Current knowledge base of cognitive impairment, its trajectory, and service options and limits;
- Level of social support;
- Psychiatric symptomology and burden;
- Existing family conflict
- Ethnic and cultural issues.

The American Medical Association website has a caregiver self-assessment tool including these topics.

Many supports and resources have been demonstrated to benefit the caregiver and patient with cognitive impairment. Increased social support has been linked to greater well-being and support from spouses and family members have lower risk for depression.\(^\text{115}\) Caregiver education increases the chances of patient treatment compliance.\(^\text{116}\) Seamless services and facilitated access to critical services is essential for both people with dementia and their caregivers.\(^\text{117}\) Evidence suggests that counseling, support group participation and access to phone support may preserve caregiver health and delay institutionalization.\(^\text{118}\)

A recent literature review found 19 studies supporting the value of caregiver interventions, including psycho-educational skill building programs, psychotherapy and counseling and multi-component interventions. Psycho-educational programs have shown to be among the most effective forms of therapy with broad impact with caregivers showing consistent improvement in measures of burden depression, well-being, ability, and relevant knowledge with a corresponding improvement in patient outcomes.\(^\text{119}\)


Cognitive Behavioral Therapy offered in group or individual settings have reduced caregiver depression and improving quality of life for African Americans, Hispanic and Caucasian caregivers.  

**Respite.** Given the challenges of caregiving, it is not surprising respite is cited as the service most needed by caregivers.  

Respite programs come in many forms and structures with a need for home-based respite, emergency respite and respite extending overnight or for several days. With so many variations, researchers did not find any evaluations of the efficacy of specific models or levels of respite that correspond with reductions in caregiver burden or delays in institutionalization.

**Caregiver Coaching: StillMee.** StillMee coaches can provide a better understanding of the mental and physical health of the person with memory loss and what s/he is experiencing. StillMee is designed to teach caregivers how to better interact with someone with memory loss. StillMee offers:

- In Home Coaching for family caregivers; face to face, by telephone and email
- Staff Training
- Public Presentations
- Assisted Living Residence Support

StillMee coaching services are designed to help caregivers to:

- Understand what cognitive impairment is and how to get a good diagnosis
- Understand and accept the behaviors commonly seen in cognitive impairment
- Learn new ways to respond to changes in behavior
- Give you confidence in making it easier for your family member to participate safely in his own care and to continue to find pleasure in life.

StillMee coaches have completed the Habilitation Therapy training course developed by Paul Raia, Ph.D. and Joanne Koenig-Coste M. Ed, who are pioneers in the field of care for individuals with cognitive impairments. This service was recommended by an Expert Panel member, but no evaluations were available to document its impact.

**Cultural Dimensions of Support.** Culturally diverse caregivers view cognitive impairment in very different ways with some cultures far more likely to view cognitive impairment as a source of shame or retribution for sins (e.g. Chinese Americans).  

As a result of caregiver cultural differences education and support must be customized to be culturally responsive. A substantial body of research and practices has evolved that incorporates sensitivity to these cultural nuances and primary care providers should be familiar with this research and culturally relevant supports.

**The Best Friends.** Given evidence that in San Francisco up to 40% of individuals with cognitive impairment will not have a family member within one-hour’s drive of San Francisco, a system of care predicated upon support from family members will be unresponsive to a significant proportion

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121 McConnell and Riggs, 1994

of our population. The Best Friends approach to Alzheimer's care was developed in the mid 1990's by Virginia Bell and David Troxel. Best Friends is predicated upon the principle that the role of caregiver need not be limited to family members. While we were unable to identify any evaluation findings as to the efficacy of the model, there are several books available on The Best Friends website outlining the model and presenting the training that the organization can provide. Similar in design to the *Living at Home* model described in Section IV.F., this is a model that San Francisco may want to explore to address the high number of individuals with cognitive impairments who are projected to be without readily accessible family members support.

**Family Caregiver Alliance.** The Family Caregiver Alliance website has tools, assessments, articles, guidelines on how to handle a wide range of legal, treatment, housing, and support issues. These support materials were developed explicitly to support caregivers. It is an excellent resource.

http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=368

**Alzheimer's Association Savvy Caregiver Training.** The six-week Savvy Caregiver Training Program, which the chapter last year began to offer, is that opportunity.” Based on research by experts, the Alzheimer's Association Savvy Caregiving series tackles caregiving as a set of learnable skills, centered around the twin goals of taking care of oneself while helping the care-receiver maintain a state of contented involvement in activities. Caregivers learn to step back, to become a skilled observer, to understand their family member through the Alzheimer's lens, and to strategize and take control of the evolving situation. Participants report an increased sense of mastery over their caregiving role.

**Powerful Tools for Caregivers Online.** Another resource for caregivers is based on the Chronic Disease Self-Management Program at Stanford University. “Powerful Tools for Caregivers Online” is a six-week, online educational course that will help the caregiver:

- manage the common stresses associated with caring for a relative or friend with a chronic medical condition
- design effective action-planning tools and time management as a caregiver
- communicate more effectively with friends, family, health care providers, and coworkers
- find resources
- cope with emotions such as guilt and depression

In early and mid-stages of cognitive impairment, the majority of community and home care is provided by unpaid family members, most often women as partners or children of the person with dementia. This section describes how to support family caregivers, however this presumes a family member or loved one to be that caregiver. San Francisco faces a unique challenge due to estimates that as many as 40% of older adults do not have a relative living within an hour of the City, about double the percentage found in other urban communities. These “un-befriended” individuals will not be able to rely upon routine family support and are likely to require assisted living or nursing home care far earlier than would be the case if they had in-home support of the kind that would typically be provided by a family member. This presents a significant challenge to San Francisco for elderly adults and it is imperative that alternative forms of in-home support be identified.

Our research did not identify the ‘silver bullet’ or model program that could address this gap in services. This may be the single greatest weakness in San Francisco. Accordingly, if not addressed, it would put pressure on the dwindling supply of affordable beds in assisted living and skilled nursing facilities.
Assisted living is an amorphous concept—not just a level of care on a continuum between independent living and nursing homes, but increasingly an alternative to nursing homes. “Assisted living” has no legal sanding as a program, rather it is a term used to describe a range of regulated facilities designed to care for the elderly. Regulations in some states specifically allow assisted living communities to care for an individual through end of life.

Some nursing homes are working on reinventing themselves to reflect the same priorities as assisted living, with the full support of the federal government’s Centers for Medicare and Medicaid Services and the state Quality Improvement Organizations. Assisted living communities are, for the most part, still privately funded. So when their residents need assistance from Medicaid they are forced to relocate to a nursing home. But in states with Medicaid waiver programs that allow Medicaid to help fund assisted living, this is not the case.

An excellent study conducted by Hyde, Perez, and Forester, *Dementia and Assisted Living*[^123] highlighted many of the challenges individuals with cognitive impairments face in entering and maintaining residence in assisted living residences. There are some constraints on moving into assisted living if a person has cognitive decline. For example, in a study of state regulations, more than half of the states studied had admission and discharge criteria that limited admission and retention of people with dementia.

Hyde also found that based on his review of six national studies, Golant (2004) concluded that assisted living residences were more likely to accept frail older persons when these people had less serious cognitive impairments and when they did not require ongoing supervision (e.g., did not wander; or did not have memory, judgment, or behavioral problems). He also indicated that less than 50% of the assisted living residences would accept older persons if they had moderate to severe dementia.

Hyde’s study cites Hawes and colleagues (2003) who found that fewer than 45% of assisted living providers would retain a resident with severe dementia. Ball and associates (2004), in their study using qualitative methods in five assisted living facilities, found that even in assisted living residences that wish to serve the most frail residents and have it be their last home, there are many issues, including impaired residents being ostracized and moved to dementia units. And when care needs are very high, residents can experience neglect that calls into question their quality of life as they age in place.

Hyde concludes by noting that assisted living was developed specifically to be responsive to residents' own definition of quality. The challenge will be to design assisted living facilities that respects that mission and honors the dignity of those whom assisted living seeks to serve; to find meaningful and appropriate ways to ask questions of people with dementia; and to measure, with reasonable reliability and validity, their responses to care and treatments.

As described above, there really is no one kind of assisted living program, indeed “assisted living” isn’t even a program designation relevant to any of the regulatory bodies responsible for overseeing residential care. Among the kinds of residential care programs:

Residential Care Facilities for the Elderly (RCFE). There are gradations of RCFEs as relates to the provision of care for individuals with mid to late stage cognitive impairment or dementia. According to Section 3.2 of the regulations governing residential care for the elderly, every facility is required to be licensed under this chapter. There are essentially three levels of RCFE licensed by the State Department of Social Services (DSS) in California:

- RCFE- The standard RCFE is not required to provide dementia-specific training for staff and does not require dementia-advised environmental accommodations. But unless a RCFE meets the requirements of Section 87705 they are not legally able to care for individuals with a diagnosis of dementia, but may care for individuals with other forms of mild to moderate cognitive impairment. In reality as individuals age in place and their impairment advances, many of these facilities do care for individuals with moderate to advanced forms of dementia despite 87705.

- RCFEs licensed through section 87705 care for individuals diagnosed by a physician with dementia. These RCFEs receive additional funding through an additional monthly charge that is based upon a sliding scale and differs by provider. Each RCFE must also comply with a range of safety, on the job training, staffing and facility requirements developed to ensure that the facility meets the needs of individuals with dementia, as advertised. In fact, the requirements are woefully inadequate and the oversight of adherence to the regulations is inadequate. What compounds access to these RCFE are that according to the RCFE regulations, all residents designated as having dementia, are technically “non-ambulatory”- a designation for the physical plant of the particular RCFE, set by Fire Marshal standards. There are general RCFE of the board and care variety and assisted living type with not particular focus on dementia care. In these facilities expect to find residents with mild to moderate dementia, or with MCI. Then there are RCFE that still have what is called a dementia waiver, referring to a prior requirement for Community Care Licensing (CCL) to approve a RCFE for admitting and retaining persons who need protective supervision. The standards are less than for those which advertise.

- RCFEs that advertise they specialize in caring for individuals with dementia have another level of regulatory compliance (chapter 87706) that specifies a range of training, facility, program activity, assessment and other requirements. For these RCFE there are requirements for annual physician reports, and re-appraisal of care needs- a requirement not required for the general RCFE facilities, despite the reality of very real longitudinal changes in care needs for the elderly residents. Again, as with the designation to care for individuals with dementia, the requirements are low and the oversight inadequate.

The problems with the above continuum of assisted living options is that high quality RCFEs specializing in care for people with dementia are scarce, especially as a person advances in the level of impairment or starts manifesting challenging behaviors. With demand outstripping an affordable supply, many people with dementia: (1) languish in residential facilities not prepared or required to address their needs; or (2) are diverted to Laguna Honda Hospital, the Jewish Home, or other nursing facilities that are costly and in short supply.

However, in nursing facilities the standards of practice for resident care, including modalities of treatment for dementia care and related behaviors, are better articulated. For instance, in nursing facilities there is clear language requiring special informed consent for psychotropic medications, and prohibiting the use of chemical and physical restraints for the convenience of staff. While RCFEs may be less restrictive, these protections are not as stringent. Aside from this, dementia care in larger institutional settings may not be as particular to the resident in terms of management of behaviors, and may not allow the possibility of establishing residential communities where consumers can flourish in a setting that is away from a medical model of care.
San Francisco is faced with the challenge of identifying or developing other models of assisted living to address the needs of people with mid-stage dementia so as to preserve the resources of Laguna Honda and the Jewish Home for later stage dementia and other rehabilitative needs. Unfortunately there are few alternative models to RCFEs. Models worthy of exploration are described below:

**Continuing Care Retirement Communities** are licensed as an insurance product. Individuals pre-pay for care that is theoretically insured to continue as they age in place. Primary oversight focuses upon ensuring that these programs are adequately capitalized so they can continue providing appropriate levels of care once care needs increase. But in reality what happens is that programs have to raise the cost of services as care needs increase often individuals are removed, often for 'behavioral' or 'safety' issues. In many cases, these individuals have invested their resources and once discharged are then dependent upon public resources for continued care. In some respects Continuing Care Retirement Communities that ‘evict’ difficult residents can be viewed as managed care with an unadvertised policy, which is made apparent at the exit door. While this approach may not be typical, the Research Subcommittee members described it as not an infrequent occurrence.

**Residential Care Facilities for the Chronically Ill (RCFCI)**. An RCFCI is an innovative model of assisted living licensed by the State DSS that emerged in the 1980s to serve the unique needs of people with HIV/AIDS. RCFCIs tend to be a more community-based model that integrate medical care services into the residential care. It is a lower cost model than skilled nursing facilities.

Maitri Compassionate Care is a “best practice” RCFCI in San Francisco. Since 1987, Maitri has been providing hospice and 24-hour care to people with AIDS. In this 15-bed facility, skilled professionals and dedicated volunteers offer nursing and personal care as well as emotional and spiritual resources to help meet the needs associated with HIV-related illness. This non-profit program is focused especially on those who might otherwise be without adequate resources or care.

**The Green House Model** has been promoted by the Robert Wood Johnson Foundation. It may be licensed as: (1) a nursing facility; or (2) either a residential care or an adult foster care facility. Green House homes transform long-term-care practices and outcomes for the most impaired residents within existing regulatory guidelines and reimbursement levels. Each Green House is designed to be a home for eight to ten elders who require a skilled nursing level of care. Each elder has a private living space and bathroom. There is a central hearth or living room with an adjacent open kitchen and dining area. All meals are cooked by the direct service staff or Shahbazim in the Green House and are eaten at a long dining table that acts as a focal point for a 'convivium', or communal meal.

One licensed nurse is available to provide skilled nursing care for two to three houses, depending on the clinical needs of the elders. Clinical staff specializing in speech therapy, recreation, diet, OT, and PT, also visit as required by the care plan. There is no nursing station. Nurses visit frequently each day. The majority of the care is provided by two Shahbazim on the day and evening shifts and one assigned to night duty. Only the Shahbazim and the elders have direct entry access to the house.

**The principles at the core of the model are:**
- Maximizing of independence.
- Resident-centered care.
- Self-managed direct-care work teams.
- Small homes focused on creating intentional communities, in which all residents of home are seen as part of a community within the house and within the larger area in which the house is located. This differs from a nursing home where the older adult is a patient and the institution does not represent a community.
Near the end of the 3rd grant, the Robert Wood Johnson Foundation Board of Trustees approved a national Green House replication effort. This $9,584,202 project (ID# 053217), which runs through October 2010, is called the Green House Replication Initiative. Its goal is to stimulate development of 50 or more Green House projects by the end of that year.

An evaluation was conducted of the Green House model in Tupelo, Mississippi by Dr. Rosalie Kane of the University of Minnesota. Findings included that Green House elders reported a better quality of life and greater satisfaction, and their family members were more satisfied with their relatives' care and with how they themselves were treated. There was less of a decline in the ability to do activities of daily living, a lower prevalence of depression, less incontinence without a toileting plan, and less use of anti-psychotic drugs without a diagnosis among residents of the Green House homes.

Green House staff reported that they felt more empowered to assist residents, they knew residents better, and they experienced greater intrinsic and extrinsic job satisfaction. They were also more likely to say they planned to remain in their jobs.

Among lessons learned:

- Green House project designers have had to revise the training curriculum and staffing patterns to better fit the facilities that used the original model and critiqued it.
- In addition, they report that some experienced CNAs find it difficult to switch to the Shahbaz model, since the daily responsibilities of a Shahbaz are, at times, significantly different than those of a traditional CNA.
- Project administrators have found that the general costs associated with running a Green House are similar to the costs incurred by a traditional nursing home facility. For example, in Tupelo, the Green House was able to operate at the Medicaid daily rate of $117 a day when it opened in 2003. However, in more expensive communities like San Francisco, a Greenhouse model program could not operate with only SSI/Medicaid to sustain it.
- While certain economies of scale are lost when operating a small residence, the Green House model is designed to shift resources away from institutional overhead towards supporting the direct care needs of residents. For example, many of the costs of conducting regular house maintenance and cooking are transferred to the daily operations of the direct-care worker.

Mission Creek Senior Community. This mixed-use development combines 140 apartments for older adults with San Francisco’s first new branch library in 40 years and an adult day health care center. Developed by Mercy Housing California, the $43.7 million project received support from the San Francisco Redevelopment Agency (SFRA). The development is in the Mission Bay neighborhood. SFRA brought together Mercy Housing California and the San Francisco Public Library to create a place for housing, care, and community.

In addition to the 7,500-square-foot branch library and a coffee house, there is a third-floor community room. One of the most important components of Mission Creek is the adult day health center (ADHC), which provides key health and social services to seniors. Many of the residents have suffered long episodes of homelessness or institutionalization. Operated by North & South of Market Adult Day Health, Inc., ADHC services include medical care and occupational and physical therapy. Clients also receive lunch. More than 50 seniors use the center daily. About 20 are residents of the building, with the others coming from the neighborhood.
The development’s biggest achievement is providing housing for very low income seniors with special needs. Fifty-one apartments are designated for formerly homeless and frail or disabled seniors. The rents for these units are subsidized by the San Francisco Department of Public Health.

Eighty-eight units are for residents earning no more than 50% of the AMI (area median income), and 51 units are for those earning no more than 20% of the AMI. All are one-bedroom units. The average income of the seniors at Mission Creek is below 20% of the AMI. There is also a manager’s apartment. Rents are as much as 90% below market-rate rents in the area.

**EliteCare, Tigard, Oregon.** Another innovative model of care opened in August 2008 in Tigard Oregon. EliteCare homes deliver relationship-based care that stresses sustained relationships with families and loved ones. Suggested by a Expert Panel member, there is little but promotional material written about the program, but it appears worth exploring as it employs a person-centered philosophy of care.

Finally, while living in any assisted living program an individual with dementia may require rehabilitative services that extend beyond what is available in even the most skilled RCFE. Currently, these patients wind up in need of transfer to a skilled nursing facility, however, at one time San Francisco.

**Comprehensive Outpatient Rehabilitation Facility (CORF)** A mid-level assisted living program, CORFs must provide coordinated outpatient diagnostic, therapeutic, and restorative services, at a single fixed location, to outpatients for the rehabilitation of injured, disabled or sick individuals. CORFs can be an effective resource for maintaining an individual in an assisted living program if rehabilitation is not available at the RCFE but is needed to remain out of a skilled nursing facility. Physical therapy, occupational therapy and speech-language pathology services may be provided in an off-site location. The following are considered “core” services that a CORF must provide:

- Consultation with and medical supervision of non-physician staff, establishment and review of the plan of treatment and other medical and facility administration activities
- Physical therapy services, social or psychological services
- CORFs are surveyed every six years at a minimum.

While a CORF exists in San Leandro, there is no CORF operating in San Francisco. Access to such a resource might extend the length of time individuals could remain in an assisted living facility.

**The absence of sufficient affordable assisted living programs appropriate for caring for individuals with dementia and related conditions places an extraordinary stress upon the shrinking number of skilled nursing facility beds in San Francisco.**

4. **NURSING HOMES & HOSPITALS:** Institutional care for people with Alzheimer’s and other dementias, from mid to late stage.

There is considerable evidence that early diagnosis of dementia, community-based treatments, and caregiver support can reduce reliance upon nursing homes and hospitals, especially for those needing early stage care. A case study conducted in Lincolnshire, England found that many people with dementia placed in acute wards no longer needed to be there. In Lincolnshire, they redirected 6.5 million pounds of funding from acute care to alternative bed and home care services and to
improve early diagnosis services. These kinds of redirections of resources are more easily achieved in capitated, managed care structures such as those found in other countries. However, it is reasonable to assume that in the USA we also have large numbers of people with dementia in nursing homes and hospitals at early and even mid-stage of cognitive impairment who, with appropriate levels of support, could reside in lower levels of care.

It is important to note that while a nursing facility is expensive, especially in the later stages of cognitive impairment, often this type of facility (particularly, the exemplary models in San Francisco such as Laguna Honda Hospital and the Jewish Home) is the most appropriate placement for the individual and the family. While every network or system tries to avoid premature placement in its highest levels of care, at times, placement in skilled nursing, especially at late stage, is in the best interest of the person with dementia and their loved ones.

Much is known about evidence-based practices in nursing facilities, some of which is applicable to living in community-based long-term assisted living facilities. The application of these research-based practices would significantly improve outcomes and quality of life of patients. However, the research has shown the difficulty of getting primary care doctors, nurses, and other health personnel to consistently apply research-based guidelines. Significant levels of training and administrative cues may be necessary to increase the use of these evidence-based practices.

