# Dementia Identification Project Manual

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Project Description: Dementia Identification Project

Earlier diagnosis and treatment of dementia has tremendous potential to help persons with dementia and their families use community-based support services to improve quality of life and significantly delay out-of-home, long-term care placement. In addition, such efforts have been shown to save public expenditures.

Partners in this Dementia Identification Project were awarded a Minnesota Department of Human Services Community Service Development Grant. They then implemented a system-change approach based on the best practices of the Chronic Care Networks for Alzheimer’s disease project, building on its successes. Project coordination was provided by the Metropolitan Area Agency on Aging.

Purpose of the Project

Improve the quality of care provided to persons with dementia and their family caregivers by:

- Enhancing earlier recognition of dementia and referral processes
- Improving care coordination and caregiver support
- Building ongoing linkages between care providers, Alzheimer’s Association and community resources.

Dementia Identification Project Goals

- Provide education and dementia identification tools to partners. Encourage referral, and care coordination practices among health-care professional to better identify and manage signs and symptoms of dementia.
- Increase rates of diagnosis and treatment of dementia at an earlier stage in the disease process to enhance quality of life and family support through referrals to primary care physicians or diagnostic clinics.
- Coordinate care provided through the health system with the supportive services provided through the Alzheimer’s Association.
- Evaluate project effectiveness and disseminate best practices to health care providers, county, and aging network staff.

Partners

Actively Involved Partners:
HealthEast Care System, St. Joseph’s Hospital
Wilder Home Health Care
Alzheimer’s Association Minnesota - North Dakota
Eldercare Partners
Family Means
Catholic Charities
MN Board on Aging
Metropolitan Area Agency on Aging

Area Counties:
• SouthEast Metro SAIL Eldercare Development Partnership of Ramsey, Dakota, & Scott Counties
• Hennepin County
• Anoka County

Supporting Partners:
Eisai/Pfizer
Veterans Administration

The Dementia Identification Project was funded by a Community Service/Services Development grant from the Minnesota Department of Human Services.

Websites for Partners

| HealthEast, St. Joseph’s Hospital | www.stjosephs-stpaul.org/ |
| Wilder Home Care | www.wilder.org/296.0.html |
| Eldercare Partners | www.eldercarepartners.org |
| Family Means | www.familymeans.org |
| Catholic Charities | www.ccspm.org |
| MN Board on Aging | www.mnaging.org |
| Metropolitan Area Agency on Aging | www.tcaging.org |
| Area Counties | www.mnaging.org/advisor/mncounties.htm |
Dementia Identification Project Training Objectives

Two training sessions were provided as part of the Dementia Identification Project. Short descriptions of these training sessions are provided below. Please contact the Alzheimer’s Association for more information about these training sessions.

### Dementia Identification Project: The Benefits of Early Detection, Diagnosis, and Referral for Education and Support

*This course is designed for professional caregivers who are caring for anyone with early signs and symptoms of dementia. Special emphasis is placed on utilizing existing tools, knowledge and processes to identify early signs and symptoms of dementia and to assist individuals with obtaining needed resources when they are in the early stages of dementia.*

**Training Objectives:**

Participants in this training will:

1. Gain a better understanding of Alzheimer’s disease and other dementias.
2. Improve processes for earlier identification of signs and symptoms of dementia in clients/patients.
3. Improve communication skills related to dementia and memory loss when addressing these issues with clients/patients.
4. Learn and implement processes for earlier identification of signs and symptoms of dementia in clients/patients within their agency or facility.
5. Enhance knowledge of community resources available for individuals with dementia and their care partners.

### Dementia Identification Project: Caregiver Support Planning Tool and Family Meeting Protocol

*This course is designed for professionals who work with families who are caring for a person with dementia. Participants learn how to use family systems theories and knowledge about stages of dementia in working with families.*

**Training Objectives:**

Participants in this training will:

1. Learn about the Dementia Identification Project and the basic concepts of dementia and the benefits of early detection, diagnosis and treatment for persons with dementia and their family members.
2. Understand the impact of dementia on the family system.
3. Learn the importance of providing patient and family caregiver support services based on the family systems principles and the disease phase of the dementia the caregiving family is experiencing.
4. Learn how to effectively use the Caregiver Support Planning Tool across the phases of the dementia journey.
5. Identify effective methods to therapeutically interact with the person with dementia and his or her family and learn the how and when to conduct effective family meetings.
6. Learn the key resources that can most likely help families reached identified outcomes based on the phase of the dementia the families is experiencing.
7. Share dialogue though case studies to understand the challenges and solutions to best assist persons with dementia and their families.
8. Share dialogue about appropriate referral to Family Consultants.
Living with Dementia: Caregiver Support Planning Tool

This tool was designed to help healthcare workers improve their readiness to assist and support family caregivers with dementia. This tool was developed by the Education and Support Advisory Group of the Chronic Care Network for Alzheimer’s disease initiative and is the joint property of the National Chronic Care Consortium and the Alzheimer’s Association. The tool uses a conceptual framework developed by Wayne Caron, Ph. D. L.M.F.T. and his colleagues at the University of Minnesota, College of Human Ecology, Department of Family Social Science, (612) 625-1790, e-mail wcaron@tc.umn.edu. This tool has been amended, with permission, based on the book: Alzheimer’s disease: The family journey, Caron, W. A., Pattee, J. J., & Otteson, O. J, (2000), North Ridge Press, Plymouth, MN, with funding provided by a Minnesota Department of Human Services Community Service/Services Development grant.

Key Concepts for Effective Use of the Caregiver Support Planning Tool

- The tasks and challenges of dementia are unique to each family. The tool is intended to identify support needs that meet family caregivers’ needs regardless of the person’s stage of disease. The Caron framework should be used for initial and ongoing training to emphasize the concept that the task and challenges faced by family caregivers of a person with dementia do not necessarily follow the same time sequence as the stages of the person’s disease.

- Families need to see a direct value in the referral. A generic referral to another provider will most likely have little value. If the referral is for a specific issue the family is currently experiencing (e.g., driving, family member denial, respite need, placement) the family is likely to see the value of the referral and use the service.

- Complete appropriate rows of the grid to increase understanding of the capabilities and resources each organization can bring to the partnership to serve the family and person with dementia.

- Develop a list of available program, materials, and services to be used for day-to-day referrals.

- Referral and service strategies are grounded in the dilemmas based on the phase model, the family system concepts, the issues that result, and the system based interventions that help families cope.

Overview of the Phase Model and Key Issues

1. Pre-diagnostic Phase: Issue/dilemma: Our loved one seems increasingly forgetful. Should we discuss our concerns? Or should we simply continue to “wait and watch.”

2. The Diagnosis Phase: Issue/dilemma: We think our loved one needs a medical evaluation. Should we seek a diagnosis now? Or should we wait for further development?