**Practices Related to Physiological Needs.** Routines that can be implemented by assisted living, nursing home, and hospital settings can significantly improve the quality of life and health outcomes for people with dementia. The recommendations that follow were identified through a review of 325 peer-reviewed studies conducted by the Alzheimer’s Association. In relation to nutrition and feeding research has demonstrated that: allowing residents to exercise more control of the eating process increases caloric intake; when verbal prompts and encouragement are offered, patients are more likely to complete meals; eating while listening to music resulted in people consuming more food and reducing anxiety; eating in small rooms immediately adjacent to the patient’s room reduced anxiety resulting from incidents in transit from living to eating area. In relation to incontinence: prompted voiding, behavior modification, and scheduled toileting should be used to reduce urinary incontinence and that even making toilets more visible increases their use.

Similar strategies for bathing, dressing, sleeping, and other daily living functions demonstrate that a pleasant environment, individually tailored interventions and supports that promote independence all contribute to reduced anxiety and improved functioning. Environmental modifications such as use of low chairs, railings, and on-skid bath mats and chairs reduce injuries due to falls. The provision of an enclosed space for wandering reduced the consequences of wandering.

The body of work on agitation and aggression in nursing homes and hospitals encompasses 20 individual intervention studies and 11 reviews of the behavioral health literature. In large part, the studies show reductions in resident agitation or aggression using a variety of interventions including morning bright light; twice daily application of lemon balm oil to residents’ hands and faces; aromatherapy using lavender oil; administration of melatonin; admission to special care units with the environment altered to reduce sound, increase visual stimulation, and facilitate safe wandering; listening to “white noise”; use of a therapy dog; one-to-one interaction between residents and research staff and residents viewing a videotape of family members talking to them; music therapy; staff training; increased nurse staffing in a special care unit; a walking program; multi-sensory stimulation program; hand massage; and individually-tailored interventions.

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124 Improving Services and Support for People with Dementia, National Audit Office, p. 11, 2007.
Although the methods of reducing agitation and aggression are diverse, the studies have several underlying themes. When residents live in environments that reduce disruptive stimulation such as excessive noise, and provide bright, entertaining areas for residents, agitation and aggression may be reduced. In addition, properly trained and supervised staff, who have training in handling the behaviors associated with dementia, have the potential to reduce residents’ agitation and aggression.

In San Francisco, Laguna Honda Hospital (LHH) and the Jewish Home are themselves best practice providers of skilled nursing care. LHH was originally created with a waiver that allowed 33 beds per ward thus making a high quality of care affordable. This open ward style of providing care is no longer the standard and the waiver has been terminated by the federal government. LHH has experienced a reduction of beds devoted to chronic care and a shift to using beds for short-term rehabilitation. LHH is now being rebuilt to become a model skilled nursing facility with 780 beds.

In the absence of a continuum of assisted living programs that maintain individuals in a lower level of care, many individuals with dementia are admitted to LHH or the Jewish Home for lack of any other assisted living options. However, as beds devoted to chronic care disappear, individuals with moderate to advanced stages of dementia have no appropriate public facility for care.

4. M. END OF LIFE & HOSPICE CARE: Terminal care for people with late-stage dementia.

Growing evidence suggests there is a lack of understanding of end-of-life issues among the general population. End of life decisions need to take into account effective pain management, the goals of the patient, (via advance directive), and patient and caregiver satisfaction. Advance directives and healthcare surrogates should be defined early while a patient can have detailed input into a variety of situations, including do-not-resuscitate orders, artificial nutrition plans, and health care proxies. Such measures ensure patient preferences are followed. A barrier to advance completing informed consent forms and appointment of surrogates is that these documents are written at high literacy levels impeding low-literacy and non-English speaking populations from completing them. Another barrier is that the legal system does not honor non-blood relatives while among some cultures rely upon “fictive kin” who are considered family and who would routinely be involved in medical decisions. In these instances it is particularly important that assistance is sought to respect these culturally honored, informal relationships.

People in late stages of dementia have limited capacity to verbalize ailments. The American College of Physicians recently recommended that primary care physicians regularly assess patients for pain, dyspnea, and depression. Assessments exist to assess pain even with non-verbal patients.

As people move from mild, to mid stage, to late state dementia, weight loss is likely. Research recommends against the use of feed tubes as it is uncertain if there are any clinical benefits, has not been proven to extend life or decrease suffering, and when used with restraints to prevent patients from removing the tubes, may increase anxiety and confusion, reducing quality of life.

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127 Ibid.
129 Qaseem et al., Annals of Internal Medicine, 148, 370-78 (2008).
However, there are perverse financial incentives for the use of feeding tubes, as they reduce the level of care required and provide for higher Medicaid reimbursement. In a New York Times article dated May, 18, 2004, Dr. Christine Cassel, an expert in geriatrics, ethics and end of life care and president and chief executive of the American Board of Internal Medicine, indicated, “We are spending a huge amount of money keeping people with irreversible brain damage alive. If the technology exists, we feel we must use it. Our colleagues in Europe consider what we do bizarre to the point of disbelief.” The decision to remove or to not insert a feeding tube is an enormously difficult decision for the family member, even with advance directive indicating this to be the preference of the person.

Predicting end-of-life of people with dementia is difficult, but necessary to obtaining entry into hospice care, which requires a prognosis of mortality within six months. Instruments have been developed for this purpose (e.g. Mini Suffering State Examination). In addition a number of conditions commonly predict immanent mortality, including:

- Dependence on others for activities of daily living
- Recurrent infections
- Multiple pressure ulcers
- Cardiovascular disease
- Need for oxygen therapy
- Weight loss
- Loss of mobility
- Recent hip fracture
- Diabetes mellitus
- Excessive sleep

Under any of the above circumstances, referral to end of life and hospice care should be considered.

**Conclusion**

One theme pervades the review of the literature above: missed opportunities. Research points the way to numerous practices, interventions, policies, and approaches each of which if implemented can identify dementia earlier, delay its progression, prevent some co-morbid conditions, or improve the quality of life of individuals with dementia and their caregivers. At each step in dementia’s progression are opportunities to improve care for the person with cognitive impairment, to better educate a caregiver, to create a treatment plan with the individual’s input, to access important pharmacological interventions, or to use environmental interventions to better protect the safety of the individual living in the community.

This literature review points to one over-arching need: a network that delivers specific, current best practice guidelines and standards to individuals, caregivers, service providers and policymakers so that they have an impact on care and on critical decisions that must be made related to interventions, placements, referrals, education and policy making. Too often decisions are based on a limited understanding of available options and their relative benefit. This is not the fault of caregivers, service providers or policy makers. Treatment advances occur rapidly and we have not identified the way to harness our advance in understanding into an easily accessible framework that would facilitate swift access to the key information needed to make the best possible decision about a prescription, referral, or placement. As a result, we continue to make decisions based upon imperfect knowledge at great fiscal and human cost.

Put simply, the service providers and other organizations and individuals involved in San Francisco’s network of health care and social services for people with dementia and their caregivers must find a way to translate what we know into what we do.

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### Appendix II: Inventory of Dementia Services & Supports
**(November 2009)**

<table>
<thead>
<tr>
<th>SERVICE</th>
<th>PROVIDER</th>
<th>DEMENTIA SEVERITY</th>
<th>FEE STRUCTURE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult Day Centers</td>
<td>Bayview Hunter's Point Adult Day Health Center</td>
<td>Mid</td>
<td>Entitlement</td>
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<td></td>
<td></td>
<td>Moderate</td>
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<td></td>
<td>Advanced</td>
<td>Fee for Service</td>
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<tr>
<td>Adult Day Centers</td>
<td>Catholic Charities CYO – Social Day Care and Alzheimer's Day Care</td>
<td>Mid</td>
<td>Entitlement</td>
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<td></td>
<td>Resource Center</td>
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<td>Advanced</td>
<td>Fee for Service</td>
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<td>Adult Day Centers</td>
<td>For Profit Adult Day Health Centers</td>
<td>Mid</td>
<td>Entitlement</td>
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<tr>
<td>Adult Day Centers</td>
<td>Institute on Aging – Irene Swindells Center for Social Day Services</td>
<td>Mid</td>
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<td></td>
<td></td>
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<td>Means Tested</td>
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<td>Adult Day Centers</td>
<td>Institute on Aging – Ruth Ann Rosenberg Adult Day Health Center and</td>
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<td></td>
<td>Alzheimer’s Day Care Resource Center</td>
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<td></td>
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<td>Jewish Family &amp; Children’s Services – L’Chaim Adult Day Health Center</td>
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<td>Adult Day Centers</td>
<td>Kimochi, Inc. – Social Day Care</td>
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<tr>
<td>Adult Day Centers</td>
<td>North and South of Market Adult Day Health Center – Golden Gate Day</td>
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<td>Health</td>
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<td>Adult Day Centers</td>
<td>North and South of Market Adult Day Health Center – Mabini Day Health</td>
<td>Mid</td>
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<td>Adult Day Centers</td>
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<td>Adult Day Centers</td>
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<td>Adult Day Centers</td>
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<td>Care Resource Center</td>
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<td>SERVICE</td>
<td>PROVIDER</td>
<td>DEMENTIA SEVERITY</td>
<td>FEE STRUCTURE</td>
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<tr>
<td></td>
<td></td>
<td>Mild</td>
<td>Moderate</td>
</tr>
<tr>
<td>Care Management</td>
<td>Institute on Aging – Multipurpose Senior Services/Linkages Programs</td>
<td>Mild</td>
<td>Moderate</td>
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<tr>
<td>Care Management</td>
<td>Janet Pomeroy Center – Traumatic Brain Injury – Specialty Care (Multi Purpose Senior Center)</td>
<td>Mild</td>
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<tr>
<td>Care Management</td>
<td>National Association of Geriatric Care Managers</td>
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</tr>
<tr>
<td>Care Management</td>
<td>Network for Elders</td>
<td>Mild</td>
<td>Moderate</td>
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<tr>
<td>Care Management</td>
<td>New Leaf Services for Our Community (LGBT)</td>
<td>Mild</td>
<td>Moderate</td>
</tr>
<tr>
<td>Care Management</td>
<td>Private Professional Geriatric Care Managers</td>
<td>Mild</td>
<td>Moderate</td>
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<tr>
<td>Care Management</td>
<td>Probate Conservatorship</td>
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<td>Advanced</td>
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<tr>
<td>Care Management</td>
<td>(Need more probate conservatorship)</td>
<td></td>
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<tr>
<td>Care Management</td>
<td>Russian Senior Center (Multi Purpose Senior Center)</td>
<td>Mild</td>
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<tr>
<td>Care Management</td>
<td>San Francisco Senior Center</td>
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<td>Care Management</td>
<td>Self Help for the Elderly</td>
<td>Mild</td>
<td>Moderate</td>
</tr>
<tr>
<td>Caregiver Services &amp; Supports</td>
<td>Paid Caregivers</td>
<td>Mild</td>
<td>Moderate</td>
</tr>
<tr>
<td>Caregiver Services &amp; Supports</td>
<td>Informal caregivers – family members, partners, friends, others</td>
<td>Mild</td>
<td>Moderate</td>
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<tr>
<td>Caregiver Services &amp; Supports</td>
<td>Adult day health centers and social day centers</td>
<td>Mild</td>
<td>Moderate</td>
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<tr>
<td>Caregiver Services &amp; Supports</td>
<td>Alzheimer’s Association</td>
<td>Mild</td>
<td>Moderate</td>
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<tr>
<td>SERVICE</td>
<td>PROVIDER</td>
<td>DEMENTIA SEVERITY</td>
<td>FEE STRUCTURE</td>
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<td></td>
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<td>Moderate</td>
</tr>
<tr>
<td>Caregiver Services &amp; Supports</td>
<td>Assisted Living Facilities</td>
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<td>Caregiver Services &amp; Supports</td>
<td>Catholic Charities CYO</td>
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<td>Caregiver Services &amp; Supports</td>
<td>Family Caregiver Alliance</td>
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<td>Caregiver Services &amp; Supports</td>
<td>Geriatric Case Managers</td>
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<td>Caregiver Services &amp; Supports</td>
<td>Hospice Programs</td>
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<td>Caregiver Services &amp; Supports</td>
<td>IHSS Consortium</td>
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<td>IHSS Public Authority</td>
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<td>Caregiver Services &amp; Supports</td>
<td>Institute on Aging</td>
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<td>Jewish Family &amp; Children’s Services</td>
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<td>Caregiver Services &amp; Supports</td>
<td>Kimochi, Inc.</td>
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<td>Caregiver Services &amp; Supports</td>
<td>Masons</td>
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<td>Caregiver Services &amp; Supports</td>
<td>Network for Elders</td>
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<tr>
<td>Caregiver Services &amp; Supports</td>
<td>New Leaf Services for Our Community (LGBT)</td>
<td>Mild</td>
<td>Moderate</td>
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<tr>
<td>Caregiver Services &amp; Supports</td>
<td>On Lok</td>
<td>Mild</td>
<td>Moderate</td>
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<tr>
<td>Caregiver Services &amp; Supports</td>
<td>Private Providers – Respite</td>
<td>Mild</td>
<td>Moderate</td>
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<tr>
<td>SERVICE</td>
<td>PROVIDER</td>
<td>DEMENTIA SEVERITY</td>
<td>FEE STRUCTURE</td>
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<td></td>
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<td>Mild</td>
<td>Moderate</td>
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<td>Caregiver Services &amp; Supports</td>
<td>Self Help for the Elderly</td>
<td>Mild</td>
<td>Moderate</td>
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<td>Caregiver Services &amp; Supports</td>
<td>Senior Centers</td>
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<tr>
<td>Caregiver Services &amp; Supports</td>
<td>Support Groups</td>
<td></td>
<td>Moderate</td>
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<tr>
<td>Caregiver Services &amp; Supports Needed</td>
<td>(Need early stage groups)</td>
<td></td>
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<tr>
<td>Caregiver Services &amp; Supports</td>
<td>VA Medical Center</td>
<td>Mild</td>
<td>Moderate</td>
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<tr>
<td>Diagnostic Assessment</td>
<td>California Pacific Medical Center</td>
<td>Mild</td>
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<tr>
<td>Diagnostic Assessment</td>
<td>Institute on Aging – Geriatric Assessment Service</td>
<td>Mild</td>
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<tr>
<td>Diagnostic Assessment</td>
<td>Kaiser Permanente Hospital HMO</td>
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<tr>
<td>Diagnostic Assessment</td>
<td>Other HMOs</td>
<td>Mild</td>
<td>Moderate</td>
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<tr>
<td>Diagnostic Assessment</td>
<td>Private Physicians – neurologists, geriatricians, geriatric nurse practitioners</td>
<td>Mild</td>
<td>Moderate</td>
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<tr>
<td>Diagnostic Assessment</td>
<td>San Francisco Clinical Research Center – Alzheimer’s and Dementia Clinic</td>
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<td>Diagnostic Assessment</td>
<td>SF General Hospital</td>
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<td>Diagnostic Assessment</td>
<td>UCSF Memory and Aging Center</td>
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<td>Diagnostic Assessment</td>
<td>VA Medical Center</td>
<td>Mild</td>
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<tr>
<td>Education</td>
<td>Alzheimer’s Association</td>
<td>Mild</td>
<td>Moderate</td>
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<td>PROVIDER</td>
<td>DEMENTIA SEVERITY</td>
<td>FEE STRUCTURE</td>
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<td></td>
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<td>Moderate</td>
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<tr>
<td>Education</td>
<td>American Society on Aging</td>
<td>Mild</td>
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<tr>
<td>Education</td>
<td>Department of Aging and Adult Services</td>
<td>Mild</td>
<td>Moderate</td>
</tr>
<tr>
<td>Education</td>
<td>(Need early state programs)</td>
<td></td>
<td></td>
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<tr>
<td>Education Needed</td>
<td>Family Caregiver Alliance</td>
<td>Mild</td>
<td>Moderate</td>
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<tr>
<td>Education</td>
<td>Institute on Aging</td>
<td>Mild</td>
<td>Moderate</td>
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<tr>
<td>Education</td>
<td>On Lok</td>
<td>Mild</td>
<td>Moderate</td>
</tr>
<tr>
<td>Education</td>
<td>Stanford Geriatric Research, Education &amp; Clinical Center</td>
<td>Mild</td>
<td>Moderate</td>
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<tr>
<td>Information and Referral</td>
<td>Alzheimer’s Association</td>
<td>Mild</td>
<td>Moderate</td>
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<tr>
<td>Information and Referral</td>
<td>211 – Community Services Information Line — operated by United Way</td>
<td>Mild</td>
<td>Moderate</td>
</tr>
<tr>
<td>Information and Referral</td>
<td>California Advocates for Nursing Home Reform — legal referral, nursing home list, violations</td>
<td>Mild</td>
<td>Moderate</td>
</tr>
<tr>
<td>Information and Referral</td>
<td>Department of Aging and Adult Services – Information, Referral, and Assistance (Long Term Care Intake and Screening Unit)</td>
<td>Mild</td>
<td>Moderate</td>
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<tr>
<td>Information and Referral</td>
<td>Ombudsman</td>
<td>Mild</td>
<td>Moderate</td>
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<tr>
<td>Information and Referral</td>
<td>Resource Centers</td>
<td>Mild</td>
<td>Moderate</td>
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<tr>
<td>Information and Referral</td>
<td>Alzheimer’s Day Care Resource Centers (see Adult Day Centers)</td>
<td>Mild</td>
<td>Moderate</td>
</tr>
<tr>
<td>Information and Referral Needed</td>
<td>(Need 24/7 dementia specific hotline)</td>
<td></td>
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<tr>
<td>SERVICE</td>
<td>PROVIDER</td>
<td>DEMENTIA SEVERITY</td>
<td>FEE STRUCTURE</td>
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</tr>
<tr>
<td>In-Home Support Services (Chore &amp; Personal Care)</td>
<td>Private Funded</td>
<td>Mild Moderate</td>
<td>Entitlement</td>
</tr>
<tr>
<td>In-Home Support Services (Chore &amp; Personal Care)</td>
<td>Public Funded</td>
<td>Mild Moderate</td>
<td>Entitlement</td>
</tr>
<tr>
<td>Legal Services</td>
<td>California Advocates for Nursing Home Reform – legal referral, nursing home list, violations</td>
<td>Mild Moderate Advanced</td>
<td>Entitlement</td>
</tr>
<tr>
<td>Legal Services</td>
<td>Family Caregiver Alliance</td>
<td>Mild Moderate Advanced</td>
<td>Entitlement</td>
</tr>
<tr>
<td>Legal Services</td>
<td>Private Counsel</td>
<td>Mild Moderate Advanced</td>
<td>Fee for Service</td>
</tr>
<tr>
<td>Mental Health Services</td>
<td>City-Wide Mental Health Services – under DPH Community Behavioral Health Services</td>
<td>Mild Moderate</td>
<td>Entitlement Means Tested Fee for Service</td>
</tr>
<tr>
<td>Mental Health Services</td>
<td>Community Mental Health Services – Medical Crisis Treatment Team</td>
<td>Mild Moderate</td>
<td>Entitlement Means Tested Fee for Service</td>
</tr>
<tr>
<td>Mental Health Services</td>
<td>Family Services Agency</td>
<td>Mild Moderate</td>
<td>Entitlement Means Tested Fee for Service</td>
</tr>
<tr>
<td>Mental Health Services</td>
<td>Institute on Aging – Center for Elderly Suicide Prevention and Grief-Related Services</td>
<td>Mild Moderate</td>
<td>Entitlement Means Tested Fee for Service</td>
</tr>
<tr>
<td>Mental Health Services</td>
<td>Jewish Family &amp; Children’s Services</td>
<td>Mild Moderate</td>
<td>Entitlement Means Tested Fee for Service</td>
</tr>
<tr>
<td>Mental Health Services Needed</td>
<td>(Need gero-psych, acute and chronic care)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Money Management</td>
<td>Conard House</td>
<td>Mild Moderate Advanced</td>
<td>Entitlement Means Tested Fee for Service</td>
</tr>
<tr>
<td>Money Management</td>
<td>Institute on Aging – Support Services for Elders</td>
<td>Mild Moderate Advanced</td>
<td>Fee for Service</td>
</tr>
<tr>
<td>Money Management</td>
<td>Lutheran Social Services</td>
<td>Mild Moderate Advanced</td>
<td>Entitlement Means Tested Fee for Service</td>
</tr>
<tr>
<td>Money Management</td>
<td>Private Guardianship</td>
<td>Mild Moderate Advanced</td>
<td>Fee for Service</td>
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<tr>
<td>SERVICE</td>
<td>PROVIDER</td>
<td>DEMENTIA SEVERITY</td>
<td>FEE STRUCTURE</td>
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<tr>
<td>Money Management</td>
<td>Public Guardian – Probate Conservatorship</td>
<td>Mild Moderate Advanced</td>
<td>Entitlement</td>
</tr>
<tr>
<td>Money Management</td>
<td>Social Security Administration – Representative Payee Program</td>
<td>Mild Moderate Advanced</td>
<td>Entitlement Means Tested Fee for Service</td>
</tr>
<tr>
<td>Money Management</td>
<td>(Need to expand money management programs)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Multi Purpose Senior Centers</td>
<td>(There are 48 Senior Centers – do you want to list them all?)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Needed Services</td>
<td>(Assisted Living Technology)</td>
<td></td>
<td>Entitlement Means Tested Fee for Service</td>
</tr>
<tr>
<td>Needed Services</td>
<td>(Grocery/Meals delivery services (pilot project): more may be needed)</td>
<td></td>
<td>Entitlement Means Tested Fee for Service</td>
</tr>
<tr>
<td>Needed Services</td>
<td>(Additional Legal and Financial Planning)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Needed Services</td>
<td>(Dementia services for homeless people)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Needed Services</td>
<td>(Medication – service exists w/ Friendship Line for reminders: is this sufficient?)</td>
<td></td>
<td>Entitlement Means Tested Fee for Service</td>
</tr>
<tr>
<td>Needed Services</td>
<td>(Transportation services specifically for dementia)</td>
<td></td>
<td>Entitlement Means Tested Fee for Service</td>
</tr>
<tr>
<td>Nursing Care &amp; Hospital</td>
<td>(Current system taxed; limited number of Medi-Cal &amp; Medicare [Medi-Medi] beds)</td>
<td>Advanced</td>
<td>Entitlement Means Tested Fee for Service</td>
</tr>
<tr>
<td>Nursing Care &amp; Hospital</td>
<td>California Advocates for Nursing Home Reform – legal referral, nursing home list, violations</td>
<td>Advanced</td>
<td>Entitlement Means Tested Fee for Service</td>
</tr>
<tr>
<td>Nursing Care &amp; Hospital</td>
<td>California Convalescent Hospital</td>
<td>Advanced</td>
<td>Entitlement Means Tested Fee for Service</td>
</tr>
<tr>
<td>Nursing Care &amp; Hospital</td>
<td>Central Gardens</td>
<td>Advanced</td>
<td>Entitlement Means Tested Fee for Service</td>
</tr>
<tr>
<td>Nursing Care &amp; Hospital</td>
<td>Convalescent Center Mission Street</td>
<td>Advanced</td>
<td>Entitlement Means Tested Fee for Service</td>
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<tr>
<td>SERVICE</td>
<td>PROVIDER</td>
<td>DEMENTIA SEVERITY</td>
<td>FEE STRUCTURE</td>
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<tr>
<td></td>
<td></td>
<td>Mild</td>
<td>Moderate</td>
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<tr>
<td>Nursing Care &amp; Hospital</td>
<td>Golden Gate Health Care Center</td>
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<td>Nursing Care &amp; Hospital</td>
<td>Grove Street Extended Care and Living Center</td>
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<tr>
<td>Nursing Care &amp; Hospital</td>
<td>Hayes Convalescent Hospital</td>
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<td>Nursing Care &amp; Hospital</td>
<td>Jewish Home for the Aged</td>
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<td>Nursing Care &amp; Hospital</td>
<td>Laguna Honda Hospital</td>
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<td>Nursing Care &amp; Hospital</td>
<td>Laurel Heights Convalescent Hospital</td>
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<td>Nursing Care &amp; Hospital</td>
<td>Mission Bay Convalescent Hospital</td>
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<td>Nursing Care &amp; Hospital</td>
<td>Sheffield Convalescent Hospital</td>
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<tr>
<td>Ongoing Medical Treatment</td>
<td>Health Maintenance Organizations</td>
<td>Mid</td>
<td>Moderate</td>
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<tr>
<td>Ongoing Medical Treatment</td>
<td>Hospice Programs</td>
<td></td>
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<tr>
<td>Ongoing Medical Treatment</td>
<td>Lakeside Senior Medical</td>
<td>Mid</td>
<td>Moderate</td>
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<tr>
<td>Ongoing Medical Treatment</td>
<td>Nurse Practitioners</td>
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<tr>
<td>Ongoing Medical Treatment</td>
<td>On Lok – PACE Sites</td>
<td>Mid</td>
<td>Moderate</td>
</tr>
<tr>
<td>Ongoing Medical Treatment</td>
<td>Private Physicians - All</td>
<td>Mid</td>
<td>Moderate</td>
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<tr>
<td>SERVICE</td>
<td>PROVIDER</td>
<td>DEMENTIA SEVERITY</td>
<td>FEE STRUCTURE</td>
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<td>Mild</td>
<td>Moderate</td>
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<tr>
<td>Ongoing Medical Treatment</td>
<td>Public Health Centers: Castro-Mission Health Center, Children's Health Center at SFGH, Chinatown Health Center, Curry Senior Center, Family Health Center at SFGH, General Medical Clinic at SFGH, Maxine Hall Health Center, Ocean Park Health Center, Potrero Hill Health Center, Silver Avenue Family Health Center, Southeast Health Center, STD Clinic on 7th Street station (PEP)</td>
<td>Mid</td>
<td>Moderate</td>
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<tr>
<td></td>
<td>Affiliated Partners: Glide Health Services, Haight Ashbury Free Medical Clinic, Lyon-Martin Women's Health Services, Mission Neighborhood Health Center, Native American Health Center, North East Medical Services, San Francisco Community Clinic Consortium (SFCCC), San Francisco Free Clinic, South of Market Health Center, St. Anthony Free Clinic</td>
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<tr>
<td>Ongoing Medical Treatment</td>
<td>San Francisco Clinical Research Center – Alzheimer’s and Dementia Clinic</td>
<td></td>
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<td></td>
<td>SF Community Clinic Consortium: Curry Senior Center, Glide Health Services, Haight Ashbury Free Clinics, Inc., Lyon-Martin Health Services, Mission Neighborhood Health Center, Native American Health Center, North East Medical Services, St. Anthony Free Medical Clinic, San Francisco Free Clinic, South of Market Health Center</td>
<td>Mid</td>
<td>Moderate</td>
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<td>SERVICE</td>
<td>PROVIDER</td>
<td>DEMENTIA SEVERITY</td>
<td>FEE STRUCTURE</td>
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<td>Moderate</td>
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<tr>
<td>Ongoing Medical Treatment</td>
<td>Tenderloin Health</td>
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<td>Ongoing Medical Treatment</td>
<td>UCSF Memory and Aging Center</td>
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<td>Moderate</td>
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<td>Ongoing Medical Treatment</td>
<td>VA Medical Center</td>
<td>Mild</td>
<td>Moderate</td>
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<tr>
<td>Other Services</td>
<td>AIDS – Related Dementia Services</td>
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</tr>
<tr>
<td>Other Services</td>
<td>Resource Centers</td>
<td>Mild</td>
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<tr>
<td>Public Policy</td>
<td>Alzheimer’s Association</td>
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<td>Moderate</td>
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<tr>
<td>Public Policy</td>
<td>California Advisory Board of Alzheimer’s Disease, Health &amp; Human Services</td>
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<td>Moderate</td>
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<td>Public Policy</td>
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<td>Moderate</td>
</tr>
<tr>
<td>Public Policy</td>
<td>Family Caregiver Alliance</td>
<td>Mild</td>
<td>Moderate</td>
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<td>Public Policy</td>
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<td>Moderate</td>
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<td>Public Policy</td>
<td>San Francisco Long Term Care Ombudsman Program</td>
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<td>PROVIDER</td>
<td>DEMENTIA SEVERITY</td>
<td>FEE STRUCTURE</td>
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<tr>
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<td>Mild, Moderate, Advanced</td>
<td>Entitlement, Means Tested, Fee for Service</td>
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<td>Entitlement, Means Tested, Fee for Service</td>
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<td>Residential Care</td>
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<tr>
<td>Residential Care Needed</td>
<td>(Need more intermediate care facilities)</td>
<td>Moderate, Advanced</td>
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<tr>
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<tr>
<td>Residential Care Needed</td>
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<td>Advanced</td>
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<tr>
<td>Residential Care Needed</td>
<td>(Need more public funded beds)</td>
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<td>Entitlement, Means Tested, Fee for Service</td>
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<tr>
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<td>Moderate, Advanced</td>
<td>Entitlement, Means Tested, Fee for Service</td>
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<tr>
<td>SERVICE</td>
<td>PROVIDER</td>
<td>DEMENTIA SEVERITY</td>
<td>FEE STRUCTURE</td>
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Appendix III: Education & Prevention - Recommendation Details