3. The Role Change Phase: Issue/dilemma: Our loved one is steadily losing skills and abilities. Which activities should we limit—in order to maintain safety and well being? And which can we preserve—-in order to maintain independence and self-esteem?
4. **The Chronic Caregiving Phase:** Issue/dilemma: Our loved one requires increasing care and attention. How can we continue to provide adequate care – which protecting and fulfilling the needs, wants, wishes, and well-being of other family members? We are exhausting family caregiving resources. Should we seek outside help? Or should we redouble our efforts and try to carry on as usual?

5. **The Transition to Alternate Care Phase:** Issue/dilemma: We think our loved one needs nursing home care. Should we seek such care now? Or should we wait?

6. **The End of Life Phase:** Issues/dilemma: Our loved one is unable to make medical decisions. Which illnesses should we treat—in order to affect cure? And which should we simple monitor—in order to maintain comfort and dignity.

**Overview of Family System Concepts**

A family is a living, changing entity that strives constantly to balance its needs for both stability and changes. Changing circumstances inevitably force family members to change expectations and to redefine their roles within the family. And changes in one part of the family system lead inevitably to changes in other parts of the family system.

**A family possesses unique organizational characteristics:**

- **Stability:** Families possess stable memberships. Shared memories and experiences and a shared family vision lend definition and stability to family life.

- **Intimacy:** Lifelong ties, common histories, shared values lead to relationships that are more emotional, more personal, and more intense. Intimate family relationships lead to deep connections and allow family members to express their real and whole selves.

- **Legitimacy:** Society gives legitimacy to family relationships. Family bonds are considered scared.

- **Constancy:** Family members are part of a long, enduring family journey, an ongoing narrative that provides constant and enduring forms of support.

- **Diversity:** Family life ranges across generation. Generational diversity and the need to meet simultaneously the requirements of the young, middle-aged, and elderly helps family members understand and respect differing needs and wants. Diversity strengthens family bonds and enriches and affirms the family culture.

**A family is a system of interrelating and interacting personalities that contain:**

- **Boundary:** Imaginary line that family members draw around their family system that defines its membership – who’s in and who’s out. This helps family members develop a sense of belonging, security, and connection and the source of support – who can I turn to, which can I count on, and who will be involved in the decision-making.

- **Structure:** The way family members interact and interrelate and behave which becomes a pattern over time and predictable. Change forces family members to redefine their expectations for themselves and others and forces revisions in behaviors and roles.
• **Culture:** A unique set of values and beliefs that guide their choices and actions. This culture possesses its own legends and myths, its own routines and rituals, its own perceptions, its own private and public language and definitions of failure and success. The family culture reveals itself through the way family members interact with one another and relate to people outside the family system. It is the glue of family life even though it remains largely covert and is rooted in the family values.

• **Values:** Values underlie two central human questions: How are we to live? And how are we to act? The how we are to live value is associated with goals of family life and include freedom, self-respect, and happiness. The how we act value or mode of conduct are associated with how we behave and include honesty, ambition, and concern for others. Individuals and families prioritize their values and they remain sufficiently stable over time.

The challenge of change. Illnesses invade and disorganize family life, challenging family stability and forces family system change. This occurs at two levels:

• **Accommodation:** Family members increase the frequency and intensity of their usual activity – Do more of the same. They cope by applying the lessons of the past to the new circumstances.

• **Adaptation:** A type of coping response in which family members discard old responses and organize in new ways to meet new challenges. Chronic illness requires an adaptive learning system.

Dementias invade families and disorganize them. Boundary must be redefined – who’s in and who’s out and family structure changes. Dementias create dilemmas with no seeming solution. Families with clear and well-defined values and beliefs can more easily resolve vexing dilemmas when they reflect on their values and make decisions that are congruent with the family culture.

**Family Resources for meeting the change:**
Dementias are insidious, pervasive, and progressive creating ambiguity, ambivalence, and demoralizing affect. Family resources to meet these challenges include:

• **Temperament:** The family activity patterns based on its typical energy level, preferred interactional distance (preferred degree of involvement), and characteristic behavioral range (flexibility and creativity). Understanding the temperament can help the family recognize its behavioral traits and perhaps respond more effectively to care challenges.

• **Family Identity:** A set of shared values, beliefs, and attitudes that gives the family its unique nature and reality, a how we go about our business. The families regulatory processes consists of the families members routines, rituals (what we celebrate), and how we solve problems (balancing stability and change needs).

By developing an adaptive learning system while maintaining overall family well-being through all the phases of the dementia families can cope with the illness.
Phase 1. Pre-diagnostic
During this time there is a growing awareness that something is wrong. Both the family and the person with dementia are trying to decide how seriously they should take memory lapses, functional impairments, or periods of confusion. This phase may last for years. A major task for the family is to monitor things over time to see if they get better, stay the same, or get worse. The primary issue during this time is arriving at a realistic understanding among family members about the illness.

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<th>Objective/Outcomes</th>
<th>Program(s)*</th>
<th>Provided By</th>
<th>Appropriate Materials*</th>
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<tbody>
<tr>
<td>1.** Know general information about dementia versus aging</td>
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<td>2. Know how to communicate with physician</td>
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<td>3.** Know steps for getting a diagnosis</td>
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<td>4. Have a positive attitude toward getting a diagnosis</td>
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<td>5. Discuss concerns openly with healthcare providers</td>
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<td>6. Believe options are available if diagnosis is irreversible dementia</td>
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<td>7. Have confidence in provider’s ability to refer for information and services.</td>
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<td>8. Call community agency with Questions</td>
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<td>9.** Know what educational and supportive services are available in the health plan and community.</td>
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*All programs and materials should be adapted to meet the needs of families with different ethnic, cultural and economic backgrounds and different primary languages.
**Most important

Phase 1. Pre-diagnostic: Suggested Intervention
Provide information that is helpful in resolving the ambiguity, educational materials on Alzheimer’s disease containing clear information to help families understand their situation, and concrete steps that families can take.

Acknowledge for person with dementia and family that their uncertainty is fueled by:

- **The difficulty in knowing (ambiguity)** due to slow and insidious onset, inconsistent expression of the illness and the person's ability to compensate, differing perceptions and interpretations of family members about the symptoms, and unclear guidelines creating a “watch and wait” response, and
• **Difficulty in deciding (ambivalence)** due to high stakes of having a progressive, irreversible, incurable disease in the family, fear of conflict, stigma, and helplessness. This ongoing uncertainty holds the potential for undermining family coping efforts and disorganizes the family.

**What to do:**

- Each family member observes and record signs of illness, look for general signs of decline (driving, socializing, recalling names, managing finances, preparing meals) and patterns of decline and departure from expected and established behavior

- Avoid speculation about why this is happening.

- Communicate through dialogue – a nonjudgmental exchange that allows all family members to freely explore and share their observations and express feelings to help family members think together, to collectively analyze an issue and to develop a picture. Communicate through discussion—focus on information they have acquired to begin to identify priorities, explore options, and lay out acceptable courses of action

- Attend to the family boundary, structure, and culture. Who needs to be in on the dialogue and discussion, what expectations or roles need to change, and what are the values they want to guide their choices and actions?

- Determine what will be accommodated (e.g., assist in balancing the checkbook) versus what will become an adaptation (a family member takes over the finances).

**Phase 2. Diagnostic**

Sooner or later, as symptoms of cognitive impairment accumulate or a single, critical event occurs—making it impossible to believe nothing is wrong—families will obtain a diagnosis. The family must deal with the emotional issues of fear, sadness, anger, and denial that will be present and begin to process the meaning of the diagnosis. They must decide whom to tell about the diagnosis and find a way to maintain family morale and hope in the face of lost dreams for the future.

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<tr>
<td>1.** Obtain an accurate diagnosis. Know how to get a second opinion if necessary.</td>
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<td>2. Understand how the diagnosis was made.</td>
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<td>3. Know how to approach the patient with news.</td>
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<td>4.** Know what possible treatments exist.</td>
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<td>5. Begin to accept the diagnosis and patient's limitations.</td>
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<td>6.** Understand the need for proactive planning, including financial, legal and care plans.</td>
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<td>7. Seek out supportive services as needed (early-stage support groups, education sessions, etc.).</td>
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*All programs and materials should be adapted to meet the needs of families with different ethnic, cultural, and economic backgrounds and different primary languages.

**Most Important**
Phase 2. Diagnostic: Suggested Intervention
Offer a one-session family consultation, the purpose of which is not to give the family more information, but rather to offer family members the opportunity to process information they have already received and to facilitate family communication and processing of the diagnosis.

- **Answers questions about why one should seek a diagnosis** (clear the air, the behavior is related to a specific medical condition, move from ambiguity to certainty for indecision to action and helps family envision a future that includes AD reality.

- **Answers questions about when to seek a diagnosis** when the family is strained, when communications between family members begins to break down – when strain begins to disrupt family relationships and family life.

- **Include the elder in the phase two discussion**. Most affected elders in the early stage understand their difficulties. Full inclusion fosters collaboration and cooperation throughout the family system, and it protects the family from the corrosive effects of secrecy and deceptions.

What to do:
- Obtain a diagnosis and if dementia, families must work to emotionally assimilating the illness by understanding the diagnosis, develop ways to acknowledge, accept, and express feelings about the diagnosis and develop responses to the demands of the illness.

- Provide information to understand the dementia so all family members can be oriented to a course of shared action.

- Allow families to process the diagnosis at the feelings level. Family dialogue is necessary to allow families to articulate, express, and share their feelings. It helps the family move toward a major and necessary conclusion that they are now a family that is coping with dementia and they must orient and adapt to this new reality.

- Families must find a way to take charge. They can take one major action and they can fully acknowledge the reality of the illness, and they can fully bring it into family life. Share the diagnosis with the elder, the family and friends makes it real.

Phase 3. Role Change
With the progression of impairment, the person with dementia changes from a competent, independent adult into a person who requires help with all activities of daily living. Family roles also change as the caregiving system is organized and the family begins to take greater control over the elder’s life. Tasks must be assigned to different family members with a means to monitor and encourage each to take a fair share. The family must understand what the person with dementia can and cannot do and adapt situations to maximize his or her participation. Both the person with Alzheimer’s and the family must deal with issues of significant loss.
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<tr>
<td>1.** Understand the disease process. Know what changes to expect.</td>
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<td>2. Know where to turn for information and support.</td>
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<td>3. Anticipate the need for greater family involvement and support.</td>
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<td>4.** Know how to talk with family about expected changes and necessary decisions (e.g., driving).</td>
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<td>5. Know that all family members are experiencing grief.</td>
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<td>6. Feel confident about potential family support and accept family limitations.</td>
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<td>7. Feel confident about ability to provide care-caregiver self-efficacy.</td>
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<td>8.** Use available services as needed.</td>
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<td>9. Attend support groups.</td>
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<td>10. Participate in research and clinical trials as desired.</td>
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**Most important.

**Phase 3. Role Change: Suggested Interventions**

Provide educational programs, parallel support groups, and individual and family counseling to help families accept the losses of roles. Services for the person with dementia are critical to help him or her maintain a sense of self and morale.

- Families face transition, a period in which family members must address not only emerging care issues but also changes within the family system—changes in expectations, roles, and relationships. Family members need to understand the ways in which the stepping in actions to help the elder changes expectations and, consequently, transforming roles and relationships. They are now creating a family caregiving system that will continue. How the family caregiving system is created constitutes the essence of the family adaptation and reorganization (what help is needed, who will provide it, and who can).

**What to do:**

- Determine how and when to step in. Stepping in actions are driven by two concerns: family members feel an obligation to prevent loved ones from engaging in risky activities (driving) and family members feel a need to compensate for a loved one’s losses—to provide support. Stepping in action cannot be avoided. Dialogue can help families define and prioritize their values and ensure their decisions reflect their family values and are congruent with the family culture. This is a time to consider family members’ interest—consequences of stepping in or not stepping in and who will perform the service (grocery shopping) if the car is gone. This is the time to consider the elder’s interest—Persons with dementia throughout the illness remain generally...
sensitive to the ways in which they are treated. They understand when they are being excluded and when they are being ignored and devalued. Secrets can divide family members, and damage relationships. A family that places a high value on openness and honesty will usually find ways to include the person with dementia in most family discussions.

- Use family dialogue to promote teamwork. Recognize phase three is a trial and error period, a transition period in which expectations, roles, and relationships are changing.
- Dialogue can help determine who is going to do what and when among the family members. Consider the family boundary, structure, and culture.
- How to “step in” can be a matching process—a process of matching the elder’s specific capabilities to specific activities or specific tasks within an activity. Family members can view an activity as a set of tasks from which they can make a judgment about the tasks the elder with dementia can perform. This provides a sense of competence for the elder and a place in the family life.
- Plan for change now to ease decision-making in later stages of the journey. Allow the person with dementia to express preferences about long-term medical treatment and difficult end of life decisions. He or she may appoint a proxy decision-maker, formulate long-term financial plans, match caregivers’ abilities to need, and see family members as a team to move from a reactive stance to a proactive stance.

**Phase 4. Chronic Caregiving**

With the continued loss of abilities, the person with dementia requires greater amounts of help with activities such as dressing, bathing, grooming, toileting, and feeding. The major challenge for the family is to stave off the physical and emotional exhaustion of caregiving. Support systems must be alert to signs of exhaustion, burnout or depression among all family members, including the person with dementia, and plans must be developed to provide respite and maintain energy in daily life. Family members can be organized as case managers to help identify appropriate services in the community and develop the means for using these services with the least amount of stress on the primary caregiver and person with dementia. At this phase the disease crowds out normal family life.

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<td>1.**</td>
<td>Use techniques for caregiving, including ways of managing difficult and dangerous behaviors.</td>
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<td>2.</td>
<td>Know ways of communicating with the patient.</td>
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<td>3.</td>
<td>Use appropriate medications for cognitive and behavioral symptoms.</td>
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<td>4.</td>
<td>Experience a caregiving partnership with physician and community agencies.</td>
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<td>5.**</td>
<td>Know how to enlist family members and others to help with caregiving.</td>
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6. Continue proactive planning for the future, including financial, legal and care plans.