EDUCATION AND PREVENTION SUBCOMMITTEE
FINDINGS AND RECOMMENDATIONS

INTRODUCTION

This document is the final report of the Education and Prevention Subcommittee, working under the auspices of the Alzheimer’s/Dementia Expert Panel investigating the crisis in dementia care. The document contains findings and recommendations and details regarding the content areas that should be included or addressed in education initiatives.

The subcommittee’s charge was to consider how best to educate the San Francisco community about Alzheimer’s and related dementias to change attitudes, beliefs, behaviors, standards of practice, and outcomes associated with the disease.

Specific topics addressed include:

- Protective factors relating to dementia, including risk factors and brain health
- Early identification of dementia
- Early access to services
- Community education
- Education of professionals and nonprofessionals, including physicians, psychiatrists and psychologists, social workers, nurses, and other caregivers, both paid caregivers and informal caregivers such as family and friends
- Ethical issues
- Policy issues

FINDINGS AND RECOMMENDATIONS

Introduction

The dissemination of accurate information about Alzheimer’s and related dementias can play an important role in delaying the onset of dementia, slowing disease progression, and improving the quality of life for people with dementia and their caregivers and the other people in their lives.

A great deal of information about dementia is available, but it is often fragmented, hard to find, or not delivered to people when they need it. For example, the subcommittee identified many good examples of educational materials appropriate for people who provide informal caregiving services to people with dementia, but at the same time found that caregivers often receive no support or information about early symptoms and little to no information or referrals at the time their loved ones are diagnosed. The opposite problem is information overload, and the need to ensure that people receive information when they need it and are able to handle it.

In addition to ensuring that information about dementia is organized and available, effective education and prevention efforts will also require countering stigma associated with older adults and with dementia.
It is also important that education and prevention efforts be culturally competent, so as to address effectively the needs of San Francisco’s diverse population. San Francisco is very ethnically diverse with a large Asian Pacific Islander population, a large Hispanic population, and a smaller African American population, with different cultural attitudes toward dementia and the person who has it. Many people from different racial and ethnic communities, especially those who are mono-lingual, require assistance with decision-making, and assistance with paperwork – for example, the paperwork required to establish a Durable Power of Attorney for Health Care.

Education and prevention initiatives must also account for differences in health literacy. This means that some information must be designed for people with low literacy, some must be in languages other than English, and materials must be accessible—this may mean making materials available in Braille or large type, having audio versions, and having materials both online and in easily-accessed neighborhood centers. Finally, materials should account for differences in learning styles and preferences. One subcommittee member suggested that a video of a person with dementia could be a valuable educational tool.

San Francisco also has a large lesbian, gay, bisexual, and transgender (LGBT) population, many of whom are in their late sixties, seventies, and eighties. While persons under age 50 tend to be more open about their sexual identity, many of those in their later years have remained closeted or return to the closet out of fear that their needs will not be met as they become unable to care for themselves. Some have partners but are often alone when the partner dies. Many do not have a younger friend or relative to serve as a caregiver should they develop dementia.

Dementia care is especially challenging for older adults who live alone. While some have forged new familial relationships, many are living by themselves, relying on friends, neighbors, their landlord, the corner grocer, or their IHSS home care worker for essential care and support.

The work of education and prevention will involve a wide range of individuals and public and private entities. As discussed below, partnerships with existing public and private agencies will be needed to better disseminate high-quality information about dementia. Organizations one doesn’t normally think of in connection with health care or social services can play an important role. The Alzheimer’s Association’s Early Detection Alliance with corporate employers is a good example of an innovative program that leverages the private sector in helping to raise awareness of the early signs of dementia and how to obtain a diagnostic evaluation.

Nine content areas were identified to be part of comprehensive education and prevention efforts. Following are these content areas with the corresponding key recommendations. These content areas and recommendations are not listed in priority order.

- **Risk Reduction – Key recommendation**: Promote cognitive health and create a culture of “brain fitness” through mental stimulation, social engagement, physical exercise, and diet.

- **Early Identification of Dementia – Key recommendation**: Educate people about the signs of dementia, how they differ from normal aging, and when and where to seek a diagnosis.

- **What To Expect as the Disease Progresses – Key recommendation**: Offer diagnosed individuals, caregivers, and health care providers information about what to expect throughout the course of Alzheimer’s and related disorders, which will help with future planning.
Services and Resources – **Key recommendation**: Ensure that caregivers are aware of and have access to community resources, training and support.

Caregiver Wellness and Support – **Key recommendation**: Help caregivers understand the stresses inherent in caring for a person with dementia and provide resources for self-care.

Disease Management for Mild, Moderate, & Advanced Dementia, Including End-of-Life Issues – **Key recommendation**: Effective management of early to moderate dementia can slow the advance of cognitive impairment, reduce the impact of co-morbidity, and delay entrance into institutional care. Informed medical management of late stage and end-of-life co-morbidities will decrease unnecessary treatment and ease the burden and suffering of the person with dementia and caregiver at the end of life.

Advanced Care Planning – **Key recommendation**: Advance care planning can help foster greater patient and caregiver understanding of the patient’s medical condition, promote more patient-centered care, and ensure that a person’s preferences are honored at the end of life.

Ethical Issues – **Key recommendation**: Create an ethics review committee/group to consult on difficult ethical situations involving persons with dementia.

Emergency Preparedness and Safety – **Key recommendation**: Promote awareness of steps to take to prepare for an emergency and to address common dangerous behaviors prevalent in persons with dementia so as to avoid catastrophic outcomes.

Education and prevention efforts should target the San Francisco population, though certain interventions will need to focus on specific segments. For example, detailed information about disease management is most appropriate for professional and family caregivers. The general public should understand that dementia is a condition caused by diseases, how to recognize the signs of dementia, and ideally should have some information about available resources.

The subcommittee identified specific information needs for:

- Persons with dementia
- Informal caregivers as well as other family, friends, and neighbors
- Physicians
- Allied health care professionals
- Other professional caregivers, including those working in home care, assisted living, and nursing home settings
- Care managers
- Social workers and other social service providers
- Elder law attorneys
- Adult Protective Services
- Emergency and safety officers, including police, fire, and emergency medical staff
- Gatekeepers such as postal workers and meal delivery services
In a limited funding environment, education and prevention strategies will have to be prioritized. Detailed findings and recommendations for each of these content areas follow.

1. RISK REDUCTION

Introduction

A growing body of scientific research shows that specific lifestyles and actions can improve the health and cognitive functioning of our brains, regardless of age. Neuroplasticity is enhanced when the rate of creation and survival of new neurons in certain parts of the brain is increased, when the rate of creation and survival of synapses (the connections between neurons) speeds up, and when a neuro-chemical environment that supports learning is nurtured.

The Centers for Disease Control (CDC) and a variety of medical groups emphasize the importance of controlling cardiovascular risk factors such as obesity and diabetes to reduce the probability of experiencing cognitive decline.

Lifestyle plays a major influence on brain health, especially aerobic and mental exercise and managing cardiovascular health risk factors. Additional influences are social engagement, stress management, nutrition, and sleep. Our goal must be more than “risk reduction”; rather it should be about promoting a culture of “brain fitness”: inspiring healthy and proactive lifestyles that can contribute to the maintenance of cognitive functions throughout the lifespan.

Recent public awareness campaigns promote a multi-pronged approach to maintaining cognitive health drawing evidence from clinical trials, epidemiological studies, and basic neurobiology. Some examples follow.

<table>
<thead>
<tr>
<th>Campaign</th>
<th>Sponsors</th>
<th>Pillars of Brain Fitness Promoted by Campaign</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Fit For Life” (2008): an ongoing initiative to promote brain health through public libraries. Pilots are underway in 18 library systems.</td>
<td>Dana Alliance for Brain Initiatives, Libraries for the Future, MetLife Foundation</td>
<td>Diet Physical exercise Intellectual challenge Mental stimulation through new experiences Socialization</td>
</tr>
</tbody>
</table>
Two additional and emerging pillars of brain fitness not explicitly promoted in major public awareness campaigns so far are: (1) managing medications to prevent drug-induced cognitive impairment and other negative cognitive side-effects from medications; and (2) cognitive training, which is targeted cognitive exercises, sometimes using a computer, that aim to improve specific cognitive functions.

NOTE: In March 2009, the consumer advocacy group, Public Citizen, released a list of 136 drugs that can cause cognitive impairment.

**Content Areas**

The following topics should be covered in education and prevention efforts related to risk reduction:

- What does brain fitness mean and why do we want to promote a culture of brain fitness?
  - People pay attention to issues based on fear (e.g., of getting Alzheimer’s disease), but they only sustain healthy habits if driven by positive language, support, and outcomes.
  - Brain Fitness is a proactive approach to maintaining a variety of important cognitive functions. It’s about performance, vitality, and quality-of-life and it draws on the intuitive understanding of the need for proactive and multi-pronged physical fitness.
  - The starting points of this approach are first that there is no magic pill; rather there is a need for a multi-pronged approach; and second, everyone needs to learn more about cognition and the brain in order to understand dementia (e.g., executive functions, early identification, etc.) and to be able to make informed decisions.

- Aerobic exercise and the impact on brain health
  - Physical fitness training can increase cognitive performance in healthy adults between the ages of 55 and 80.
  - As little as three hours a week of brisk walking has been shown to halt or even reverse the brain atrophy (shrinkage) that starts in a person’s forties, especially in the regions responsible for memory and higher cognition. Higher-intensity aerobic exercise seems to be even better at building basic capacities—the heart rate must go up for significant benefits to kick in.

- Cognitive stimulation and the cognitive reserve
  - Cognitively stimulating activities help build a neuro-protective cognitive reserve. Multiple epidemiological studies since the 1990s show that individuals more exposed to mentally stimulating activities through education, jobs, or leisure pursuits present have 30-50 percent lower risk of developing Alzheimer’s symptoms, controlling for other factors. No ceiling has been found to this relationship, so the more cognitive activity, the less risk. Building a larger “cognitive reserve” of neurons and abilities seems to offset the losses caused by pathology.
  - To a population that mostly views doing one more crossword puzzle as the best cognitive exercise, emphasis should be on the importance of novelty, variety and challenge to maintain if not enhance cognitive functions.
  - Key messages: ‘It’s never too late to start’; and ‘the more, the better.’

- Managing cardiovascular health risk factors
  - Controlling cardiovascular risk factors such as obesity, diabetes, and smoking reduces the risk of experiencing cognitive decline.
• Stress management
  ➢ Prolonged exposure to high levels of stress can damage the brain, including blocking the formation of new neurons in the hippocampus and even leading to cell death.
  ➢ Learning how to manage stress efficiently is an important life skill to develop.

• Nutrition
  ➢ Experts usually recommend a balanced diet, that is, getting healthy nutrients from the food we eat rather than by ingesting supplements.
  ➢ Most studies have shown that supplements such as gingko biloba are not beneficial to brain health, and there may be contra-indications with medications.

• Managing medications
  ➢ A wide array of commonly prescribed medications can cause cognitive impairments, often temporary, while taking the drug.
  ➢ This problem, often overlooked, becomes especially important when people are taking multiple medications.

• Cognitive training
  ➢ Specific perceptual and cognitive abilities that tend to decline with age respond to training. The effects of that training last beyond the training itself. (Reference: See the latest MindAlert by the American Society on Aging/MetLife Foundation, which includes an in-depth review article by Michael Marsiske.)
  ➢ Given growing interest and media attention, consumers and professionals need to understand and navigate claims about cognitive training. The promising evidence, however, does not support proposing/endorsing specific cognitive training interventions in a public awareness campaign.

Existing Services

There are a number of non-profit, for-profit and online resources. People also should be able to obtain comprehensive and quality information at easily accessible physical locations.