7.** Accept paid help with caregiving as needed, (e.g., aides, adult day care, respite services).

8. Use needed services, including skill training.

9. Begin grieving task without losing hope.

*All programs and materials should be adapted to meet the needs of families with different ethnic, cultural, and economic backgrounds and different primary languages.

**Most Important

Phase 4. Chronic Caregiving and Shared Care: Suggested Interventions

Provide psycho-educational programs for the entire family to minimize caregiver stress and connect caregivers with community services such as day care programs, support groups, and caregiver skills training programs to provide concrete guidance in caring for the person with dementia, the caregiver, and the family system.

Acknowledge for the family that:

- The person with dementia needs 24 hour support.

- The family challenge is to maintain energy and vitality in light of person’s increase losses and growing care demands. The caregiver is experiencing fatigue and exhaustion from the emotional loss and pain that accompanies changing family relationships (more so then from the physical work). The ill person is “there but not there” This is called boundary ambiguity (Pauline Voss, Ambiguous Loss). The emotional pain surrounding the changes can cause family members to step back and distance themselves from the elder in an effort to avoid the pain resulting in a loss of family energy and vitality. The family caregiving system must be taken care of.

- Dementia care poses special challenges; the caregiving is open ended with no sense of achievement, there is little give and take in the relationship, and the caregiver feels isolated. Families need support navigating through the difficulties.

What to do:

- Understand and recognize the nature of the strain. It is intellectual; having the skills to solve the problems they encounter? Is it the physical labor of caregiving? Is it the emotional work, caregiving is sad work? When we understand that strain cannot be relieved by fixing problems and reducing care demands, they are able to turn their attention elsewhere and focus on maintaining the caregiving system’s energy by supporting its boundary, structure and culture

- The caregiving system consists of all those individuals who contribute to care – both directly and indirectly. As caregiving needs mount the caregiving system must expand its boundary, bring others into the system. A reaching out that is a conscious effort to other family members for more help. Not reaching out results in fatigue and isolation. Continual and ongoing communication helps families overcome natural barriers and helps them address specific questions about what is needed to guard against fatigue and exhaustion. The caregiving system must expand, include new people and continue to
define, redefine and organize individual caregiving roles. Problem solving around who will do what, when. By discussing their core family values and using them as guides to decision making they can maintain confidence in their decision – What part of family life to we want to preserve and protect. This will keep the caregiving system energized and organized.

- Family members must stay connected to a vital family life. Maintain the stability, intimacy, legitimacy, constancy and age diversity. Maintain family events and activities, nurture and foster family life. Pay attention to family’s day-to-day routines and rituals.

- Anticipate need for outside help. An adaptive family system looks to the future and anticipates the time when it will need outside help. Outside assistance is a legitimate part of the family care. Early identification of resources can help family members obtain the right kind of help at the most appropriate and needed time.

- Address the why a family should seek outside help and when. Outside help can include informal and formal support. Informal support can be friends, neighbors, religious organization, self-help groups and others. Formal support includes program and services usually licensed by a governmental organization and available for a fee. Seeking helps involves family adaptation. When to see outside help is sometimes determines by markers such as a serious illness or incontinence. A focus on the caregiver and overall family well-being is important. It is important to get outside help when communications among family members becomes stained and difficult, when emotional connections loosen, and family members find themselves less and less involved in each other’s lives, when family members lose their ability to work as a problem solving team and lose their own way, when family routines and rituals begin to wither and fade, and when tension and discord begin to permeate family life.

- Seek help as a family, that can benefit the elder (monitor overall health, keep function at a optimum level, address environmental barriers, psychological well-being, treat coexisting disabilities, structured environment), benefit the caregiver, and benefit the family and then seek help (education and emotional support, problem solve, direct care services).

- Dialogue about the barriers that are keeping the family form seeking help. Identify and explore available health services based on needs (What is the biggest concern, what care task are most fatiguing, what part of life has been taken over). Initiate contact with the health-care system often through the primary care physician or nurse. Establish a relationship with health-care system.

**Phase 5. Transition to Alternative Care**

As caregiving resources are exhausted, it is often no longer possible to care for the person with dementia at home, necessitating placement in an adult foster home, assisted living, nursing home or other care facility. The family must be provided assistance to help identify the point at which placement should occur, making sure to consider the needs of all family members. This traumatic event marks the end of personal caregiving and requires a shift into collaborative caregiving with appropriate role expectations.
<table>
<thead>
<tr>
<th>Objective/Outcomes</th>
<th>Program(s)*</th>
<th>Provided By</th>
<th>Appropriate Materials*</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.** Know what alternative care options are available in the community.</td>
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<tr>
<td>2. Explore care options before a crisis occurs.</td>
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<td>4.** Discuss options with family.</td>
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<td>5.** Know what kinds of financial assistance the patient may qualify for.</td>
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<tr>
<td>6.** Accept the need for alternative care, and feel positive about the process of selecting a provider.</td>
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<tr>
<td>7. Navigate the admission process, including knowing how to make the move easier for all.</td>
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<tr>
<td>8. Know how to create a new role for the family in collaboration with the care provider.</td>
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<tr>
<td>9. Acknowledge as a family that placement is a loss that will be associated with grief.</td>
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</tbody>
</table>

*All programs and materials should be adapted to meet the needs of families with different ethnic, cultural, and economic backgrounds and different primary languages.

**Most Important

Phase 5. Transition to Alternative Care Suggested Interventions

Offer services that address the demoralization families experience with placement, and facilitate development of collaborative care relationships between family and facility staff.

- Address the family why and what questions. The family seeks nursing home placement when the benefits associated with nursing home care significantly outweigh the burdens. This is the foundation for the family dialogue and discussion. What are the physical, psychological, and emotional burdens of continued home care for the elder, to other family members, and to the family? What are the benefits and burdens of nursing home care? How can the nursing home enhance the well-being of all the family members and safeguard the well-being of family life?

- Benefits for the elder include knowledgeable staff and can address specific dementia symptoms and behaviors. Specific dementia programs and activities are provided that are stimulating and provide companionship. This can create a caring and comfortable environment with structure routines. Coexisting medical conditions can be monitored.

- Benefits to the caregivers include relief from the daily demands of care and can focus on the elders psychological and emotional needs offering nurturance and support only family caregivers can provide. Family life can be reclaimed, there is assurance that care needs are being meet, and isolation can be relieved.
Most families wait too long to place a loved one in a nursing home. They wait for a critical incident that prevents them from deliberate planning. Barriers about social stigma, abandonment of family obligation and betrayal of loved ones need to be explored through family dialogue and discussion.

What to do:

- Anticipate and plan for nursing home placement early on and include the elder in the discussion. Recognize the family values which will guide choice and actions. Use family dialogue and discussion to problem solve.

- Gather information about nursing home and visit them to evaluate them and reach a consensus as a family about placement, when and where.