• AARP’s Brain Health program offers resources and lifestyle advice.
• Maintain Your Brain includes resources and lifestyle advice provided by the Alzheimer's Association.
• PBS's The Secret Life of the Brain is a fun website which includes a history of the brain, anatomy, illusions, brain scanning, and development from child through adulthood.
• SharpBrains offers a blog, providing free informational resources, and brain teasers.
• The Society for Neuroscience’s Neuroscience Core Concepts is a “Brain 101” curriculum for educators.
• The Dana Foundation offers several excellent online resources: Brainy Kids Online, which offers children, teens, parents and teachers links to games, labs, education resources and lesson plans; Brain Resources for Seniors, which provides older adults and their caretakers with links to sites related to brain health, education and general information; and a new Staying Sharp DVD.
Approaches to Education and Prevention

- Partner with places of mental or physical exercise to piggyback on their efforts. Special opportunity: health clubs, libraries, bookstores, and schools.
- Conduct public awareness campaigns through television, radio and print ads; note opportunity to take advantage of unused advertising inventory in current economic climate.
- Distribute written materials (such as a bookmark) in multiple languages through health fairs, city offices, library and hospital systems, and community agencies.
- Offer workshops and classes in schools, libraries, and universities.
- Create websites and blogs.
- Distribute a monthly or quarterly newsletter.
- Approach public television and radio stations about promoting brain health messages and community programs.

Recommendations

- The best prevention is to invest in education, public awareness, and citizen empowerment.
- Promote a culture of brain fitness by partnering with health clubs (promote physical fitness) and libraries (promote mental fitness).
- Partner with media outlets to offer public service announcements, as well as incorporating messages about early identification in existing programs focused on brain health (especially those that already promote brain health products).

2. EARLY IDENTIFICATION OF ALZHEIMER’S AND RELATED DEMENTIAS

Introduction

Growing societal attention to Alzheimer’s and related dementias is bringing much needed awareness to early identification of the disease, but we must prevent unwanted and counterproductive fears. The public at large needs to learn how to differentiate healthy aging from dementia and when and where to seek a medical evaluation and diagnosis.

It is important to note with regard to diagnosing early stage dementia that there is no consensus about how to diagnose mild cognitive impairment (MCI), and experts debate the wisdom of general population screening for dementia. For example, the Alzheimer’s Foundation of America calls for regular cognitive screenings after the age of 75, or 65 for people at high risk. The Alzheimer’s Association is opposed to memory screenings for the general public at this time and instead promotes awareness of signs of cognitive decline that require medical attention. At such time as disease altering drugs become available, the notion of broad cognitive/memory screening will likely become less controversial, though still challenging to implement, especially in a highly ethnically and culturally diverse area such as San Francisco.

Public awareness should be raised about early signs of dementia and of screening by health care professionals. Broad screening at the population level should be considered if research demonstrates the benefits of doing so outweighs the costs. Screening would be used to assess the need for a more comprehensive evaluation, possibly including referral to a specialist for a thorough diagnosis. Dementia services should be provided as soon as there are symptoms of cognitive impairment.
Content Areas

The following topics should be covered in education and prevention efforts related to early identification of dementia:

- What cognitive changes are normal through healthy aging?
  - It takes longer to learn new information in unfamiliar domains, such as using the latest technologies.
  - We experience—and joke about—our imperfect memories: we don’t remember the name of someone we met last week, we forget one or several of the many items we wanted to buy in the grocery store, which is why we tend to use lists.

- What cognitive changes may indicate early stages of dementia?
  - New and noticeable loss of cognitive functions that disrupts aspects of daily life.
  - Early dementia often manifests itself as loss of attention/executive capacities such as cognitive flexibility, self-monitoring, lack of judgment, and reasoning, in ways that raise concerns about the ability to live independently. These symptoms tend to precede impairment in perceptual and language functions so just looking for perceptual, language, or “memory” problems doesn’t help with early identification.

- What factors other than dementia contribute to cognitive impairments?
  It is important to rule out other potential causes for the new cognitive problems experienced, such as:
  - High stress
  - Depression
  - Sleep disorder
  - Medications
  - B12 deficiency
  - Cardiovascular disease
  - Alcohol
  - Substance abuse

- When and where should a medical evaluation be sought?
  - See doctor/primary care center to express concern and ask for evaluation or referral
  - Visit diagnostic centers, such as memory clinics, neuropsychologists, or geriatrics clinic

- What should be done after diagnosis?
  See Content Summaries for Education about Services and What to Expect as the Disease Progresses

- What services are available?

Existing Services

- Alzheimer's Association workshops, brochures, and new curriculum (e.g., “Understanding Memory Loss and Alzheimer’s” and “Know the 10 Signs”)
  Some specific early warning signs, based on Alzheimer’s Association’s new campaign on 10 Warning Signs of Alzheimer's Disease, are:
- Asking for the same information repeatedly (shows difficulty in learning/memorizing new information)
- New difficulties in managing a budget/ monthly bills (shows difficulty in solving problems and planning ahead)
- Suddenly giving a large amount of money to telemarketers (shows difficulties in judgment)

- Family Caregiver Alliance fact sheets
- Institute on Aging conferences for providers
- DAAS trainings for service providers
- Kaiser Permanente educational workshops & materials

Recommendations

Ideally, the office that diagnoses dementia—generally the primary care provider—would have a social worker, nurse practitioner or physician’s assistant to make referrals. A model for this is On Lok, but this is unusual. The alternative is for the care provider to refer to a community agency that can make detailed referrals. The Alzheimer’s Association and Family Caregiver Alliance have a process where providers (physicians, social workers, nurses) can fax a HIPAA compliant referral to request follow-up for the patient and caregiver. Instead of the typical two-year lag between the time of diagnosis and accessing help, families receive immediate connections. This type of proactive contact is highly desirable. But both of these agencies have finite resources and they would require additional funding to handle increased use of this service.

Policy Implications

The standard of care should be to refer people to services immediately upon identification of cognitive impairment. This should be a requirement for San Francisco contractors.

3. WHAT TO EXPECT AS THE DISEASE PROGRESSES

Introduction

A common challenge for diagnosed individuals, caregivers, and health care providers is understanding what to expect as dementia progresses. This is due to the variability in symptoms and progression in persons with the same diagnosis and to variability associated with different types of dementia. A common saying in the Alzheimer’s provider community is: “When you’ve met one person with Alzheimer’s disease you’ve met one person with Alzheimer’s disease.” Because of this variability, future planning is of critical importance as it is often unclear how long diagnosed individuals will have the capacity to make decisions for themselves.

There are no studies that demonstrate specifically the impact of training about what to expect as dementia progresses. There is, however, evidence that persons with dementia do better when they are identified earlier and when their caregivers access community resources, training, and support. While research shows that it continues to be rare for health care providers to refer patients and families for non-pharmacological services, persons with dementia who receive these referrals
experience better outcomes. There exists considerable information on the progression of dementia, but it can be challenging for families to find this information when they need it.

Content Areas

The following topics to be covered in education and prevention efforts related to what to expect as the disease progresses:

- Common signs and symptoms in the early, middle, and late stages of dementia
- Importance of planning for the future
- Available treatments and interventions at each stage
- Identifying key helpers
- How to partner with medical and allied providers
- Safety issues
- Behavioral challenges
- Common co-morbidity issues and causes of delirium
- Supervision
- End of life decision making including Physicians’ Orders for Life Sustaining Treatment (POLST), use of feeding tubes, and use of antibiotics

For each stage:

- In general, it’s important to teach people to be realistic about what can and cannot be fixed. It’s also important that people know that it’s not their fault—it’s normal for body systems to fail eventually.
- It is important to plan for the future in terms of finances, health care decision making, and advanced directives, including POLST—physicians’ orders for life sustaining treatment. Recognize that at this point the diagnosed individual is able to actively participate in decision making and care planning.
- Learn what treatments/interventions are available at this point in the disease, how to access them, and how effective they are (e.g., at this point they are not disease altering but they may temporarily help with symptom reduction).

Specific to mild Dementia:

- Common signs and symptoms in the early stages of dementia include difficulties with memory, language, judgment and reasoning.
- Identifying key helpers is important. Is there a caregiver? An interested neighbor?
- How to partner with medical and allied providers for medical care and social services.

Moderate Dementia:

- Common signs and symptoms of the middle stages of dementia include increasing difficulty with memory, language, judgment, and reasoning.
- Clarify safety issues and behavioral challenges and how to deal with these issues if and when they arise.
- Learn the types of over the counter and prescription medications to avoid due to anti-cholinergic effects.
- Learn common co-morbid issues and causes of delirium, how to spot them, and how and when to get help.
- Identify key helpers and resources. Consider daycare and in-home care.
- Supervision of the individual becomes critical.
Advanced Dementia:

- Common signs and symptoms in the advanced stages of dementia include increasing personal care needs, incontinence, frailty, behavioral symptoms, and wandering for persons who are physically able.
- If it hasn’t already happened, it may be necessary to have the individual conserved in order to access care and services on their behalf if no other legal planning has taken place. Medi-Cal eligibility and other financial planning are necessary if it hasn’t already taken place.
- In many cases, providers may need to address when to stop treatments/interventions.
- Identify key helpers and resources (consider assisted living, nursing home care, hospice etc.)
- Discuss end of life decision making including POLST, use of feeding tubes, use of antibiotics.

Existing Services

- Alzheimer’s Association
- Family Caregiver Alliance
- Institute on Aging
- Department of Aging and Adult Services
- Medical providers including Kaiser Permanente and California Pacific Medical Center
- UCSF Memory and Aging Clinic
- Veterans Administration Medical Center
- California Association of Nursing Home Reform & Legal Aid Society

Approaches to Education and Prevention

- Written materials in multiple languages widely distributed through health fairs, city offices, library and hospital systems and community agencies
- Workshops and classes
- Websites

Recommendations

- Centralize information about available resources, but also create decentralized access points to this information (e.g., in public libraries, health fairs, city offices, hospital systems, and community agencies), so that it is easily accessible.
- Consider having simple information on the DAAS website or having a diagnosis hotline.
- Offer annual in-service trainings on dementia for DAAS’s Integrated Intake Unit, the Network of Support for Community Living, and 211 personnel.
- Aim to have every person with dementia in San Francisco prepare advanced directives, including POLST (Physician Orders for Life Sustaining Treatment).
4. SERVICES AND RESOURCES

All too often, persons with dementia are not diagnosed until late in the disease, and when they are diagnosed, they may not be referred to critical services. A tremendous gap exists between available services and those who might use them.

There already exists considerable information about the progression of dementia but it is a challenge for family audiences to find what they need when they need it.

There are no studies that specifically show the impact of educating people about what to expect as dementia progresses. There is, however, evidence that persons with dementia who are identified earlier and whose caregivers access community resources, training, and support do better than those identified later or whose caregivers do not access these resources. While research shows that it continues to be rare for health care providers to refer patients and families for non-pharmacological services, those that do experience better outcomes.

Content Areas

The following topics should be covered in education and prevention efforts related to information about services and resources:

- Services available for persons who need to get a diagnosis:
  - Where to get a diagnosis and what does it entail?
  - What about non-English speaking individuals?

- Services available for early stage dementia:
  - Medical care and treatments
  - Social support and services
  - Education and training for diagnosed individuals and care partners
  - Early stage support groups
  - Financial and legal planning
  - Safety services, (e.g., MedicAlert + Safe Return and earthquake preparedness)
  - Home care and day care services
  - Housing
  - Financial aid
  - Brain health and fitness programs
  - Exercise programs
  - Senior centers

- Services available for middle stage dementia:
  - Medical care and treatments
  - Social support and services
  - Education and Training for caregivers
  - Caregiver support groups
  - Financial and legal planning
  - Safety services (e.g., MedicAlert + Safe Return and earthquake preparedness)
  - Home care and day care services
  - Housing, residential and nursing home care
  - Financial aid, Medi-Cal eligibility
• Services available for late stage dementia:
  ➢ Medical care and treatments
  ➢ Social support and services
  ➢ Education and Training
  ➢ Caregiver support groups
  ➢ Financial and legal planning
  ➢ Safety services (e.g., MedicAlert + Safe Return and earthquake preparedness)
  ➢ Home care and day care services
  ➢ Housing, residential care home and nursing homes
  ➢ Financial aid
  ➢ Hospice care

Existing Services

San Francisco offers an array of community services for people with dementia including: UCSF’s Memory and Aging Center and other diagnostic clinics; private and public home care agencies; day care centers for older adults including people with dementia; residential care facilities for the elderly; PACE (Program of All Inclusive Care for the Elderly) programs; support groups on early stage dementia and other related topics; workshops and conferences; a 24-hour helpline; and counseling.

Service Providers Include:

• Alzheimer’s Association
• Family Caregiver Alliance
• Institute on Aging
• Department of Aging and Adult Services
• Medical providers including Kaiser Permanente and California Pacific Medical Center
• UCSF Memory and Aging Clinic
• Veterans Administration Medical Center
• California Association of Nursing Home Reform & Legal Aid Society

NOTE: See Appendix II for a comprehensive list of services and supports.

Approaches to Education and Prevention

• Written materials in multiple languages widely distributed through health fairs, city offices, library and hospital systems and community agencies
• Workshops and classes
• Websites

Recommendations

• Centralize information about available resources. Fortunately, to do this, the service delivery network can use the DAAS Integrated Intake Unit as the central door of the “no wrong door” strategy to access information about services and resources. This is available for older adults and adults with disabilities, including adults with MCI or dementia of any kind.
• Create decentralized access points for information (e.g., in public libraries, health fairs, city offices, hospital systems, and community agencies), so that it is easily accessible.

• Consider having simple information on the DAAS website or having a diagnosis hotline.

• Offer annual in-service trainings on dementia for DAAS’s Long Term Intake and Screening Unit, the Network of Support for Community Living, and 211 personnel.

• Aim to have every person with dementia in San Francisco prepare advanced directives, including POLST (Physician Orders for Life Sustaining Treatment).

• Educate the staff of 211, the United Way’s Community Service Information telephone service, about existing resources. This could be provided by the Alzheimer’s Association.

• Place information on resources on the DAAS website, or on the Network of Support for Community Living website. Doing so will require an evaluation of this website and working with its administrators so that all dementia resources are very visible and very easily accessed.

• Ensure that all websites with dementia resources have a link to the Alzheimer’s Association fact sheet on dementia.

• Be certain all decentralized access points that provide information about services and resources also address the stigma connected to Alzheimer’s and related dementias, in community-based education centers, possibly located in neighborhood public libraries.

• Ensure that DAAS will promote awareness of all existing services and resources.

5. CAREGIVER WELLNESS AND SUPPORT

Introduction

Caring for a person with dementia is often stressful and demanding as the caregiver watches memories disappear and skills erode. For both caregivers and their loved ones, this often produces difficulties in communication and an emotional wall of confusion, anger and sadness. Caregivers usually learn through trial and error the best ways to communicate with the person with dementia and to help maintain routines for eating, hygiene, and other activities at home.

Content Areas

The following topics should be covered in education and prevention efforts related to caregiver wellness and support:

• Unique challenges and rewards for caregivers

  Challenges:
  ➢ Overwhelming emotions as capabilities lessen.
  ➢ Fatigue and exhaustion as caregiving demands increase.
  ➢ Isolation and loneliness as independence disappears.
  ➢ Financial and work complications as cost rise and resources are challenged.
  ➢ Lack of education about disease and supportive services.
  ➢ Conflicts with other family members regarding who will provide care.
  ➢ Living with uncertainty and ambiguity.
Rewards:
- Bonds deepen through care, companionship and service.
- Problem solving and relationship skills grow through experience.
- New relationships form through education and support.
- Unexpected rewards develop through compassion and acceptance.

- How to develop skill in coordinating services for the person with dementia

- How to support caregivers and protect them from exhaustion/burnout during dementia care, including warning signs of caregiver burnout and tips for self care

Planning support for Alzheimer’s caregivers
- Balancing the enormous task of caring for a cognitively impaired adult with other responsibilities requires skill, attention and diligent planning.
- Planning for one’s own care is also vitally important.
- How to handle the unexpected.

Because care giving is such a hard work, one must learn to protect oneself. Warning signs of caregiver burnout or exhaustion include:
- Excessive stress and tension.
- Debilitating depression.
- Persistent anxiety, anger, or guilt.
- Extreme irritability or anger with the patient.
- Decreased overall life satisfaction.
- Relationship conflicts and social isolation.
- Lower immunity and greater need for health care services.
- Excessive use of medications, drugs, or alcohol.

Tips for self care:
- Schedule mini workouts throughout the day.
- Take time to play.
- Try something new.
- Keep them laughing. Humor is a well-known antidote to stress, sadness, and illness.
- Join a support group or find another caregiver with whom to converse. In addition to emotional support, you’ll likely pick up practical tips as well. Professionals network with each other all the time to get emotional support and find answers to problems or situations they face. You can do this too.

- How to be an effective advocate with the health care system and social services and with public officials

What is an advocate?
- Personal advocate on behalf of the person with dementia
- Social advocate on behalf of all affected

How to become your own care coordinator
- Educate yourself on the nature of the disease or disability with which you’re dealing.
- Write down your observations of the present situation including:
- Your loved one’s ability to function independently, both physically and mentally.
The availability of family and/or friends to form a support network to share the care.

The physical environment: is it accessible or can it be adapted at reasonable cost?

Your other responsibilities at work, at home, and in the community.

Your own health and physical abilities.

Your financial resources, available insurance, and the existence of health care or end-of-life documents.

Three ways to become an effective Alzheimer's/dementia advocate:

1. Develop your own advocacy pitch. Before contacting anyone, decide what you are going to say. It's always important to share your own story about how Alzheimer's has affected you, your loved one, and/or other family members and friends. Also choose one or two policy recommendations to focus on, such as increased research funding, more support for caregivers, or better access to affordable long-term care for people with Alzheimer's disease.

2. Contact your elected officials. You can find them by using the Alzheimer's Association's Elected Official Search Tool. Contact them in a way that's most comfortable to you, such as by phone, letter, email, or personal visit, if you can schedule one. Many elected officials can now be contacted through their own websites, which means you can make your voice heard at any time from the comfort of your own computer.

3. Contact the Obama-Biden Administration, which has set up an unprecedented online system for the public to contribute thoughts and ideas about policy. At the Administration's health care page, advocates can share why they think health care is important and what should be included in health care reform. Be sure to share your personal story along with your recommendations.

The Alzheimer's Association has created a National Alzheimer's Advocate Network to keep advocates informed of advocacy-related issues and to provide guidance for becoming an effective Alzheimer's advocate. It's free to join and it's a great way to connect with other Alzheimer's advocates so that our collective voice can be heard loud and clear.

- How to understand the job of the caregiver

Existing Services

- Alzheimer's Association (e.g., “Savvy Caregiver” program; pilot program on mindfulness for caregivers)
- Family Caregiver Alliance (e.g., “It Takes Two” program)
- Institute on Aging
- National Family Caregivers Association

Approaches to Education and Prevention

- Websites
- Workshops and classes on the subject of caregiving.
- Support groups, including faith-based and social support groups.
- Pilot mindfulness program for caregivers as a way of reducing stress.
- Consider doing a needs assessment relating to specific content areas to cover in support groups, how best to do outreach, need for culturally specific groups; and where to hold
groups to make them accessible; could lead to expanded training for group facilitators or focus on different content areas (e.g., stress reduction techniques).

**Recommendations**

- Expand resources for caregiver education. More awareness in the community will generate support.
- Create more support groups that are social or faith based.
- Offer workshops or classes for caregivers to equip them with skills to be effective caregivers and at the same time protect themselves from exhaustion/burnout.
- Increase local and state government resources available to support caregivers.
- Train facilitators in stress reduction techniques for caregivers.

**6. DISEASE MANAGEMENT FOR MILD, MODERATE & ADVANCED DEMENTIA, INCLUDING END OF LIFE CARE**

**Introduction**

Research shows that effective management of early and moderate dementia can slow the advance of cognitive impairment, reduce the impact of co-morbidity on persons with dementia and their caregivers, and delay entry into institutional care.

Persons who are in the late stages of dementia are totally dependent for all activities of daily living and need total supervision as they are unable to remain in the community without 24/7 care. They are not able to communicate their needs and rely totally on external support from either informal or formal caregivers.

Special needs occur at the end of life that must be addressed by medical personnel, hospice, and family caregivers. These include management of co-morbidities such as incontinence, nutrition, hydration, pain, and other chronic conditions, as well as follow through on advance care planning decisions. People in the late stages of dementia often require placement in a skilled nursing facility or an assisted living facility or board and care until the end of life.

Research clearly demonstrates the benefit of disseminating knowledge about the management and treatment of the disease, community resources, and caregiver education and support.