- Family members benefit from making the move a “joint venture” including as many family members as possible.

- Establish a relationship with the nursing home staff. Establish a partnership with the facility staff. The nursing home staff brings professional expertise to dementia care and the family brings intimate knowledge of the elder, a keen understanding of the elder’s temperament and personality, likes and dislikes peculiarities and eccentricities. Think in terms of the family system and the nursing home system coming together in mutually beneficial ways that reflect on the boundary, structure and culture. Boundaries must be expanded; dialogue around expectation, roles, and relationships must take place and dialogue to find congruent values and an understanding of the family culture. Share the elder’s history and facilitate the partnership.

- Accept and recover. Use the transitional time to reflect on the families accomplishments – to take stock of the ways in which the family provided care. Focus on what is the nature of the journey we have been traversing and what will be the nature of the journey on which we are now launched?

Phase 6. End of Life

Families are faced with many decisions regarding care the treatment of potentially life-threatening illnesses. The family must not only witness but also participate in the dying of the person with dementia. Based upon the foundation of values and benefits unique to each family, the ethical dilemmas faced in making end-of-life treatment decisions must be resolved. The family must be helped to develop an image of a “good death,” including important rituals and legacies, which will help bring closure and meaning at the point of death.

<table>
<thead>
<tr>
<th>Objective</th>
<th>Program(s)*</th>
<th>Provided By</th>
<th>Appropriate Materials*</th>
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</thead>
<tbody>
<tr>
<td>1.**</td>
<td>Understand the end-stage process and physical care issues.</td>
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<tr>
<td>2.**</td>
<td>Understand the key decisions that will have to be made by the family before an emergency.</td>
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<tr>
<td>3.</td>
<td>Understand how to use any existing Advance Directives.</td>
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<tr>
<td>4.</td>
<td>Understand methods of communication that may work well</td>
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</tbody>
</table>
with the patient.

5.** Know how to access hospice care, if desired. Visit hospice programs, if desired.

6. Feel a sense of peace about decisions that are made in this phase.

7. Know how to arrange an autopsy, if desired.

8. Be aware of bereavement services available to the family after the patient’s death.

*All programs and materials should be adapted to meet the needs of families with different ethnic, cultural, and economic backgrounds and different primary languages.

**Most Important

**Phase 6. End of Life: Suggested Intervention**

Support families as they anticipate death and multiple difficult decision-making situations. Involving the primary medical provider to educate the family on treatment options is crucial

- The end-of-life phase evokes a mix of feelings – sadness and grief, for example coupled with a sense of relief. Two challenges arise: how to ensure a good death for the elder and how to ensure closure for caregivers and other family members.

- A good death for the impaired elder means a death the elder would of choose if he or she were able to decide. For the family it involves end-of-life decisions that are congruent with the elder’s wishes and values. Families are uniquely positioned to interpret and represent these wishes and values. Caring (not curing) is the chief goal, the attempt to ensure comfort, dignity, and quality of life. Living wills and durable power of attorney are helpful. Medical professionals can help chart a course.

- For the family, closure involves saying “goodbye” to the elder and “letting go” of the illness. It involves recapturing of the elder that family members once knew before the illness and a reclaiming of family life. For Alzheimer’s family members, grieving begins early and continues throughout the disease journey. Pain and sadness accompany all phases of the disease. Even though the end feels like a welcomed change, it can also leave a void, an empty space in the family life that needs to be filled.

**What to Do:**

- Families need to recognize the void in their life. Reflect on the disease journey, to look back on its course and to consider its effect on the family life to gain a perspective on the Alzheimer’s experience. They can see the accomplishments and understand the triumphs and the challenges they have faced and overcome. Family dialogue helps family members relieve feelings of guilt and regret and consider the benefits form the disease experience. Has it provided opportunities for personal growth and strengthen family bonds along with imposing burdens on the family.
• The family must reclaim the elder; regaining a memory of the individual they once knew before the illness to honor the legacy for all generation. This occurs through conversations about the elder.

• Reclaim the family life. Family members must consciously begin to reclaim family life by reinvesting in the family life and relationships, to reorganize and take up familiar activities and routines.

The following six tables are examples of what a completed form for each phase might look like.

### Phase 1. Pre-diagnostic

<table>
<thead>
<tr>
<th>Objective/Outcomes</th>
<th>Program(s)*</th>
<th>Provided By</th>
<th>Appropriate Materials*</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.** Know general information about dementia versus aging</td>
<td>1. Info. Helpline 1-800-232-0851 2. Sr. Linkage Line 1-800-333-2433</td>
<td>1. Alzheimer’s Association 2. Metro Area Agency on Aging</td>
<td>(Family History, Genetics Info, Normal Aging/Memory Loss Fact Sheet), NIH website, ADEAR web site</td>
</tr>
<tr>
<td>2. Know how to communicate with physician</td>
<td>1. Partnering with Your Doctor Class</td>
<td>1. Alzheimer’s Association</td>
<td>Medication logs, Behavior Logs,</td>
</tr>
<tr>
<td>3.** Know steps for getting a diagnosis</td>
<td>1. Info. Helpline 1-800-232-0851 2. Family Education</td>
<td>1. Alzheimer’s Association 2. Alzheimer’s Association</td>
<td>Steps to Getting a Diagnosis Fact Sheet, Dementia Clinics List</td>
</tr>
<tr>
<td>5. Discuss concerns openly with healthcare providers</td>
<td>1. Partnering with Your Doctor Class</td>
<td>1. Alzheimer’s Association</td>
<td>1. Logs available through class or Alzheimer’s Association</td>
</tr>
<tr>
<td>6. Believe options are available if diagnosis is irreversible dementia</td>
<td>1. Understanding Memory Loss Class</td>
<td>1. Alzheimer’s Association</td>
<td>Understanding Memory Loss Fact Sheet, Alzheimer’s Disease and Related Dementias Fact Sheet</td>
</tr>
</tbody>
</table>

### Phase 2. Diagnostic

<table>
<thead>
<tr>
<th>Objective/Outcomes</th>
<th>Program(s)*</th>
<th>Provided By</th>
<th>Appropriate Materials</th>
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<tbody>
<tr>
<td>2. Understand how the diagnosis was made.</td>
<td>1. Info. Helpline 1-800-232-0851 2. Family Education</td>
<td>1. &amp; 2. Alzheimer’s Association</td>
<td>Steps to Getting a Diagnosis Brochure and Fact Sheet</td>
</tr>
</tbody>
</table>
### Phase 3. Role Change