**Content Areas**

The following topics should be covered in education and prevention efforts related to disease management:

- Consistent knowledge of and use of effective pharmacological interventions, and in particular, issues related to over-treatment at end of life and under-treatment of pain
- Consistent knowledge of and use of effective non-pharmacological interventions
- Early and effective symptom reduction
- Management of co-morbidity throughout the disease
Special issues include management of incontinence, nutrition, hydration, pain, skin integrity, reduced mobility, and other co-existing medical conditions.

Pharmacological and Non-pharmacological Interventions

Interventions for difficult behaviors and psychotic symptoms need to be readily available for professionals with the most current effective treatments recommended. A resource: is psychguides.com. End of life care, including pain, skin integrity, incontinence, and nutrition (tube-feeding)

• End of life care, including pain, skin integrity, incontinence, and nutrition (tube-feeding)

• Caregiver supports and training, including the disease process, community resources, communication and advocacy with medical settings, placement, and spiritual needs

Placement Issues:

• Caregivers of persons with dementia need support and information regarding when, where, and how to place a person with dementia in the level of care that is the least restrictive and provides the highest quality of life possible. (Resources: Alzheimer’s Association and Family Caregiver Alliance.)

• Persons with late stage dementia need a place that provides quality care that can manage their needs on an ongoing basis without the threat of their having to move to another setting.

• Available affordable assisted living, board and care, or skilled beds are essential for maintaining the care of persons with late stage dementia who have special needs at the end of life.

• Persons at end of life must have access to hospice services or at the least palliative care.

• Coordination of care along the disease continuum, including utilization of advanced care planning

• Case management services must be available to provide follow through and consistency with advance directives and care planning needs of caregivers and persons with dementia.

• Continued discussion of special issues around decision-making such as tube-feeding, pain management, use of antibiotics, and flu shots needs to occur with health care professionals throughout the disease process and especially near the end of life. A team approach including a physician, social worker, nurse case manager, and spiritual advisor is best.

• Identification of criteria for hospice eligibility for persons with dementia

Audiences

• Family caregivers need education regarding the disease process in late stage dementia and support for continued care planning and decision-making.

• Professional caregivers need education regarding the disease process and management of special needs and challenges that occur in the late stages of dementia and requirements for following advance directive of persons with dementia.

• First responders need education regarding POLST, to understand clearly with home caregivers and facility personnel regarding advance directives. They also need training on how to communicate with persons with dementia in distress.

• Physicians, social workers, nurses, and therapists need coordination of care services and information about best practices.
Approaches to Education and Prevention

- Workshops, written materials and web-based programs and information
- Team-based coordinated care (see research section IV.C, pp. 25-30)
- Use of capitated, managed care (models: On Lok, PACE)
- Use of evidence based care practices (see research section IV.L, pp. 57-58)
- Case management to provide educational, psychosocial and spiritual support for informal caregivers and persons with dementia
- Hospice and palliative care at end of life
- Case consultation for individual cases carried out by a multidisciplinary team; this could be done by specific agencies or a resource center

Existing Services

Education regarding late stage and end stage dementia is available through the following agencies:

- 211 - United Way’s Community Services Telephone Information Line
- Alzheimer’s Association
- American Society on Aging
- California Association for Nursing Home Reform
- Department of Aging and Adult Services
- Family Caregiver Alliance
- Hospice organizations in San Francisco such as Zen Hospice
- Institute on Aging
- Bay Area End of Life Task Force
- National Hospice Organization
- Physician Orders for Life Sustaining Treatment (POLST)
- On Lok
- Stanford Geriatric Education Center
- Laguna Honda Hospital (a best practice provider; see research p. 58, lines 28-35)
- Jewish Home (a best practice provider; see research p. 58, lines 28-35)

Service Gaps

- Adult day center, assisted living, and SNF placements are all available but taxed by increasing demand; limited availability of low cost/affordable care
- Education of physicians and associated medical personnel regarding appropriate efficacy and use of pharmacological interventions, especially regarding over-treatment
- Education for professionals and family caregivers on special needs of persons with late stage dementia and end of life care
- No central website for best practices and guidelines in late stage dementia care
- Lack of knowledge regarding over-treatment and disease process at end of life
- Need for better pain management and management of co-morbidity throughout the late stages and end of life
- Need for increased case management services for informal caregivers of persons with dementia throughout the disease process
- Identification of needs and services available for homeless persons with dementia
Recommendations

- Provide a central website for primary care physicians to find information quickly regarding best practices in pharmacological and non-pharmacological management of late stage dementia.
- Assist physicians to better understand the benefit of certain medications during late stage dementia.
- Provide comprehensive care coordination services that assist persons with dementia and their caregivers to manage persons at home and to navigate the placement process.
- Increase the number of available slots for adult day care.
- Increase the number of affordable assisted living and skilled nursing beds.
- Require minimum levels of dementia care training that includes specific issues regarding late stage dementia and end of life care, especially for professional caregivers, facility staff, physicians, registered nurses, certified nursing assistants, social workers, therapists, and other direct service providers.
- Identify and make available criteria for end of life and hospice care.
- Educate family members about changes and needs of persons with dementia at end of life and make support available.
- Educate Adult Protective Services, emergency personnel, ER personnel, and police regarding end of life issues that can be misinterpreted as neglect, such as management of pressure sores and nutrition challenges.

Policy Recommendations:

- Identify Best Practices standard for city including:
  - Creating a central website for MD’s, family caregivers, professionals
  - Requiring a set number of hours of training for providers
  - Provide a “best practices resource center” to provide technical assistance and consultation on dementia-related cases and programs.
- Utilize existing training resources to provide state of the art training to city agencies and staff, especially adult day centers, clinics, and staff in assisted living, skilled nursing, home health care, including person-centered care.
- Offer specialized training in co-morbidity, pharmacology by UCSF, California Pacific Medical Center, Stanford Hospital, and the VA Medical Center.
- Provide case manager, care coordination training at San Francisco State University, DAAS, and Stanford.
- Enhance informational resources from 211 and 311.
- Support periodic update conferences California Association for Nursing Home Reform, American Society on Aging, Alzheimer’s Association, Family Caregiver Alliance.
- Provide funding for existing training institutions and agencies to train personnel
- Fellowship at UCSF in Geriatric Practice.
- Internships for city case managers, registered nurses, social workers.
- Develop an incentive program from the city to reinforce approved training and encourage agencies to provide training.
- Educate Adult Protective Services, emergency personnel, and police about end of life issues that can be misinterpreted as neglect, such as management of pressure sores and nutrition challenges.
• Expand primary care physician training related to end of life care to include issues regarding over-treatment (unnecessary procedures) and under-treatment (pain management) and hospice criteria for persons with dementia.
• Include a spiritual component to care to address the needs of caregivers and persons with dementia at all stages of the disease process.

7. ADVANCED CARE PLANNING

Introduction

Advance care planning (ACP) is a process in which persons, anticipating a time in the future when they may not be able to make medical decisions, document preferences and requests that can guide health care providers and surrogate decision-makers. Encouraging ACP can help foster greater patient and caregiver understanding of the patient’s medical condition, can help foster more patient-centered care, and can help ensure that a person's preferences are honored at the end of life.

Every older person should engage in ACP and identify a surrogate decision-maker. Completing an advance directive and completing a Durable Power of Attorney for Health Care are the two most common components of ACP. Unfortunately, despite efforts to improve the rates of ACP in the general population, most people do not engage in ACP prior to becoming incapacitated.

Although all dementia guidelines recommend ACP at the time of diagnosis and regularly thereafter, there is little published research on ACP in early to mid dementia; most of the research has been on people in nursing homes or at the very end of life.

Since dementia eventually causes people to lose capacity to make medical decisions, it is especially important that people with a diagnosis of early dementia engage in ACP promptly, while they still have the mental faculties to do so. Engaging newly diagnosed people with dementia in ACP is universally recommended in dementia guidelines, but in practice often does not occur. The barriers are many, but two stand out: providers lacking time to guide patients through the process; provider discomfort with the subject; and patient reluctance, which may be cultural and/or related to limited health literacy. A recent systematic review concluded that there is moderate evidence supporting the value of ACP led by skilled facilitators who engage key decision makers.

In some health care settings, advance care planning may be carried out by social workers. Although social workers do bring valuable skills to this task, many experts now recommend that physicians and other providers be closely involved in the ACP process, since an adequate understanding of a person’s underlying health status and prognosis is necessary for the person to plan appropriately. Research has shown that people often have an inadequate understanding of dementia and its overall prognosis.

Many people are most familiar with instructional advance directives, in which a person specifies which procedures they would or would not want to have. These types of documents, however, often fit poorly with the complex decision-making situations that often occur at the end of life. Experts therefore now tend to recommend that people focus on articulating preferences and goals rather than specific directions regarding procedures and interventions. This allows surrogates and providers more flexibility when choices ultimately must be made, while still providing guidance about how to honor the person’s preferences.
Content Areas

The following topics should be covered in education and prevention efforts related to advanced care planning:

- **What is Advanced Care Planning (ACP)?**
  - A process of making plans for a future time when one won’t be able to make medical decisions.
  - Recommended for everyone, but especially important for people who are older or chronically ill.
  - The products of ACP include advance directives and Durable Powers of Attorney for Health care.
  - Products may also include pre-hospitals DNRs and/or POLST (Physician Orders for Life-Sustaining Treatment).
  - Includes early planning, such as creating the basic care network, and determining whether the family should put the PWD in a home or not.

- **Why is it especially important that people with dementia engage in ACP?**
  - ACP is especially important for people diagnosed with dementia, because dementia eventually causes people to lose the mental capacity needed to make medical decisions and other complex decisions.
  - People diagnosed with dementia need to think ahead so that health care providers and surrogates will later be able to provide care in accordance with their preferences.

- **Who should be involved in the ACP process and why?**
  - A primary care provider or other provider, because people with dementia need to have an adequate understanding of their underlying health status, their prognosis (which may be very uncertain), and their treatment options before they can engage in meaningful and appropriate advance care planning.
  - Caregivers, close family, and/or people likely to become surrogate decision-makers.

- **What specific issues should be covered during ACP?**
  - The list can vary, however at very least it should include identification of a surrogate decision-maker. Preferences regarding life support and CPR in the setting of a terminal illness are also usually covered. A more sophisticated process can address what would constitute a good death.
  - Hospice and palliative care.

- **What are the steps involved in ACP?**
  - The need to engage in ACP should be raised by health care providers. It can also be raised by empowered patient or caregiver.
  - A guided discussion should be planned.
  - Information regarding underlying health status, prognosis, and treatment options should be offered and clearly understood. A recent study found that showing people videos helped them understand what having advanced dementia is like.
  - Goals and preferences should be elicited.
➢ Advanced directives and other paperwork documenting the advance care planning should be completed.
➢ Goals, preferences, and advance directives should be periodically reviewed and revised, especially after a significant change in medical condition.
➢ ACP is a longitudinal and iterative process. Providers and patients should expect to revisit ACP periodically, since preferences and goals can change over time.

• What is POLST?
  ➢ POLST (physicians order for life sustaining treatment) is a physician’s order that outlines a plan of care reflecting the patient’s wishes concerning care at life’s end. The POLST form is voluntary and is intended to assist physicians, nurses, health care facilities, and emergency personnel to honor patients’ wishes for life-sustaining treatment. See http://finalchoices.org/polst-consumers.html#faq.

• Code status while in hospital
  ➢ People are often taken by surprise when they are asked about code status when hospitalized.

Approaches to Education and Prevention

• Improving participation rates of ACP is known to be difficult. Educational initiatives targeting health care consumers, people with dementia, and health care providers are unlikely to have an impact unless they are combined with other efforts to systematically encourage and facilitate ACP. Examples of systematically facilitating ACP include providing a trained nurse facilitator in clinic and reimbursing providers for spending time on ACP.
• Written materials in multiple languages widely distributed through health fairs, library and hospital systems and community agencies
• PSAs and other television, radio and print ads
• Workshops and classes
• Websites
• Completion of advance directives is monitored by the Veterans Administration; San Francisco could consider similar monitoring and feedback to providers to promote ACP.

Existing Services and Service Gaps

• California Coalition for Compassionate Care has a good website: http://finalchoices.org/acp-talking.html
• California Health Care Foundation is currently paying to promote POLST
• The Institute for Health care Advancement has an easy-to-read California Advance Directive form available on their website, in English, Spanish, and Chinese. http://www.iha4health.org/index.cfm/CFID/26763611/CFTOKEN/87482075/MenuItmID/266.htm
• California Association for Nursing Home Reform (CANHR) offers free assistance with advance directives
• Legal Aid Society offers free assistance with advance directives
• AARP has a publication called “Prepare to Care” that addresses ACP
Recommendations

- Systematically encourage and facilitate ACP through such means as providing a trained professional in clinics or reimbursing providers for spending time on ACP.
- Make informational/educational materials available in print and online.
- Consider a public education campaign to raise awareness of what ACP is and why it’s important.
- Because the research on how best to engage elders and people with dementia in ACP is ongoing, the plan to educate providers and health care consumers needs to be dynamic.

Policy Implications

- Currently many people with dementia die in the hospital after receiving fairly intensive medical care. Many people, however, when given comprehensive information about their underlying health status, prognosis, and treatment options, express a preference for more comfort-oriented care at the end of life. There is the potential for some cost-savings if unwanted intensive medical care is avoided at the end of life.
- A standard of care mandated by San Francisco could require providing resources to help ACP occur or to make sure it has occurred.

8. ETHICAL ISSUES

Introduction

Persons diagnosed with Alzheimer's and related dementias, their families and professional care providers face ethical issues throughout the course of the disease. Dementia of any kind can be difficult and taxing—for both the person with the diagnosis and the primary caregiver. Changes in the person’s ability to understand, to make decisions and to control behavior make caregiving challenging. The traditional approach to decision-making involves the person with dementia, the individual’s primary care physician, and his or her spouse, life partner, or other family member.

Basic to decisions by the physician, the designated caregiver and others involved in the person with dementia’s care is the need to know the value and attitudes of the person before becoming unable to make decisions. If the person presents for care without an advanced directive, physicians must consider the value to the person of palliative care versus restorative care. The value of the care to the person’s quality of life needs to be part of any decision—making the physician undertakes on the individual’s behalf in the absence of an advanced directive.

Alzheimer's and related dementias can bring up ethical questions, including:

- Obtaining and discussing a dementia diagnosis (e.g., Is it okay not to share the diagnosis with the patient?)
- Appropriate care at different stages of disease (e.g., When is treatment prolonging suffering rather than improving quality of life?) and,
- Who should be responsible for overseeing care over the course of the disease (e.g., What happens when individuals are alone or have uninvolved family?).
- What happens when the patient’s and his/her significant other’s relationship is not legally recognized or culturally accepted by formal care providers, who traditionally have not recognized non-blood relationships?
• Who should make care decisions in the absence of a designated representative? How can a decision making process avoid conflicts?
• When are restraints appropriate?
• Situations involving sexuality and intimacy between persons with limited capacity to make such decisions (Who decides whether an individual with dementia living in a care home can consent to an intimate relationship with another resident? What happens if the family is opposed to the decision?)
• How do we balance the rights of the individual to independence verses the need for public and personal safety (e.g., driving, living alone, wandering)?
• Who determines whether a person with dementia can take part in research studies?

Existing Resources

The Alzheimer’s Society of Canada developed ethical guidelines in 1997, and then revised them six years later “to provide information and guidance to persons with Alzheimer’s and related dementias, their families, health care professionals and researchers as they navigate the difficult issues raised by Alzheimer’s disease.” These guidelines are available on the Internet at alzheimer.ca/english/care/ethics.htm.

The Alzheimer’s Association has several helpful fact sheets on the following topics:

• An Alzheimer’s Bill of Rights (for persons with a diagnosis)
  ➢ Every person diagnosed with Alzheimer’s disease or a related disorder deserves:
  ➢ To be informed of one’s diagnosis.
  ➢ To have appropriate, ongoing medical care.
  ➢ To be productive in work and play as long as possible
  ➢ To be treated like an adult, not a child.
  ➢ To have expressed feelings taken seriously.
  ➢ To be free from psychotropic medications if at all possible.
  ➢ To live in a safe, structured and predictable environment.
  ➢ To enjoy meaningful activities to fill each day.
  ➢ To be out-of-doors on a regular basis.
  ➢ To have physical contact including hugging, caressing, and hand-holding.
  ➢ To be with persons who know one’s life story, including cultural and religious traditions.
  ➢ To be cared for by individuals well-trained in dementia care.

• Principles of a Dignified Diagnosis (for providers making and disclosing the diagnosis)
  ➢ Talk directly to the person with dementia.
  ➢ Tell the truth.
  ➢ Test early.
  ➢ Take concerns seriously, regardless of age.
  ➢ Deliver the news in plain but sensitive language.
  ➢ Coordinate with other care providers.
  ➢ Explain the purpose of different tests and what you hope to learn.
  ➢ Give tools for living with this disease.
  ➢ Work on a plan for healthy living.
  ➢ Recognize individuality and variability in disease.
  ➢ Alzheimer’s is a journey, not a destination.
• End of life decision-making
• Clinical Studies (how to participate)
• Genetic Testing (pros and cons)
• Love, Sex & Alzheimer’s (workshops and materials)
• Driving http://www.alz.org/living_with_alzheimers_driving.asp
• Guidelines for Quality Dementia Care:
  http://www.alz.org/national/documents/brochure_DCPRphases1n2.pdf
• Physicians Orders for Life Sustaining Treatment (POLST)—described in the Advanced Care Planning section of this document

Existing processes—5150, conservatorship, public guardian, etc. —have gaps (5150 is short term, Adult Protective Services and the Public Guardian are often overwhelmed. Durable Powers of Attorney for Health Care can determine answers for some treatment issues, but many people may not have them in place.

Content Areas:

• Values and Guiding Principles
• Communicating the Diagnosis
• Driving
• Living alone
• Decision-making/ capacity to give consent
• Sexuality & Intimacy
• Quality of life
• Participation in clinical trials and research

Phases of clinical trials
  ➢ Preclinical studies
  ➢ Phase I trials
  ➢ Phase II trials
  ➢ Phase III trials
  ➢ Phase IV trials
  ➢ Ensuring accuracy of study results
  ➢ Designs for clinical trials: “placebo-controlled” or “double-blinded”
  ➢ Monitoring safety behind the scenes—how to decide whether to take part
  ➢ Informed consent: Knowing what to expect
  ➢ Matching participants to studies
  ➢ How to find a study near you

• Genetic testing
  ➢ Having the APOE-e4 gene does not mean a person has or will develop Alzheimer’s disease.
  ➢ The presence of a gene associated with Alzheimer’s disease should not be used to deny access to housing, employment, health care, insurance or any other goods and services.
The presence of a gene associated with Alzheimer's disease does not qualify an individual for disability-related benefits. Disability support should be based on functional criteria rather than a genetic test.

Because of possible social consequences or discrimination, anonymous testing should be available, thereby making the fact of and results of genetic testing for Alzheimer's disease invisible on an individual’s medical records.

If performed, genetic testing for Alzheimer’s should be done with pre- and post-test counseling, which includes a full discussion of the implication of the test and provides the individual with all information necessary to make an informed decision. All genetic counseling and information should be provided in culturally and linguistically appropriate formats and should take into account an individual’s literacy level.

- Restraints

Approaches to Education and Prevention

- Workshops, conferences & classes
- Printed and web based materials
- Case consultation groups and discussions

Recommendations:

- The City should explore the creation of an independent ethics panel to assist in decision-making. This body could provide advice and counsel in situations in which acute needs of involuntary treatment are present. An ethics panel might also make policy recommendations on related issues. Research should be undertaken that includes: (1) the existing ethics project in San Francisco; and (2) models already developed in Santa Clara, Contra Costa, and Alameda Counties. A workgroup should be established to investigate this option.
- Discuss/review ethical issues in case-based education for providers and having the Geriatric Fellows provide consultation on these issues.
- Consider a new model for handling 5150s in a demented, geriatric population (look to other counties such as San Mateo as a model).

9. EMERGENCY PREPAREDNESS AND SAFETY

A disaster situation, such as an earthquake or power outage, can significantly add to the stress and confusion of someone with Alzheimer's or related dementias. This can lead to unsafe and distressing behaviors, such as wandering or agitation. Sixty percent of persons with dementia will wander away from home at some point in their illness and 70% will do so repeatedly.

If not found within 24 hours, up to 46% will be seriously injured or even die. These incidences occur in both community and institutional settings. In a study of nursing home elopement insurance claims, 70% of elopement claims involve the death of a resident; 45% of elopements occurred within the first 48 hours of admission; and 80% of elopements involved chronic wanderers.