<table>
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<tr>
<th>Objective/Outcomes</th>
<th>Program(s)*</th>
<th>Provided By</th>
<th>Appropriate Materials*</th>
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<tbody>
<tr>
<td>4.** How to talk with family about expected changes and necessary decisions (i.e. Driving)</td>
<td>1. Info. Helpline 1-800-232-0851</td>
<td>1. Alzheimer’s Association</td>
<td>1. Driving and Dementia Fact Sheet, Hartford Driving and Dementia information</td>
</tr>
<tr>
<td>7. Feel confident about ability to provide care-caregiver self-efficacy.</td>
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<td></td>
<td>1. Caregiver Burden Scale or Stress Inventories</td>
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<tr>
<td>8.** Use available services as needed.</td>
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</tbody>
</table>
9. Attend support groups.
   1. Support Groups
   2. Grief and Loss Support Groups
   1. Alzheimer's Association
   2. Allina
   1. SG lists available from www.alzmndak.org or 1-800-232-0851
   2. www.allina.com/ahs/grief.nsf/page/supportgroups

10. Participate in research and clinical trials as desired.

Phase 4. Chronic Caregiving

<table>
<thead>
<tr>
<th>Objective/Outcomes</th>
<th>Program(s)*</th>
<th>Provided By</th>
<th>Appropriate Materials*</th>
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<td>and dangerous behaviors.</td>
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<td>from 1-800-232-0851 and classes</td>
</tr>
<tr>
<td>5.** Know how to enlist family members and others to help with caregiving.</td>
<td>1. Family Meetings</td>
<td>1. Alzheimer's Association</td>
<td>1. How to Hold a Family Meeting Fact Sheet</td>
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<tr>
<td></td>
<td>2. Family Care Consultation</td>
<td>2. Alzheimer's Association</td>
<td>2. What is Care Consultation Fact Sheet</td>
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<td>DARTS, Family Means...</td>
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<td>care plans.</td>
<td>2. LSS Guardianship &amp; Conservator Services</td>
<td>2. Lutheran Social Services</td>
<td>2. <a href="http://www.lssmn.org/guardianship">www.lssmn.org/guardianship</a></td>
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<tr>
<td></td>
<td>4. Care planning tips for hospitalization</td>
<td>4. ADEAR Hospitalization</td>
<td>4. <a href="http://www.alzheimers.org">www.alzheimers.org</a> or 1-800-438-4380</td>
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<td></td>
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<td>Happens handout</td>
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<tr>
<td>7.** Accept paid help with caregiving as needed, (i.e. g., aides, adult day</td>
<td>1. Long Term Care Consultation</td>
<td>1. County of Residence</td>
<td>1. <a href="http://www.mnaging.org/seniors">www.mnaging.org/seniors</a></td>
</tr>
<tr>
<td>care, respite services.)</td>
<td>2. Care Management</td>
<td>Long Term Care Consultants</td>
<td>2. <a href="http://www.elderarepartners.org">www.elderarepartners.org</a>,</td>
</tr>
<tr>
<td></td>
<td>4. Care Consultation</td>
<td>Eldercare Partners,</td>
<td>4. 1-800-232-0851 or fax referral for care consultation to 952-830-0513</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Family Means, DARTS,</td>
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<td>Anoka County, Catholic</td>
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<td>Charities,</td>
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<td>San Diego etc.</td>
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<td>4. Alzheimer's Association</td>
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<td>8. Use needed services, including skill training.</td>
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<td></td>
<td></td>
<td>2. Eldercare Partners</td>
<td>affiliated support groups or <a href="http://www.elderarepartners.org">www.elderarepartners.org</a> for other community/agency</td>
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<td></td>
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<td>support groups</td>
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Phase 5. Transition to Alternative Care

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<tr>
<th>Objective/Outcomes</th>
<th>Program(s)*</th>
<th>Provided By</th>
<th>Appropriate Materials*</th>
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</thead>
<tbody>
<tr>
<td>1.** Know what alternative care options are available in the community.</td>
<td>1. Care Options Network Guidebook and Residential</td>
<td>1. Care Options Network</td>
<td>1. Care Options Network Guidebook</td>
</tr>
<tr>
<td></td>
<td>Care Listings</td>
<td><a href="http://www.careoptionsnetwork.org">www.careoptionsnetwork.org</a></td>
<td>1. Care Options Network Residential Care</td>
</tr>
<tr>
<td></td>
<td>2. Senior Housing Listings</td>
<td>763-225-4077</td>
<td>Listings</td>
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<td></td>
<td></td>
<td>800-333-2433 through the Area Agency on Aging</td>
<td>Line Staff</td>
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<td></td>
<td>1. Guide to Choosing a New Home brochure also from Alzheimer's Association MN-ND</td>
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</tbody>
</table>
4. ** Discuss options with family.
   1. Family Meetings and Care Consultation
   1. Alzheimer's Association, caregiver coaches or care managers
   1. How to Hold a Family Meeting Fact Sheet
   1. Alzheimer's Association Info Helpline 1-800-232-0851 ask for care consultant
   1. www.eldercarepartners.org
   1. www.familymeans.org
   1. www.ccspm.org

5. ** Know what kinds of financial assistance the patient/client may qualify for.
   1. Long Term Care Consultation
   2. Info. re: eligibility guidelines for publicly funded programs
   1. County of residence
   2. DHS
   1. Assessment completed by long term care consultant
   1. www.eldercarepartners.org
   1. www.familymeans.org
   1. www.ccspm.org

6. ** Accept the need for alternative care, and feel positive about the process of selecting a provider.
   1. Printed resources
   2. Info Helpline 1-800-232-0851
   1. Office of the Ombudsman for Older Minnesotans 651-296-0382 or 1-800-657-3591
   2. Alzheimer's Association MN-ND
   1. Consumer Tips for Choosing a Nursing Home Handout
   1. Residential Care Fact Sheets available

7. Navigate the admission process, including knowing how to make the move easier for all.
   1. Printed resources
   2. Info Helpline 1-800-232-0851
   1. Office of the Ombudsman for Older Minnesotans 651-296-0382 or 1-800-657-3591
   2. Alzheimer's Association MN-ND
   1. Consumer Tips for Choosing a Nursing Home Handout
   1. Residential Care Fact Sheets available

8. Know how to create a new role for the family in collaboration with the care provider.
   1. Care Conferences
   2. Family Meetings and Care Consultation
   1. Residential care facility or community agency
   2. Alzheimer's Association, caregiver coaches or care managers
   1. Care plan, personal preferences, history of the person with dementia
   2. Alzheimer's Association Info Helpline 1-800-232-0851 ask for care consultant
   2. www.eldercarepartners.org
   1. www.familymeans.org
   1. www.ccspm.org

9. Acknowledge as a family that placement is a loss that will be associated with grief.

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### Phase 6. End of Life

<table>
<thead>
<tr>
<th>Objective/Outcomes</th>
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<th>Provided By</th>
<th>Appropriate Materials*</th>
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<tbody>
<tr>
<td>2. **</td>
<td>Understand the key decisions that will have to be made by the family before an emergency.</td>
<td>1. Communication &amp; Behavior Family Ed. Class</td>
<td>1. Alzheimer's Association</td>
</tr>
<tr>
<td>3.</td>
<td>Understand how to use any existing Advanced Directives.</td>
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<tr>
<td>7.</td>
<td>Know how to arrange an autopsy, if desired.</td>
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</table>
Alzheimer’s Association Minnesota – North Dakota Resources and Services

For up-to-date, detailed descriptions of the resources and services available through the Alzheimer’s Association Minnesota – North Dakota please visit their website at: www.alzmndak.org/gethelpandinfo.