Wandering is one of the leading factors that cause caregivers to place the person with dementia in assisted living or nursing home settings. Research indicates that simply delaying by one month entry into skilled nursing facilitated would result in savings by 2020 of $1.3 billion annually in combined out of pocket state and federal expenditures.
There are no studies that specifically show the impact of training to address emergency preparedness and safety issues. However, there is evidence that caregivers who have received training on approaches to managing difficult behaviors experience better outcomes.

**Content Areas**

The subcommittee identified the following topics to be covered in education and prevention efforts related to emergency preparedness and safety:

- **What are the unique needs of persons with dementia in emergency situations?**
  - The impact memory and language impairment has during emergencies
  - Wandering behaviors/getting lost
  - Frail elders with dementia
  - Younger persons with dementia
  - Examples from Katrina

- **What kinds of emergencies do we need to prepare for?**
  - Earthquakes, fire, flood, tsunamis
  - Wandering episodes/getting lost
  - Flu or other epidemics
  - Power outages or other extreme conditions
  - Caregiver injury leaving PWD unattended at home

- **How to plan ahead**
  - Create an emergency plan, including legal documents such as advanced directives and powers of attorney.
  - Communicate the plan
  - Steps to do ahead of time:
    - Enroll the person in MedicAlert® + Alzheimer's Association Safe Return®, a 24-hour nationwide emergency response service for individuals with Alzheimer’s or related dementia who wander or who have medical emergencies.
    - If the PWD lives in a residential facility, find out about its disaster and evacuation plan. Ask who will be responsible for evacuating the PWD.
    - Make sure evacuation plans address the specific needs of the PWD.
    - Prepare an emergency kit. Keep it in a watertight container and store it in an easily accessible location.
  - What to do if a pending disaster is about to occur
  - What to do during an evacuation
  - Tips for preventing agitation

- **Addressing day-to-day safety**
  - Wandering prevention
  - Home modification
  - Crime prevention
  - Poison control
  - Agitation and aggression
Approaches to Prevention and Education

- Partner with the Red Cross and others to piggyback on their efforts with messages specific to persons with memory impairment.
- Public service announcements and other television, radio and print ads.
- Written materials in multiple languages widely distributed through health fairs, city offices, police and fire departments, libraries, hospital systems, and community agencies
- Workshops and classes
- Websites

Existing Services

- Alzheimer’s Association DVD’s, curricula, materials in print and online
- MedicAlert & Safe Return Program
- Training DVD’s for family caregivers and police officers
- Family Caregiver Alliance
- Institute on Aging
- Department of Aging and Adult Services
- alzonline.phhp.ufl.edu/en/topics/fact sheets on emergency preparedness and wandering
- www.annalsoflongtermcare.com/article/6200 includes an article on Disaster Preparedness for Long-Term Care Facilities
- www.preparenow.org
- www.72hours.org
- San Francisco Community Agencies Responding to Disaster - www.socard.org

Recommendations

Share information with the Red Cross, SF Card and 72hours.org to see if they can incorporate dementia specific information into their materials, workshops and on the web. They have some great tips already for disabled persons but nothing on memory impaired individuals.

Policy Implications

Ideally every person with dementia in San Francisco should be enrolled in the MedicAlert Safe Return program, though cost is a barrier ($55 one-time enrollment and $25 per year thereafter).

The fire and police departments should have annual in-services on how to respond to wandering and other situations involving persons with dementia (accidental shoplifting).

Some states are considering a silver alert system to notify the public of a missing person with dementia; San Francisco could consider implementing this type of program.
Appendix IV: Finance Detail

As part of this effort, the Finance Subcommittee reviewed the results of a comprehensive study and analysis of the costs of services for individuals with Alzheimer's and other dementias. This study examined the total formal and informal care costs attributable to Alzheimer's disease for persons living in the community as well as for individuals living in institutions in San Francisco. Data for the study were collected from ninety-three non-institutionalized Alzheimer's disease patients and their primary caregivers and from ninety-four institutionalized Alzheimer's disease patients, their primary caregivers, and staff of the institutions in which the patients resided. Special efforts were made to obtain broad representations by age, gender, socioeconomic status, race, and ethnicity.

Individuals with co-morbid conditions that might also result in dementia were excluded so that costs specific to Alzheimer's disease could be isolated. Primary caregivers were identified as unpaid persons who had primary responsibility for helping the patient with activities of daily living (ADLs), instrumental activities of daily living (IADLs), or both. This person provided more hours of care to the individual than anyone else. In an effort to further isolate costs attributable to Alzheimer's disease, caregivers were asked to describe only services used above and beyond what the patient would require if he or she were not demented. The researchers and Finance Subcommittee members recognized that the study population is not a random sample and may not be representative of the overall Alzheimer's population. Nevertheless, a broad range of Alzheimer's patients and their caregivers are included in this study, which represented the largest primary data collection effort to date using a sample of persons with Alzheimer's disease studied for cost implications.

A baseline interview of all primary caregivers in their homes included demographic, caregiving, and service use questions about themselves and the patients. Primary caregivers of non-institutionalized patients were also asked to assess the patient’s capacities in ADLs. During the baseline interview a Mini-Mental State Examination (MMSE) was administered to patients who resided in the community. Patients in institutional settings were administered the MMSE during a separate visit, and facility staff familiar with the abilities of the patient were asked to assess ADL functioning. Caregivers were provided a calendar to record time spent on tasks related to caring for the patient, formal services used, formal costs associated with caring for the patient, and reimbursement received from Medicare, Medicaid, or private insurance. These data were obtained from caregivers through twelve monthly telephone interviews conducted by trained interviewers.

The economic cost of Alzheimer’s disease represents the value of resources used or forgone as a result of the disease. Both formal and informal care services are estimated. Formal services refer to those rendered for a price in the traditional medical and social service marketplace, where dollars are explicitly exchanged for services. Informal services refer to services rendered outside those markets and for which providers are not reimbursed. Because the present study focuses on the cost of care rather than the total cost of the disease, indirect productivity losses are not estimated, however other studies have identified significant indirect productivity losses for both the individual with dementia and the informal caregiver. The incremental costs associated with caring for a demented person and attributed to the disease were measured. To exclude costs associated with conditions other than Alzheimer’s disease, primary caregivers determined whether a formal service or an aspect of informal care was required because of the patient’s demented condition. Billing records were also requested from primary caregivers and formal service providers for all formal services. Included in

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134 The Economic Burden Of Alzheimer's Disease Careby Dorothy P. Rice, Patrick J. Fox, Wendy Max, Pamela A. Webber, David A. Lindeman, Walter W. Hauck, and Ernestine Segura
formal care costs are expenditures for hospital and nursing home care, physician services, social services, medications, and other items or services used for the care of the person as a direct result of Alzheimer's disease. Social services are those that do not require the delivery of skilled medical care but that contribute to the health and welfare of the patient.

For most of these services, charges are used as a proxy for costs. Informal care provided to the patient as a result of Alzheimer's disease is valued using a replacement cost approach by imputing a market value for services performed. An alternative approach is to estimate the opportunity costs of caregivers' services by estimating the dollar value of their time had they been employed or engaged in other activities. Data were collected on missed wages and job and lifestyle changes that resulted from caregiving responsibilities.

Applying a common opportunity wage to all caregivers, as has been done elsewhere, would not consider the varying circumstances of the caregiver. Furthermore, market wages undervalue the time of women, the elderly, and minorities, who suffer from labor market discrimination. Thus we selected the replacement cost approach as the preferable methodology.

Monthly data on the hours spent per week on fourteen possible services that an informal caregiver might perform were collapsed into four broad categories: assistance with ADLs and IADLs, behavioral management, social/recreational activities, and other activities. If the patient had no system of informal support, similar services would have been performed by a paid employee appropriate to that need for services. An appropriate wage for each type of worker was used, reflecting 1990 California wages (including fringe benefits), which was updated to 2007 wage levels for this process as were the projected costs for formal, assisted living, and institutional care.
Appendix V: Inventory of Plans in Other Jurisdictions

Plans Relating to or Focused on Alzheimer’s Disease: Elements and Themes

Senate Bill 491, Alquist, Statutes 2008, charges the Alzheimer’s Advisory Committee to review existing documents when making policy and planning recommendations. The Committee is to: “Consider recommendations of other state plans, including but not limited to, the Olmstead Plan, the Long-Range Strategic Plan on Aging, and the California Department of Aging’s State Plan on Aging.”

This document organizes recommendations of several plans, including: the Strategic Plan for an Aging California Population and the California Olmstead Plan as well as Alzheimer’s Disease Plans from Iowa, Kentucky and Vermont as well as two counties. The California Department of Aging will be issuing a draft State Plan on Aging for 2010 for comment during the spring of 2010. Recommendations of the plans reviewed thus far fall into several broad themes, including:

➢ Medical and Health Care
➢ LTC and Caregiver Support
➢ Data and Research
➢ Outreach and Education
➢ Legal Issues

For the complete text of the plans referenced, please see citations:

CALIFORNIA:
SF: San Francisco Alzheimer’s Advisory Committee Meeting Recommendations

IOWA:

KENTUCKY:

VERMONT:

MICHIGAN:
Medical and Health Care

Health Promotion

- Promote health and reduce the risk for developing Alzheimer’s disease or related disorder. (IA)
  - Provide physical and mental activity programs using evidence-based programs designed for older adults such as EnhanceFitness, Eat Better & Move More, and Healthy Aging.
  - Provide chronic disease self management programs using evidence-based health promotion programs such as Stanford Chronic Disease Self Management.
  - Promote dietary quality for older adults through provision of nutrition education programs such as Eat Better & Move More.
  - Provide nutrition counseling by registered dietitians to older adults determined to be at high nutrition risk.
  - Provide brain health education programs to help Iowans reduce their risk of Alzheimer’s disease or related disorders.

- Encourage primary care doctors to perform an annual first level Alzheimer/dementia assessment for their patients over 65 years of age to identify early markers of Alzheimer’s disease so diagnosis can be made prior to manifestation of symptoms (CA)

- Promote dementia case detection and assessment. (MI)

Acute care

- Enhance capacity of services to meet needs of persons with Alzheimer’s disease or related disorder. (IA)
  - Provide technical assistance to current service providers to enable the diversification of their service base.

- Require and provide training and the subsequent provision of evidence based practices in programs and services supported by State funds. (KY)

Chronic disease care

- Pilot new care models where providers offer chronic care management to individuals, particularly those with dementia, who are incapable of managing their own chronic conditions, and need that assistance. (CA)

Mental Health

- Dementia recognized as MH issue with access to available services (Marin)

- Advocate for legislation mandating coverage for dementia under Community Mental Health. (Marin)

- Advocate for the development of a Med-Psych unit for differential diagnosis (Marin)

- Require mental health parity. (KY)

- Convene a workgroup on a regular basis to address psychogeriatric needs of persons with Alzheimer’s disease in Iowa. The workgroup would be tasked with identifying mechanisms for funding of in-patient mental health services, expanding the statewide availability of services, establishing education pathways for providers, and enhancing the availability of emergency crisis intervention. (IA)

- Better geropsychiatric services in the community to avoid institutionalization (SF)

- Improve pharmacology mismanagement

- Support a pilot demonstration project to address the problem of facility discharges of residents exhibiting challenging behavior. (KY)
End of life care

- Create a cadre of academic faculty trained in the principles of palliative care at all of the state’s medical schools, teaching hospitals and schools for related medical professionals (i.e., Social workers, nurses, etc.). This training curriculum should include non-cancer diagnoses, persons with dementia, and working with caregivers as it relates to palliative care. (CA)

Care Management and Quality Improvement

- Establish a dementia quality initiative to direct efforts to measure and improve dementia care across health care settings, including home-based care, and promote person and family centered services (Vermont).
- Advocate for integrated systems of healthcare and support that are effective for individuals with Alzheimer’s disease or related dementias and their families. (e.g., disease management strategies, practice guidelines, home and community based care, hospice care and chronic care management) (KY)
- Support and assist the rapidly increasing numbers of individuals with Alzheimer’s disease or related disorder by providing a wide array of home and community based services such as adult day services, respite care, and affordable transportation as well as assisted living, occupational therapy, speech therapy, social work services, dieticians, and others as these may delay premature nursing facility placement. (IA)
- Subject to funding, establish the Geriatric Comprehensive Care Management Program for persons over 60 with more than one chronic condition. Components of the program should include: (CA)
  - A continuum of integrated accessible service options
  - A nurse/social worker geriatric team as part of every primary health delivery system
  - Development of a care plan with the consumer that considers the person or caregiver’s ability to follow the plan based on their mobility, cognitive status, mental health, medication management status, transportation and nutrition needs
  - Consideration of the needs of family caregivers
  - Early diagnostic tests for Alzheimer’s
- Correlate stages of Alzheimer’s disease or related disorder with interventions to assist caregivers and service providers to make care decisions and to navigate the delivery system through the: (IA)
  - Identification of intervention
  - Identification of service needs
  - Identification of safety needs (including home environments)
  - Identification of caregiver needs
- Enhance capacity of services to meet needs of persons with Alzheimer’s disease or related disorder. (IA)
  - Develop recommendations which reflect Alzheimer’s disease or related disorder capable and friendly practices.
- Identify and promote wide use of evidence based practices through the development of an Evidence-Based Practice Guide specific to Alzheimer’s Care. (KY)
- Establish Alzheimer’s disease and related disorder Diagnostic Centers of Excellence strategically throughout the state that would serve as multi-disciplinary centers to serve patients with Alzheimer’s disease or related disorder and their caregivers. (IA)
  - The ideal center would have physician services, social services, nursing, and special interest in the care of persons with Alzheimer’s disease or related disorder.
Various organizations focused on patient needs in this area could join forces to ensure efficiency and effectiveness. For example, existing memory centers could joint venture with the Alzheimer’s Association and mental health advocate organizations to establish multiple centers across the state that would provide easy access to comprehensive services. These services would include history, physical, lab, x-ray, social support, and treatment.

- Provide timely assessments for persons in institutions to determine supports and services needed for individuals to transition and live successfully in the community. Provide assessments for persons living in the community, who are at risk of placement in an institution or more restrictive setting, to remain in the community in the least restrictive setting. Assessments should result in an informed choice for the consumer as to the most appropriate and integrated setting. (CA Olmstead)

- Continually improve quality of services based on desirable outcomes and measures and increase the level of consumer satisfaction. (CA Olmstead)

**Medical and Health Care Workforce Issues**

- Create an optional specialized certification for health and human services professionals to provide quality care and improve the quality of life for people with Alzheimer’s disease or related disorders. (LA)

- Engage in initiatives which increase supply, distribution and quality of the dementia care workforce. Dementia care workforce may include conventional health care professionals and paraprofessionals as well as first responders, police, area agency on aging staff, housing providers and other critical workforce professions. (Vermont)

- Require mandatory dementia-specific training for emergency room staff including nurses, physicians and related services technicians such as radiology. (KY)

- Fund public awareness efforts and educational efforts for providers, caregivers, and state oversight and monitoring personnel. (IA)

- Implement a statewide campaign to educate health and human services professionals regarding early detection instruments, such as AD8 and Mini-Cog, as early detection could prepare patients and families for what to expect. (LA)

- Address the preparedness of the workforce to provide care and services in support of persons with Alzheimer’s disease or related disorder and their caregivers. (IA)

  Recruit and retain workers across care settings.
  Maximize the utilization of information technology to expand the access and availability of health professionals.
  Promote the interdisciplinary team approach for planning and care delivery.

- Support an interdisciplinary effort to develop a core set of geriatric competencies and a common language across the health, mental health and social service professions. (CA)

  These should include patient-centered care, the bio/psycho/social needs of the aging, evidence-based practice, interdisciplinary teams, quality improvement and problem solving.
  Train providers on core competencies in order to encourage patient centered care
  Core competencies should incorporate caring for people with dementia.
Promote training requirements in dementia issues for health professionals and other persons who are likely to be interacting with or providing care to persons with Alzheimer’s. These professionals include but are not limited to, mental health professionals, residential facility and personnel (including assisted living and skilled nursing), and emergency room and other in-patient hospital staff. (CA)

Work with the universities to develop specific training and recruitment options including: (KY)

- The development of optimal training content standards for licensed health professionals; target Kentucky’s professional schools to integrate it into curricula.
- Create a “Bucks for Brains” program to recruit and train geriatric psychiatrists, geriatricians, and other geriatric specialists.
- The development of residencies or fellowships for training of geriatric psychiatrists, geriatricians, and other geriatric specialists.
- The development of a specific track on Alzheimer’s disease related dementias and dementia related diseases for medical students and residents.
- Institute State policies and procedures to provide additional support to ensure the health, safety and welfare of individuals with Alzheimer’s and Related Dementias Related Disease. (KY)

Establish a certification process for trainers and educators of the standard curriculum model. (LA)

Increase the spectrum of educational resources available by using on-line courses, community colleges and make subsidized educational opportunities available for those wishing to specialize in this field. (LA)

Encourage geriatrics and gerontology studies in every curriculum regardless of specialty. Encourage all physicians, nurses, pharmacists and other healthcare professionals to know how to care for older patients, including patients with dementia. (CA)

Initiate a forum for dialogue among providers serving this population (Marin)

Disseminate information on services and related activities for individuals with Alzheimer’s disease and related dementias to the medical and healthcare community, academic community, primary family caregivers, advocacy associations and general public (KY)

Broader the spectrum of people who are required to receive training specific to Alzheimer’s disease or related disorders to those who work in direct contact with people diagnosed with Alzheimer’s disease including but not limited to administrators, directors, dietary staff, administrative and management staff, hospital direct care staff, state employees with responsibility for long term care oversight/monitoring, and ombudsmen. (LA)

Fund public awareness efforts and educational efforts for providers, caregivers, and state oversight and monitoring personnel. (LA)

Require mandatory dementia-specific training as part of DOCJT yearly in-service training for emergency personnel (e.g. firefighters, emergency medical technicians, police officers). (KY)

Promote use of Primary Care Dementia Network (PCDN) education modules. (MI)

Support dementia component of the Geriatric Education Center of Michigan (GECM) inter-disciplinary community geriatric team outreach and education project in eight communities: Marquette, Traverse City, Grand Rapids, Lansing, Saginaw, Flint, Detroit, and Kalamazoo. (MI)

The GECM and PCDN developed five educational modules for primary care physicians and identified and distributed numerous other resource materials to primary care practices. Available at www.dementiacoalition.org (MI).
Financing

- Explore options to increase insurance coverage for individuals with Alzheimer’s and Related Dementias (KY)
- Explore changes needed to ensure Medicaid eligibility for individuals with early onset Alzheimer’s Disease or Related Dementias (KY)
- Explore potential for Medicaid waiver specific to Alzheimer’s Disease and Related Dementias (KY)
- Review the current Medicaid programs to ensure “dementia friendly” approaches and policies (KY)
- Review the “Resource Utilization Groups” (RUGs) system to determine values of behavior management and evidenced based interventions
- Increasing opportunities for self-determination.
- Identify challenges to admission and eligibility requirements
- Explore services and options available under private insurance entities (KY)
- Given that the Medicaid Waiver is a long process, undertake a three-step approach to address the needs of persons with Alzheimer’s disease or related dementia (IA)
  - Step 1: Allow individuals with a diagnosis of early on-set Alzheimer’s disease or related disorders to be served in excess of the current maximum number of clients under the Ill and Handicap Waiver.
  - Step 2: Increase the expenditure limits under the Elderly Waiver to give parity with other waivers including but not limited to the Ill and Handicapped Waiver, the Brain Injury Waiver, and the Mental Retardation Waiver for persons with a diagnosis of Alzheimer’s disease or related disorder. (This recommendation affects patients older than 65)
  - Step 3: Establish a Alzheimer’s disease or related disorder specific waiver to place greater importance on the issue and needs comparable to the Brain Injury Waiver and the HIV/Aids waiver and without regard to the age of the person with Alzheimer’s disease or related disorder.
- Determine the implications of funding and policy on niche populations including Down’s syndrome and Young onset Alzheimer’s disease or related disorder (IA)
- Evaluate inequities in insurance and Medi-Cal reimbursement to providers (CA)
  - Subject to the availability of resources, allow drug coverage for treatment of Alzheimer’s and related disorders.
- Identify differential costs of mild/moderate/severely impaired individuals with dementia or related disorders (SF)
- Identify co-morbidity costs of individuals with dementia or related disorders (SF)
- Enhance capacity of services to meet needs of persons with Alzheimer’s disease or related disorder (IA)
  - Examine the caps on waiver funding.
  - Review current re-imbursement rates across all state programs.
- Explore changes needed to support the purchase and provision of evidence based practice training and education (KY)