Community-Based Supportive Health, Psychological, Legal, Financial and Other Resources

To Obtain Information about Community Services and Resources Contact:

- **1-800-232-0851 – Alzheimer’s Association – [www.alzmndak.org](http://www.alzmndak.org):** The Alzheimer's Association provides information and resources for individuals with dementia and their care partners with their 24/7 Information Helpline. The Information Helpline can provide translation in 120 languages and some printed material in different languages.

- **1-800-333-2433, Senior LinkAge Line®:** A program of the MN Board on Aging and Area Agencies on Aging. Information can also be provided for communication service for the deaf, State services for the blind, English as a second language and nation-wide services.

- **211 - United Way’s First Call for Help:** This agency also provides contact phone numbers for those who speak other languages (Russian, and Spanish).

- **1-800-677-1116 - ElderCare Locator:** a nationwide directory-assistance service designed to help older people and care partners locate local resources.


See below for a brief alphabetical listing of a variety of community resources available to individuals with dementia. This list is intended to provide a general description of the network of services available, but it is not all-inclusive.

**Adult Day Services:**

Adult day programs provide social, recreational, and health activities and services in a group setting that helps participants maintain their present level of functioning, promotes the individual’s maximum level of independence, provides support, education and respite to care partners and fosters socialization and peer interaction. Adult day programs serving more than five participants per day must meet license requirements set by the Minnesota Department of Health and Human Services. Some adult day programs offer a separate program for people with dementia. Others may serve those with memory loss in the same group as other participants. Please visit the website of the Minnesota Adult Day Services Association at [www.madsa.org](http://www.madsa.org) to learn more.
Adult Protection/Elder Abuse:
Each county offers adult protection programs to protect vulnerable adults from abuse, neglect, or exploitation through formal investigation and short-term follow up. Contact the Senior LinkAge Line® (1-800-333-2433) for the contact information for the county in which services are required.

Advocacy/Ombudsman Services:
Advocacy encompasses a broad range of political and non-political activities, which may include lobbying to affect public health care policy, advising older adults and their families about resident’s rights, advocating for independent living, and supporting elder crime victims. A local advocacy resource is the ElderCare Rights Alliance, (952) 854-7304 or 1-800-893-4055 www.eldercarerights.org. Ombudsman services include programs that advocate and protect the rights of residents in long-term care facilities by investigating complaints, mediating and resolving disputes, and initiating corrective actions. The Ombudsman office can be reached at 1-800-657-3591.

Assistive Devices:
Assistive devices and aids for daily living are items and equipment designed to help persons accomplish activities of daily living more easily. These special products can include robotic devices to help with tasks, mechanical lifts, and devices to improve environmental safety.

Behavioral Health/Psychological Services:
Most individuals with dementia experience changes in their behavior such as depression, suspiciousness, agitation, and a loss of interest in past enjoyed activities that impacts their quality of life. Care partners of persons with dementia also often experience depression and a decreased sense of quality of life. Many of the education and support services provided by the Alzheimer’s Association are designed to assist both the person with dementia and the family care partners. They help to adjust the environment to enhance the family’s sense of pleasure and comfort or at least to mitigate the environmental stressors that affect behavior. The primary care physician can prescribe medications and can make referrals to mental-health professionals. Contact the Alzheimer’s Association MN – ND’s 24/7 Information Helpline for additional information.

Books/Magazines and Newspapers:
A listing of recommended books, magazines and newspapers that explore all aspects dementia for patients, families, care partners and professionals can be obtained from the Alzheimer’s Association or the Senior LinkAge Line® (1-800-333-2433).

Care Partner Education:
Family and professional education is offered through a variety of sources and group sessions are offered in a variety of settings. Information regarding the type of classes offered and the frequency of classes is available on the Alzheimer's Association’s MN – ND’s website. A partial listing of care partner education sessions offered within the seven county metro area can also be found at www.eldercarepartners.org.
Chore Services:
Chore services are available that may assist with the following homemaking duties: light housekeeping, laundry, meal preparation and shopping, light-to-heavy cleaning services and home maintenance such as lawn mowing, snow shoveling, cleaning gutters, minor home repair and other routine chores. Several providers are available. Contact the Senior LinkAge Line® (1-800-333-2433) for a list.

Cognitive Performance Testing:
Many individuals with dementia and their care partners benefit from an assessment of how well they can perform activities of daily living (e.g., dressing, preparing a meal, taking medication). The Cognitive Performance Test (CPT; Burns, Theresa, Dementia Care Clinic, Minneapolis, Veterans Affairs Medical Center, MN) helps to predict a person’s activity performance associated with cognitive disability, provide guidelines for task or activity performance, and needs for supervision. The information provided by cognitive performance testing enables providers to support their person with dementia and their family care partners at various stages of the disease. The CPT can be ordered by the patient’s doctor.

Conservators/Guardians:
When an older adult is no longer able to manage property and financial matters, the court can appoint an individual, (who may be a family member, friend, or professional conservator) to act on the senior’s behalf.

County Social & Public Health Services:
Counties offer a variety of services to their residents. These include Long-Term Care Consultation, Adult Protective Services and Public Health Nursing. County staff can also provide information on financial assistance for persons with limited income and resources or grant money for persons at risk of being placed in a long-term care facility. Phone numbers for all county human service agencies in Minnesota can be found at www.mnaging.org/advisor/mncounties.htm. Or call the Senior LinkAge Line® (1-800-333-2433) to ask for contact information for your county.

Culturally Specific Care Partner Programs:
Many agencies throughout the metro area provide support and resources specifically for the diverse cultural groups living within the area. The Alzheimer's Association provides translation in 120 languages on their 24/7 Information Helpline and they can also provide printed materials in a variety of languages. Below is a partial listing of other culturally specific programs for elders and their families:
- African American – Volunteers of America MN – (612) 339-7581
- CLUES (Chicanos Latinos Unidos en Servicio) – (651) 291-8174
- UCAM (United Cambodian Association of Minnesota) – (651) 222-3299
- Vietnamese Social Service of Minnesota – (651) 644-1317
- Hmong Elder Connection – Volunteers of America Minnesota – (612) 377-4472
- Korean Service Center – (612) 342-1345
- Lao Assistance Center – (612) 374-4967
- Oromo Community of Minnesota – (612) 338-5282
- Minneapolis American Indian Center – (612) 879-1746
Dementia Clinics:
Dementia clinics can provide diagnostic testing and ongoing treatment for individuals with memory loss and signs of dementia. These services are also available at primary care clinics.