Policy

- Establish policies, procedures, and incentives to incorporate evidence based practices into training, service, and program activities (KY)
Long Term Care and Support

Skilled Nursing Facilities

☐ Support a pilot demonstration project to address the problem of facility discharges of residents exhibiting challenging behavior. (KY)

☐ Develop regulations or waiver protocol inviting development of new approaches to facility design that preserve resident safety, recognize special needs of persons with memory loss and pursuant to evidence based practice show promise for improving the quality of their lives. (KY)

☐ Divert individuals from entering institutions and ensure that they are served in the most integrated setting appropriate, based on informed consumer choice. (CA Olmstead)

☐ Transition individuals from institutions to the most integrated setting appropriate, based on consumer choice. (CA Olmstead)

Residential Care Facilities for the Elderly

☐ Review overlapping requirements for licenses for personal care homes and assisted living facilities such as medication management including oversight, assistance, administration and monitoring and recommend appropriate regulation changes to accommodate the needs of persons with dementia. (KY)

Home care and Community Services

☐ Develop a demonstration to test the feasibility and cost-effectiveness of adult day care clients receiving services in other long-term care settings traditionally considered “institutional” in order to expand access and accommodate anticipated growth in demand. (KY)

☐ Utilize the Council to evaluate state regulations on home care, adult day and home health to assure they are “dementia friendly”. (KY)

☐ Expand the continuum of community-based services inside and outside the home throughout the state including, but not limited to: care coordination/navigation, home health, home aid, in-home supportive services (IHSS), independent living centers (ILC) and day care, including Adult Day Health Care (ADHC) and Alzheimer’s Day Care Resource Centers (ADCRCs). (CA)

☐ Develop a full array of community services so that individuals can live in the community and avoid unnecessary institutionalization, including participating in community activities, developing social relationships, and managing his or her personal life by exercising personal decisions related to, among other things, housing, health care, transportation, financial services, religious and cultural involvement, recreation and leisure activities, education, and employment. Services should be appropriate to individuals living with and without family or other informal caregivers. Increase capacity for local communities to divert consumers from institutionalization and re-institutionalization. Support family caregivers by providing an array of information and services that will allow them to support a family member with disabilities in their home. (CA Olmstead)

☐ Expand the availability of housing options for persons with disabilities. Ensure the availability of housing options that can be augmented by supports that facilitate the full inclusion of the person into the community. (CA Olmstead)

☐ Identify and promote use of best community caregiver assessment tools and practices, ie. develop a statewide Best Practices Award for dementia day services (MI)
Develop recommendations for community service agencies regarding provision of long-term care dementia information and assistance to avoid gaps, minimize unnecessary duplication, and ensure consumer needs are met. (MI)

Caregiver support

- Develop respite care resources (Marin)
- Utilize the Council and stakeholder community to revise the current definition, eligibility and service requirements for the provision of respite. (KY)
- Develop incentives beyond tax incentives for caregivers (KY)
- Provide Additional Support for Vulnerable Caregivers. (CA)

Intensive intervention efforts should be targeted to vulnerable caregivers, including those who are poor, socially isolated or who have health problems of their own. Intervention should also target those who experience high stress levels, and care for persons with problematic behaviors, dementia, or a high level of daily dependency.

- Disseminate information on services and related activities for individuals with Alzheimer’s disease and related dementias to the medical and healthcare community, academic community, primary family caregivers, advocacy associations and general public (KY)
- Develop a profile of Michigan’s home-based dementia caregivers to aid planning and advocacy efforts. (MI)
- Promote existing tools and resource materials including Effective Caregiver Interventions, in-home and community-based respite best practices, technology lexicon/assistive technology, and other selected resources. (MI)
- Facilitate and promote access to in-home and community-based dementia respite care in Michigan. (MI)
- Provide input in development and implementation of Alzheimer’s Disease Demonstration Grant to States (ADDGS) home and community-based caregiver support services. (MI)

Case management / Infrastructure repairing and building

- Support the development and sustainability of local, regional and statewide health and human service, dementia informed systems of care. These systems will include specialty clinics for the assessment and diagnosis of cognitive impairment, settings providing for the multidisciplinary care of persons with dementia within the home, community, residential and nursing home environments, plus hospitals and hospice programs. (Vermont)
- Establish State Protocol on Appropriate Interface and Choices for Individuals with Alzheimer’s and Related Dementias and Their Families. (KY)
- Ensure system of care coordinators & benefit counselors in each of 15 ADD regions. (KY)
- Develop a process/protocol to permit persons with dementia to remain in their current living environment despite a change in their condition (e.g. challenging behaviors or other disease symptom) that under existing regulations might otherwise promote their move to a different level of care; this protocol should assure that the provider can adequately demonstrate that the person’s care needs can be safely and effectively met without the disruption of moving. (KY)
- Require the Unit and Council to develop a protocol detailing how to interface with individuals with Alzheimer’s and related dementias and their families. The protocol should include appropriate placement care options based on the stages of Alzheimer’s and related dementias. (KY)
☐ Correlate stages of Alzheimer’s disease or related disorder with interventions to assist caregivers and service providers to make care decisions and to navigate the delivery system through the: (LA)

  Identification of intervention
  Identification of service needs
  Identification of safety needs (including home environments)
  Identification of caregiver needs

☐ Support and assist the rapidly increasing numbers of individuals with Alzheimer’s disease or related disorder by providing a wide array of home and community based services such adult day services, respite care, and affordable transportation as well as assisted living, occupational therapy, speech therapy, social work services, dieticians, and others as these may delay premature nursing facility placement. (LA)

☐ Establish a dementia quality initiative to direct efforts to measure and improve dementia care across health care settings, including home-based care, and promote person and family centered services (Vermont).

☐ Implement a comprehensive service coordination system that will improve the long-term care system so that California residents, regardless of disability, will have available an array of community service options that allow them to avoid unnecessary institutionalization. This comprehensive system would include elements such as the following (CA Olmstead):

  A standardized diversion process for individuals at risk of placement in institutions. Multi-disciplinary teams will be used that include the appropriate expertise (e.g., dementia expertise for a person with Alzheimer’s Disease).

☐ Provide timely assessments for persons in institutions to determine supports and services needed for individuals to transition and live successfully in the community. Provide assessments for persons living in the community, who are at risk of placement in an institution or more restrictive setting, to remain in the community in the least restrictive setting. Assessments should result in an informed choice for the consumer as to the most appropriate and integrated setting. (CA Olmstead)

☐ Provide comprehensive information regarding services to persons with disabilities in order to make informed choice and for service planners for planning purposes. No individual with disabilities should be prevented from living in the community due to a lack of information. Develop information, education, and referral systems, as needed, to meet this goal. (CA Olmstead)

LTC Workforce Issues

☐ Increase and enhance training and education requirements about Alzheimer’s disease or related disorders for all direct care employees including, but not limited to, long-term care settings, assisted living, elder group homes, residential care, adult day service facilities and home health care. (LA)

  Establish or broaden the number of hours for training for direct care staff to a minimum of 8 hours classroom instruction and a minimum of 8 hours of supervised interactive experience.

  Establish or broaden the number of continuing education/in-service hours for direct care workers on the topic of Alzheimer’s disease or related disorders to a minimum of 8 hours annually.

  Add a competency component following Alzheimer’s disease or related disorders training.

  Establish a standard curriculum model that will include, but not be limited to: the diagnostic process, the progression of the disease, communication skills
(including the person with the diagnosis, family, friends and caregivers), family stress and challenges, nutrition and dining information, activities, daily life skills, caregiver stress, the importance of building relationships and understanding the personal history, expected challenging behaviors and non-pharmacologic interventions, and medication management.

- Develop and implement an evidence-based training curriculum and implementation strategies for Long Term Care facilities (KY)
- Develop a portable certification program for para-professional direct caregivers with standardized content designed to enhance their understanding of memory impairment and their performance in caring for individuals with Alzheimer’s and related dementias. (KY)
- Require geriatric and dementia training/education for all owners and managers of assisted living/residential and nursing facilities. (CA)
- Enhance capacity of services to meet needs of persons with Alzheimer’s disease or related disorder. (IA)
  - Ensure the availability of trained workers for facility and community based services.
- Require and provide training and the subsequent provision of evidence based practices in programs and services supported by State funds. (KY)
- Broaden the spectrum of people who are required to receive training specific to Alzheimer’s disease or related disorders to those who work in direct contact with people diagnosed with Alzheimer’s disease including but not limited to administrators, directors, dietary staff, administrative and management staff, hospital direct care staff, state employees with responsibility for long term care oversight/monitoring, and ombudsmen. (LA)
- Fund public awareness efforts and educational efforts for providers, caregivers, and state oversight and monitoring personnel. (IA)
- Engage in initiatives which increase supply, distribution and quality of the dementia care workforce. Dementia care workforce may include conventional health care professionals and paraprofessionals as well as first responders, police, area agency on aging staff, housing providers and other critical workforce professions. (Vermont)
- Address the preparedness of the workforce to provide care and services in support of persons with Alzheimer’s disease or related disorder and their caregivers. (LA)
  - Recruit and retain workers across care settings.
  - Train caregivers across disciplines to meet the unique needs of persons with Alzheimer’s disease or related disorder.
  - Promote the interdisciplinary team approach for planning and care delivery.
  - Integrate strategies for planned environmental interventions to aid staff, caregiver and person with Alzheimer’s disease or related disorder.
- Promote training requirements in dementia issues for health professionals and other persons who are likely to be interacting with or providing care to persons with Alzheimer’s. These professionals include but are not limited to, mental health professionals, residential facility and personnel (including assisted living and skilled nursing), and emergency room and other in-patient hospital staff. (CA)
- Provide training to drivers in how to safely transport older adults with dementia. (CA)
- Develop a dementia competencies self-assessment tool and dementia competencies guide for direct care workers, to be used by the LTC system to promote dementia competency among direct care providers. (MI)
Quality Improvement

☐ Establish Quality Care measures with system benchmarks for facility and community based care for persons with Alzheimer’s disease or related disorder. (LA)

☐ Enhance the capacity of services to meet the needs of persons with Alzheimer’s disease or related disorder. (LA)

Examine current administrative rules for nursing facilities, CCDI, assisted living, adult day services, home and community-based services, and Medicaid elderly waiver case management programs (administered by the departments of Human Services, Elder Affairs and Public Health).

☐ Continually improve quality of services based on desirable outcomes and measures and increase the level of consumer satisfaction. (CA Olmstead)

☐ Identify and develop information focusing on key points to be made in advocacy for people with dementia as they pertain to the various long-term care workgroups and initiatives. (MI)

Financing

☐ Provide tax incentives for individuals who purchase long-term care insurance. (KY)

☐ Make Medicaid Waivers a significant factor in helping address the many needs of individuals dealing with problems associated with Alzheimer’s disease or related disorder, such as adult day services, assisted living, respite care, occupational therapy, speech therapy, social work services, dieticians, and affordable transportation as a means to delay premature institutionalization. (LA)

☐ Explore changes in the certificate of need requirements in order to foster expansions of Alzheimer’s and dementia specific services. (KY)

☐ Enhance the capacity of services to meet the needs of persons with Alzheimer’s disease or related disorder. (LA)

Examine the caps on waiver funding.

Review current re-imbursement rates across all state programs.

☐ Require training for providers and State staff associated with any of the Medicaid home and community based waivers. (KY)

☐ Advocate for Medi-Cal to supplement SSI payments in residential care settings. (Marin)

☐ Advocate for SSI beds and mixed income residential care facilities (Marin)

☐ Request an increase in the Alzheimer’s Respite Services line item in the State budget. (KY)

☐ Support legislation for a caregiver tax credit for people who provide in-home care for dependent relatives who have little to no income, and have been diagnosed with Alzheimer’s Disease and related dementias. (KY)

☐ Offer tax credits to families for the purchase of locator devices. (KY)

☐ Develop a “Money Follows the Individual” model to provide resources for individuals to live in the community rather than an institution. Seek opportunities to increase resources and funding options. (CA Olmstead)
Data and Research

Surveillance

☐ Require the Alzheimer’s and Related Dementias Unit to coordinate a statewide effort to develop, and implement a statewide data collection system. (KY)

☐ Collect data and monitor at a minimum the following data: (KY)

- The prevalence of dementia related diseases across the state;
- The prevalence of dementia related diseases by county;
- The prevalence of early onset dementia and related diseases across the state;
- The prevalence of inpatient geriatric psychiatry beds;
- The availability of geriatric services and specialists;
- The availability of dementia related services and supports;
- The availability of assessment services for Alzheimer’s and related dementias;
- The number and location (county) of individuals who are currently providing care in their home to a family member.

☐ Develop an improved standardized minimum data set for each reporting entity from Planning and Service Areas (PSA) to nursing homes. Include disability and dementia data in order to fulfill Federal and State requirements, while simultaneously supporting care navigation and the longitudinal database. (CA)

☐ Develop Standard Definitions – Establish a team representing the range of long term care programs, public and private, to develop standard definitions for each data element to be collected across all sectors in California that provide services to the aging, persons with dementia and/or the disabled. Encourage collaboration with other data groups to keep abreast of other related efforts. (CA)

☐ Capture data on a 10% sample of client data from the gamut of long term care and service providers, including, but not limited to: Residential Care Facilities for the Elderly, Multipurpose Senior Services Program, Adults Day Services, Adult Day Healthcare Centers, Alzheimer’s Day Care Resource Centers, and all home and community-based service providers. (CA)

☐ Direct the Council to study new technologies that can help locate missing persons and to make recommendations about implementation strategies. (KY)

☐ Compile an analysis of Iowa’s population by county and age to determine current utilization and future service needs of caregivers and persons with Alzheimer’s disease or related disorder to support development of programs and services. (IA)

☐ Review current trends and the impact in the Long Term Care rebalancing efforts affecting persons with Alzheimer’s disease or related disorder. (IA)

- Bed occupancy, length of stay in a nursing facility, increase number in elderly waiver, acuity level of nursing facility residents, growth of assisted living programs.
- Availability of adult day services.
- Senior Living Coordinating Unit (SLCU) long-range plan (need to ensure strategies to include those to support service for persons with Alzheimer’s disease or related disorder and their caregivers).
- Determine impact of Direct Care Worker shortages on availability and access to services.

☐ Modify existing community needs assessment process to include questions that would identify and quantify at-risk people with Alzheimer’s disease or related disorder. This would include local public health
community needs assessment, Area Agency on Aging area planning process, and other agencies that receive federal and state funding for services to the aging population. (LA)

- Enhance the capacity of services to meet the needs of persons with Alzheimer’s disease or related disorder. (LA)

- Task the Senior Living Coordinating Unit (SLCU) to formally examine the findings of the University of Iowa’s Adult Day Services study (Sanders and Saunders), make recommendations, and track implementation progress across the Unit agencies.

- Improve information and data collection systems to improve the long-term care system so that California residents will have available an array of community care options that allow them to avoid unnecessary institutionalization. (CA Olmstead)

**Research**

- Increase dementia-related research activities in the state by attracting scientific investigators, increasing grant-funded research and increasing participation in dementia-related research that can benefit State’s population. (Vermont)

- Explore processes for distributing state funds to University faculty and determine feasibility of designating state funds specifically toward Alzheimer’s research. (KY)

- Explore additional funding sources for Alzheimer’s research through universities and other resources. (KY)

- Identify and explore ways to further evaluate existing evidence based practices with populations. (KY)

- Continue exploring grant opportunities to provide empirical evidence of nationally recognized evidence based practices as well as practices that are already occurring in the state (e.g., Best Friend’s model of care). (KY)

- Collaborative efforts are developed with state agencies, policymakers and academic centers are developed to engage in policy-related research activities which advance State’s understanding, and improvements, in dementia care. (Vermont)

- Provide input in development and implementation of Alzheimer’s Disease Demonstration Grant to States (ADDGs) home and community-based caregiver support services. (MI)

- Look for grants to support stated objectives and consider other appropriate objectives to match available funding opportunities. Support organizations that are seeking grant opportunities that match the workgroup’s stated objectives.

**Outreach and Education**

**General public**

- Design a broad based dementia and brain health public information campaign. (Vermont)

- Design a grass roots information dissemination campaign. (Vermont)

- Create a summary of resources specifically addressing Alzheimer’s and dementia care programs and services. (Marin)

- Increase public visibility of the Adult & Aging Information and Assistance Number. (Marin)

- Promote educational resources for better understanding Long Term Care financing. (KY)

- Enhance the DAIL website to include Alzheimer’s information and links. (KY)
Develop an Integrated, One-Stop Consumer Information System (CA)

Enhance and improve the user friendliness of CalCareNet. For example, consider the use of intuitive/illustrative icons similar to the American Automobile Association hotel guides, to describe the features of RCFEs or nursing homes. Include information on RCFE’s having dementia waivers.

Establish initiatives which promote a sense of responsibility and provide the necessary resources to support active involvement in advocacy, care and self management. (Vermont)

Establish Alzheimer’s disease and related disorder Diagnostic Centers of Excellence strategically throughout the state that would serve as multi-disciplinary centers to serve patients with Alzheimer’s disease or related disorder and their caregivers. (IA)

The public could initially access information about the Centers through an 800-number manned by a non-profit entity (such as the Alzheimer's Association). Various organizations focused on patient needs in this area could join forces to ensure efficiency and effectiveness. For example, existing memory centers could joint venture with the Alzheimer's Association and mental health advocate organizations to establish multiple centers across the state that would provide easy access to comprehensive services. These services would include history, physical, lab, x-ray, social support, and treatment.

Disseminate information on services and related activities for individuals with Alzheimer’s disease and related dementias to the medical and healthcare community, academic community, primary family caregivers, advocacy associations and general public (KY)

Educate communities regarding the Olmstead decision. Provide background information on the Americans with Disabilities Act, the Fair Housing Amendments Act, and other related federal and state laws, to community decision makers, to ensure that they take the needs of individuals with disabilities into account when making decisions regarding public services and resources. Provide information to California communities so that community planning can be conducted to address the needs of that community’s individuals with disabilities. (CA Olmstead)

Explore with Alzheimer’s Association Chapters, the Office of Long-Term Care Supports and Services, and the Primary Care Dementia Network how best to maintain and disseminate information on dementia assessment providers. (MI)

Continue to provide quarterly newsletters with Network updates, dementia news, and information about dementia resource materials. (MI)

Work with Geriatric Education Center of Michigan (GECM) community geriatric teams to identify, develop and disseminate materials that help increase public awareness. (MI)

Promote dissemination of information through eblasts: (MI)

Promote Michigan Dementia Coalition participant dissemination of eblasts.

Prepare public awareness talking points and slides for dropping in PowerPoint presentations and promote their use among Michigan Dementia Coalition participants. (MI)

Promote broad dissemination of Worried About Memory Loss (WAML) cards. (MI)

Enhance WAML website with additions and more frequent updates. (MI)

Expand educational outreach (for example, to Local Health Departments, medical professional...
associations, and Medicaid managed care organizations). (MI)

First encounter and other non-medical/LTC service providers

☐ Establish an office for Alzheimer’s disease or related disorders within state government. This office would not replace or duplicate any services currently offered by the Area Agencies on Aging, the Alzheimer’s Association, or other agencies, but would act as a referral source to local services. This office would: (IA)

- Increase public awareness for services currently available at the local or state level.
- Collaborate with various stakeholders including serving as a point of contact for people diagnosed with the disease, caregivers, professionals and consumers for information, education, training and referrals.
- Create a senior alert program for local, regional or statewide notification of missing senior adults.
- Coordinate efforts to continue the work of this task force and research the work of experts in both national and international settings.
- Create an advocacy system for people not currently living in long-term care facilities who have been diagnosed with Alzheimer’s disease or related disorder and their families.
- Be guided by a multi-disciplinary commission (board) to continue the work of this task force.

☐ Broaden the spectrum of people who are required to receive training specific to Alzheimer’s disease or related disorders to those who work in direct contact with people diagnosed with Alzheimer’s disease including but not limited to administrators, directors, dietary staff, administrative and management staff, hospital direct care staff, state employees with responsibility for long term care oversight/monitoring, and ombudsmen. (IA)

☐ Work with law enforcement to implement a coordinated protocol or swift and appropriate action upon report of a missing adult with dementia. (KY)

☐ Identify specific training resources for targeted audiences across the state. (KY)

☐ Develop relationships with police and community partners to develop and implement training (such as, but not excluding including but not limited to, bankers, attorneys, police, emergency personnel, etc.). (KY)

☐ Develop and implement an evidence-based training curriculum and implementation strategies for targeted audiences (i.e. Department for Mental Health and Mental Retardation, Office of Inspector General surveyors, Comprehensive Care Centers, family caregivers, etc.). (KY)

☐ Increase training for state adult protective services workers on Alzheimer’s dementia. (KY)

☐ Use stakeholders to promote innovation and a proactive approach to emerging issues in dementia care. (Vermont)

☐ Establish a strategy to link and coordinate services and activities of State agencies, other service providers, advocacy groups and other entities throughout the State such as emergency personnel, police, universities and attorneys and other staff associated with the legal system. (KY)

☐ Require the Unit and DAIL to provide training to staff within the Cabinet for Health and Family Services on the protocol including but not limited to adult protective services workers, guardianship/social workers, and staff from the Office of Inspector General and the Department for Mental Health and Mental Retardation on the protocol. (KY)
Require mandatory dementia-specific training as part of DOCJT yearly in-service training for emergency personnel (e.g. firefighters, emergency medical technicians, police officers). (KY)

Educate Police and Fire Departments as potential population safety net (Marin)

Ensure that all task force recommendations coalesce with other initiatives and programs within the state, such as the Direct Care Worker Task Force Recommendations, Alzheimer’s Association, Area Agencies on Aging, the Hartford Center Grant, Iowa Respite and Crisis Care Coalition and the UI Center on Aging and Geriatric Education Center. (IA)

Help plan the dementia conference day of the annual Issues on Aging Conference. (MI)

Financing

Establish Alzheimer’s disease and related disorder Diagnostic Centers of Excellence strategically throughout the state that would serve as multi-disciplinary centers to serve patients with Alzheimer’s disease or related disorder and their caregivers. (IA)

The state would provide funding to support establishment of new centers.

Explore funding for public education messages for community groups like Faith in Action to use. (MI)

Ask major health plans to participate in campaign. (MI)

Ask major health plans, Employee Health Plans, and drug companies to add WAML link to their websites. (MI)
Appendix VI: California Workgroup and Alzheimer’s Association of Northern California and Northern Nevada
Guideline for Alzheimer’s Disease Management

2008 California Guideline for Alzheimer’s Disease Management

This new California Guideline updates and expands the 2002 version. This guideline was developed by the California Workgroup on Alzheimer’s Disease Management through a collaborative effort of healthcare providers, consumers, academicians, and representatives of professional and volunteer organizations that included a review of scientific evidence supplemented by expert opinion when research has been unavailable or inconsistent.

What is covered in the Guideline:

- Support for a team approach to quality management of Alzheimer's disease
- Importance of an accurate assessment
- Treatment options - including a new class of medication
- Approaches to patient and caregiver education and support - including evidence that links positive patient outcomes to caregiver education and support
- Legal considerations
- New evidence on management of the disease in very early and end stages

Please view the entire document at:

http://www.alz.org/californiasouthland/in_my_community_professionals.asp#Clinical_guidelines
This strategy provides a strategic framework within which local services can:

- Deliver quality improvements to dementia services and address health inequalities relating to dementia;
- Provide advice and guidance and support for health and social care commissioners and providers in the planning, development and monitoring of services; and
- Provide a guide to the content of high-quality services for dementia.

Please view the entire document at:


- Download Living well with dementia: a National Dementia Strategy (PDF, 1560K)
- Download accessible summary (PDF, 681K)
- Implementation plan
- Download impact assessment (PDF, 400K)
- Download equality impact assessment (PDF, 92K)
Appendix VIII: Additional Standards and Guidelines

Following are excellent resources for compiling such a set of standards and guidelines, which have been identified by the Evidence-Based Practice and Emerging Research Subcommittee:


- **Practice parameter: management of dementia (an evidence-based review).** Report of the Quality Standards Subcommittee of the American Academy of Neurology. According to the guideline developer, this guideline has been reviewed and is still considered to be current as of October 2003. This review involved new literature searches of electronic databases followed by expert committee review of new evidence that has emerged since the original publication date. This review identified over 2500 studies, 380 of which met the criteria for inclusion in the meta-analysis. Practices then were rated: Standard (highest evidence of benefit), Guideline (moderate level of documented benefit) and Practice Option (where there was significant uncertainty of benefit).


  Guideline 86 is a national clinical guideline from Scotland with evidence-based recommendations for diagnosis, pharmacological and non-pharmacological treatments, and services for patients and caregivers.

  [http://www.sign.ac.uk/guidelines/published/support/guideline86/index.html](http://www.sign.ac.uk/guidelines/published/support/guideline86/index.html)

- **Improving Services and Support for People with Dementia,** National Audit Office, July 2007.

  This document is a very current and exhaustive summary of the literature relating to services and supports for caregivers of individuals with cognitive impairments.


  This document is a nearly 500-page review of the Australian system’s national demonstration project. The document includes both literature citations, reviews of randomized clinical trials, and evaluations of outcomes on four short-term case management-caregiver education demonstrations and four long-term case management models.

Following are some questions that could be considered by the Guidelines and Standards Workgroup in assembling a set of guidelines related to dementia care:

What are the parameters of excellence in dementia care?

- Do they include an assessment of the person with dementia and the caregiver that is person-centered and not diagnoses-centered?
- Do they focus on assessment, care and treatment, and patient and family education and support?
- Do they include humane ways to intervene when adverse behaviors arise from group living experiences?
- Do they include state of the art pharmaceutics and good medical model of care?
- Do they include staff ratios of three residents to one staff for all shifts, with consistent assignment of caregiver staff?
- Do they include physical plant, landscaping and architectural inputs?
- Do they include guidelines related to minimal chemical restraints?
- Do they include a schedule of follow-up by medical providers for chronic care issues that arise in co-morbid complex care?
- Do they include advanced discussion of feeding and hydration issues, with adequate stand-by assist for eating?

These and many other questions will be posed and answered in the process of assembling a set of guidelines. Likely, the process will be ongoing with a set of core guidelines established initially and others being added over time.
Appendix IX:
Managed Chronic Care Demonstration Project Requirements

A managed chronic care demonstration project in San Francisco would need to be based on a combination of federal Medicaid waivers such as: (1) a 1915(c) Home & Community-Based Services Waiver; and (2) a 1115 Demonstration Waiver. Both of these federal waivers would provide access to Medicaid (Medi-Cal in California) funds for covered home and community-based services because they waive the normal Medicaid requirements that focus more on covering the costs of institutional care. The cost of this managed chronic care program would have to be equal to or less than the cost of services provided without the waivers.

The combination of an 1115 Demonstration Waiver with an expanded version of the 1915(c) Home and Community-Based Services Waiver can:

- Expand the array of funded community-based services beyond what MSSP now offers;
- Enhance flexibility in use of existing services, e.g., share IHSS workers in cluster housing arrangements;
- Create new funding mechanisms, like capitation and block grants, to allow use of current nursing home;
- Provide funds to support some of these community services; and
- Operate a system alternative on a community-wide basis without restrictions on enrollment caps.

Initially, San Francisco could target people coming out of Laguna Honda Hospital (LHH) and people being diverted from nursing home placement. The intent would be to take 90% of what Medicaid paid for nursing home care at LHH and use that to cover the cost of community-based care.

Many details would have to be addressed in defining precisely the target population, eligibility criteria, and services covered. For example, should the demonstration project assume responsibility for nursing home care? If not, what process would be needed to allow individuals to dis-enroll once a need for nursing home care or hospital care arose? The Oversight Committee will need to convene a workgroup to investigate the feasibility of this recommendation and, if feasible, develop a proposal that addresses these and other issues.
Appendix X: Key Informant Interviews

As part of an investigation into current approaches to Alzheimer’s and dementia-related services in San Francisco, the research team conducted a series of key informant interviews with recognized local experts, service providers, caregivers, and administrators. The objectives were to: 1) improve our understanding of the demographic context of the current demand for the full spectrum of services and supports needed for all stages of cognitive impairment; 2) appreciate how effectively the current array of services is meeting the existing demand; and 3) shed light on the current state of family and informal caregiver support. Interviews were designed to supplement input from the Expert Panel and subcommittee meetings on current network capacities, practices, strengths and challenges. In conjunction with a variety of other quantitative and qualitative data sources, the key informant interviews provide context and rationale for the Expert Panel’s recommendations.

The research team conducted a total of 42 interviews. Eighteen (18) interviews focused on family and informal care giving, 22 interviews focused on the components of a network of care, and two interviews, with Catherine Dodd, Former Deputy Chief of Staff of the Mayor’s Office, and Mitch Katz, M.D., Director of Health, Department of Public Health, focused on administration and oversight. Interviewees were selected in an effort to garner representation from the widest range of service components and institutions, including governmental, for-profit and not-for-profit, large and small. In light of the Expert Panel’s interest in responding to the needs of caregivers, nearly half the interviews specifically focused on this group of stakeholders.

Each interviewee responded to a series of standardized questions. The first set of questions asked respondents to describe the services provided by their agency, organization or department; service delivery methods and best practice models; target populations; and capacities to meet current demand for services. The second set of questions asked respondents to broaden their perspectives and describe other agencies/organizations providing similar services within San Francisco; how well they communicated and shared resources; and the strengths and challenges of the current service delivery network. The final set of questions asked respondents to consider the full spectrum of services and supports offered to persons with Alzheimer’s and related dementias and their caregivers within San Francisco, and how successfully they collaborate, communicate and share resources and best practices. Respondents were asked how easy or difficult it is for individuals and caregivers to understand and access the full array of available services and supports.

The themes, strengths and weaknesses summarized below reflect: (1) the key-informant interviews; (2) the notes taken at all Expert Panel and Subcommittee meetings; (3) topics focused upon in research, data, local, and national and international reports; and most importantly, (4) the extensive knowledge and experience of the Panel members themselves.
### Key Informants

<table>
<thead>
<tr>
<th>Name</th>
<th>Title and Organization</th>
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<td>Tessa ten Tusscher, PhD</td>
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### Caregiver Interviews (professionals and family members)

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Challenges in San Francisco: Caregiver Issues

Informal Care
The Backbone for Dementia Care

Informal care is uncompensated care for individuals with dementia.
Informal Care
The Backbone for Dementia Care

- Informal care is provided by immediate and extended “family” members or other loved ones.
- “Family” includes domestic partners, extended family and informal family structures, including neighbors and caring friends.
- 75% of caregivers are women.

Informal Caregivers
Caregiver Concerns

- Responsibilities change as the condition advances.
- Caregivers report that the first stages are the most demanding.
- The lack of information and understanding of the future creates tremendous uncertainty.
What do caregivers do?

Early-Stage

- Obtain information about dementia and how it progresses;
- Obtain information about resources, insurance coverage, legal issues;
- Navigate access to services;
- Begin long-term planning;
- Provide emotional support; and
- Support daily living needs.

What do caregivers do?

Mid-Stage

- Increase the level of in-home support;
- Seek formal in-home support;
- Seek respite and adult day program options;
- Arrange and manage other care, including primary and specialty care for other medical conditions;
- Manage increasingly difficult behavioral symptoms; and
- Plan for assisted living care.
What do caregivers do? Late-Stage

Often individuals remain in the community requiring virtually round-the-clock support, or once this is no longer possible, caregivers:

- Support the individual in assisted living, nursing home or hospital setting;
- Negotiate with health care staff about services, treatments and interventions;
- Ensure adherence to advance directives; and
- Manage end-of-life care and/or facilitate access to hospice.

Informal Caregiving

What would it cost if we paid for informal care?

Research conducted by Patrick Fox and Brooke Hollings from UCSF indicate that if informal care were paid for at prevailing wage rates it would cost:

- $63,000 per year while an individual is living in the community with mild-moderate impairment; and
- $71,500 per year while an individual is living in the community with severe impairment.

For 2008, for the estimated 20,000 San Franciscans living in the community with dementia, this amounts to $1.2 billion in uncompensated care.
Informal Caregiving
How does providing care impact the caregiver?

Research indicates that fiscal costs are not the only caregiver burden:

- Caregivers are at extreme risk of developing cardiovascular disease, depression, stress and anxiety;
- It is estimated that for every year of caregiving, caregiver life expectancy is reduced by one year; and
- As a result, often caregivers do not outlive their loved ones with dementia.

Informal Caregiving
What Caregivers Say

During interviews caregivers said:

- “There is so much information—it is confusing. When agencies work together there is a real benefit to us.”

- “We face so many decisions like, ‘Should we buy this vitamin?’ I worry about things being overstated in the brain fitness area. But who do I ask?”
Informal Caregiving
What Caregivers Say

During interviews caregivers said:

- “Respite helped me have moments for myself. It also helped me get used to someone else caring for my husband."

- “I broke my back for my dad and then when I had to put him in nursing care, I felt like I’d failed him.”

Informal Caregiving
The Importance of Support

Research indicates that you can reduce caregiver stress and co-morbidity and improve outcomes for the individual with dementia if you promptly deliver:

- Comprehensive caregiver assessment,
- Education and information; and
- Coordinated, easy access to community services and caregiver support.
Informal Caregiving
The Importance of Support

Social support for caregivers has been linked to greater well-being and lower risk for depression for both caregivers and individuals with dementia.


Informal Caregiving
The Importance of Support

Seamless services and facilitated access to critical services is essential for both people with dementia and their caregivers.

Informal Caregiving
The importance of Support

Counseling, support group participation and access to phone support may preserve caregiver health and delay institutionalization.


Informal Caregiving
What Resources are Available?

A range of caregiver assessment, education, referral and support services is available for caregivers.

It is unfortunate that referral to these resources is not an automatic ‘next step’ when a person is diagnosed with dementia.

_A list of specific resources is included in handouts provided by the Family Caregiver Alliance._
Informal Caregiving
What happens when there is no caregiver?

In the absence of an involved caregiver:
- Individuals with dementia must access paid in-home support; or
- Must enter assisted living, nursing home or hospital placement prematurely.
- Since there is no public funding for assisted living, this inevitably means placement in nursing homes or hospitals for moderate to low-income individuals.

Informal Caregiving
What happens when there is no caregiver?

San Francisco has a growing number of individuals with no loved one nearby:
- An estimated 40% of older adults in San Francisco have no relative within a 20 minute drive of San Francisco.
- In the absence of a system to provide in-home support, these individuals face the prospect of being institutionalized prematurely.
Informal Caregiving
What happens when there is no caregiver?

Models for volunteer and peer-based support exist, however:

- None have been developed explicitly to address the needs of individuals with dementia.
- Models for other populations would require significant modifications and while worth exploring may be impractical given the extensive needs for support even in early stages.

Informal Caregiving
What happens when there is no caregiver?

Public costs increase significantly when an individual is placed in assisted living or institutional care:

- Assisted living expenses are **twice** the formal care costs incurred when an individual lives in the community.
- Hospital and nursing home care costs **five times** as much as all formal care when an individual lives in the community.
Informal Caregiving
What happens when there is no caregiver?

The Finance Subcommittee of San Francisco’s Expert Panel for Dementia Care estimated that:

- If each of the San Franciscans with dementia were to delay being institutionalized by just one month, care costs would be reduced by $6 million.

Informal Caregiving
What happens when caregivers are supported?

A Finnish study found that those enrolled in a program of systematic comprehensive support by a nurse or dementia family care coordinator remained living in the community over 250 days longer than the control group.

Informal Caregiving
What happens when caregivers are supported?

In another study, when caregivers received “comprehensive caregiver support,” 65% of individuals with dementia were living at home after 30 months compared to 26% in the control group.


Informal Caregiving
What happens when there is no caregiver?

While there are good reasons for placing an individual in assisted living or institutional care, these placements should be delayed until behaviors or medical conditions require it.
Informal Caregiving
What must we do?

San Francisco faces a significant challenge:

- Develop a capacity to deliver timely, comprehensive caregiver support; and
- Develop easier access to services and supports; and
- Develop approaches that provide in-home support to individuals without informal caregivers; OR

Informal Caregiving
What must we do?

Face an increasing and expanding crisis in dementia care.
Informal Caregiving
What must we do?

Fortunately, we know what needs to be done.

Caregivers have told us what they need.
Research has provided models; and

The *Strategy for Excellence in Dementia Care* provides a roadmap to get it done.
Appendix XIII:
Comments from external review team consisting of: (1) Andrew Scharlach, PhD, School of Social Welfare, UC Berkeley; and (2) Kristine Yaffe, MD, Chief of Geriatric Psychiatry and Director of the Memory Disorders Clinic at the San Francisco VA Medical Center

Overall, this is an excellent report, and all those who have contributed to it are to be congratulated for their work. The report is comprehensive, well-documented, and surprisingly detailed given the time frame and diverse constituencies involved. The case is made very well in this report for the unmet and growing needs of those with dementia and caregivers of those with dementia in San Francisco. The vision for integrated care is quite compelling.

As the report notes, San Francisco is especially vulnerable to the effects of dementia, in part because of its comparatively old population and its large number of single-person households. A community-wide effort comparable to the City's response to the AIDS epidemic is indeed justified.

Following are additional thoughts to consider during the implementation of this report:

1. As noted, dementia includes a wide range of conditions and symptoms. While some attention is given to the stages of dementia, more could be said about the types of supports needed at each stage and by individuals suffering from non-Alzheimer's related dementia. Especially important is differentiating between cognitive impairments and behavioral disturbances. Such disturbances are considerably more problematic, but also more responsive to a variety of interventions.

2. More attention could be given to the possibilities of enhancing functioning and quality of life, rather than just maintaining safety. There are a wide variety of evidence-based interventions that can preserve or even enhance cognitive functioning and/or reduce behavioral disturbances, so as reduce excess disability. Just one simple example: MacLynn's problem (presented as part of the human face of dementia) forgetting to turn off the stove could easily be solved with an automatic shut-off valve. Environmental accommodations such as this are an inexpensive yet overlooked solution to a number of common problems.

3. Goals might include maximizing quality of life for afflicted people and loved ones, preserving personal autonomy to the extent possible, reducing barriers to active community participation, maximizing continued contributions to the lives of families and communities, etc.

4. Greater reference could be provided in relation to cultural variations regarding the meaning of the disease, family roles, access to services, community-based supports, etc. Supporting existing cultural strengths is an economical way to reach underserved individuals.

5. Mention is made of public educational and some other service provider aids. Given the explosion of information and communication technologies, more of this information could be put in the hands of individuals and their families, thereby lessening the burden on professionals.

6. The point of diagnosis is an important time of intervention, and more care coordination and information dissemination could occur at that point. Referrals to other organizations is a start, but even better would be health care-based multidisciplinary care teams (e.g., nursing, social work, OT, family support, social networks) that are activated seamlessly.
7. Beds could be reserved at Laguna Honda Hospital for short-stay residential care, a huge asset for families. Something like 50% of NH admissions in Australia are for short-stay respite and assessment.

8. Skilled nursing facilities are poorly equipped for residents who have cognitive impairment but relatively little physical impairment. Residential Care Facilities for the Elderly and Green House models make a lot more sense and are more economical.

9. How about a city-wide number to call for information or advice about dementia?

10. While the recommendations and associated action plan involve a wide range of potential partners, the emphasis is primarily on the provision of services. Especially in light of state and local budget constraints and associated program limitations, it would seem advisable to consider more carefully how to use limited public resources to support and enhance voluntary and communal support structures that may already be in place at the local level (e.g., churches, community centers, cultural groups). The most obvious example would be the development of neighborhood-based support structures that enhance and focus existing social capital; while San Francisco Village is a notable example, many San Francisco neighborhoods and communal organizations have a lengthy history of social support.

11. The private sector receives little mention other than health care providers, yet a comprehensive solution must reflect its interests and involvement as well. Employer health care and leave policies, for example, have a substantial impact on caregiving family members. Even more fundamentally, "dementia-friendly" companies would be good places for people with dementia to work and to do business.

12. One might well imagine a "dementia-friendly" community, where individuals with dementia are not unnecessarily discriminated against. Following the example of Americans with Disabilities Act (ADA) curb cuts, the focus would be on modifying the built environment to provide cognitive accommodations as well as physical accommodations, so that individuals who are "cognitively challenged" can function as fully as possible. We need to begin to see ourselves as "temporarily mentally fit," and embrace our commonality with those who are less mentally fit at any given time. Only then will we be willing (as individuals and as a community) to invest in the changes that are truly needed, many of which are identified in this excellent report.

13. A concern: this is an enormous undertaking. How this will plan really get implemented? This will require an extremely well orchestrated effort over an extended period of years.

14. Finally, long term care service providers should already be "dementia capable". While we know that this is variable, the recommendation begs the question, why aren't they already dementia capable if 50% of their population has cognitive impairment? In other words, if they have not become so yet, why not - and how do you accomplish this from this point forward?