Driving Assessment Services:
Dementia can significantly impact a person’s ability to drive due to changes in response time, safety awareness and the potential difficulty in following directions causing an increased potential to get lost. Driving assessment services are available offering a comprehensive behind the wheel assessment. This is done by an occupational therapist and a driver evaluator. The following locations provide assessments:
• Courage Center (Golden Valley & Stillwater) (763) 520-0425
• Drive Safe, www.drivesafeinc.net, (651) 730-6597
• Hillcrest of Wayzata, (Occupational Therapy Department), (952) 473-5466
• Minnesota Highway Safety & Research Center, St. Cloud, Advanced Driving Skills Program, 1-888-234-1294
• SPOT Rehabilitation, St. Cloud, (320) 259-4151 or 1-888-404-7768

Financial and Legal Management Services:
A person with dementia and his or her family may have unique financial and legal needs. These issues include:
• Medical claims and assistance
• Medicare and Medicaid management
• Social Security and disability claims and appeals
• Supplemental health insurance
• Long-term care health insurance issues
• Disability planning
• Health-care directives
• Living wills and trusts
• Durable power of attorney
• Conservatorship or guardianship
• Estate planning
• Home equity conversions
• Retirement benefits
• Probate
• Tax planning and preparation
• Long-term care placement and issues
• Elder abuse
• Fraud recovery
• Housing issues,
• Age discrimination
• Veterans benefit

The Senior LinkAge Line® can provide contacts for MN attorneys who specialize in legal aid services, housing issues, tax help or general elder services. Also, visit the Alzheimer's Association MN – ND’s website for more information about legal issues.

Geriatric Care Management Services:
This is a field in which trained health specialists, known for geriatric care management, help to design and coordinate care plans for individuals with dementia or other health care needs. These professionals can be helpful to both primary and professional care partners and can help to keep care services organized, efficient, and well-coordinated saving care partners extra time and work. The Senior LinkAge Line® can provide a variety of care managers to contact. An individual’s health insurance provider often has a Senior Services Division that provides case management services as well.
Government Funded Support Services:
There are several waivered programs through the state of Minnesota that can provide financial assistance for services to enable seniors to remain living in their own homes as long as possible. The Elderly Waiver Program and the Alternative Care Grant program are two of these programs, commonly used by elderly individuals in their homes. Some of the services covered under the waivered programs include meals on wheels, home health aides, adult day care, respite care and equipment. Each county administers the waivered programs for their residents. For a list of phone numbers for county human service agencies in Minnesota, please visit [www.mnaging.org/advisor/mncounties.htm](http://www.mnaging.org/advisor/mncounties.htm).

Health Care Directive:
Minnesota has created a legal document, MN Health Care Directive, that provides an opportunity for a person to provide instructions to health care providers and family members regarding what he or she wants done in case of certain medical situations such as dementia. Health Care Directive Forms can be obtained by calling the Senior LinkAge Line® (1-800-333-2433).

Home Delivered Meals:
Home delivered meals are provided through the Senior Nutrition Program designated for each specific neighborhood. This program provides a nutritious meal to individuals at risk of losing their independence. If you are want to locate the Senior Nutrition Program for a specific neighborhood call the Senior LinkAge Line® (1-800-333-2433).

Home Health Care:
Home health care takes place in an individual’s residence to maintain or restore their health and well-being. Home health care providers offer a wide variety of services to those who require some assistance in meeting their health care needs. These services fall into two general categories: skilled care and supportive services. Skilled care is generally provided under the direction of a physician, or results from a physician’s order. Examples of skilled care include: rehabilitative services such as physical or occupational therapy or a home health nurse. Supportive services are adjunct to skilled care and help enable a person to continue independently living at home. Examples of supportive services include: assistance with personal cares such as bathing, dressing and grooming and chore services such as housekeeping. Home health care may be provided through private agencies (profit and nonprofit), hospitals (public and private) and public health departments. Insurance covers the costs of some home health care services. More information about home care can be found at [www.mnhomecare.org](http://www.mnhomecare.org) or by calling the Senior LinkAge Line® (1-800-333-2433).

Hospice & Palliative Care:
Hospice and palliative care focus on the comfort and dignity of the person with dementia at the end stages of their lives. This type of care can be provided in the home, hospital or residential care setting. The focus of hospice and palliative care is comfort, not on aggressive treatment of symptoms. The Hospice benefit is a part of the Medicare program. You can learn more about hospice by visiting the website of Hospice Minnesota at [www.mnhospice.org](http://www.mnhospice.org).
Insurance Counseling:
Health insurance counseling services and programs can provide information on Medicare, Medical Assistance (Medicaid), health insurance, long-term care insurance and other benefit plans. Call the Senior LinkAge Line® (1-800-333-2433) for information and assistance. Referral information can also be provided for Alternative Care Grants and Elderly Waivers for those who are at risk for being placed in a long-term care facility.

(For Legal Planning See “Financial and Legal Management Services”)

Parish Nursing Program:
Parish nursing is a combination of nursing and ministry. Parish nurses minister to individuals and families within a faith community, using health education. Some programs offer this service to non-members of their faith community.

Prescription Drug Programs:
Many drug manufacturers provide free brand name prescription drugs to low-to-moderate income patients. RxConnect is a free service offered by the State of MN. Call the Senior LinkAge Line® to learn more (1-800-333-2433).

Research Participation:
An individual with dementia and their family may benefit from participation in local research projects. These research studies are designed to improve the quality of life for persons with dementia.

Residential Placement:
There are many choices for individuals seeking a change in residence. The appropriate choice will depend upon the individual’s needs and the impact their memory loss may have on their safety and ability to meet their own needs. There are memory care specific residential care homes, assisted livings and nursing homes/nursing home units.

- The classification of residential care home encompasses a number of different licensed settings. It generally has 20 or fewer residents and is located in a residential home and neighborhood. Residential care home licenses may include; Adult Foster Care, Board and Lodging with Services and/or Assisted Living Home Care Provider.

- Assisted Living settings may vary in the level of care they provide. They also vary in size and many offer individual rooms or apartments.

- Nursing home care is provided under licensure with the Minnesota Department of Health and is most appropriate for residents who require skilled nursing care. Many nursing homes have dementia or memory care units which may be secured to prevent residents who wander from eloping.

It is important to ask questions of any of the above service providers related to the individual with dementia’s needs. These questions may relate to the management of behaviors, staffing levels, prevention of wandering, falls prevention techniques, and/or activities available for individuals with memory loss. Call the Senior LinkAge Line® (1-800-333-2433), the Alzheimer's Association MN – ND’s 24/7 Information Helpline, or go online and visit www.MinnesotaHelp.info for specific assistance with residential resources.
**Respite Services:**
Respite can be provided in a person’s home, through adult day service providers or through residential care settings. Respite services are intended to provide care partners with break they may need from their care giving responsibilities. County social and public health providers can provide the most current respite provider listings. A partial list is also available through the Alzheimer’s Association MN – ND’s 24/7 Information Helpline or website.

**Support Groups:**
Support groups offer individuals with dementia and their care partners a unique way to cope with dementia. Support groups may be offered by nursing homes, adult day programs, community services providers, senior centers, churches, hospitals, etc. Support groups that are affiliated with the Alzheimer's Association MN - ND are offered monthly unless otherwise noted. They are offered without any fee and are an excellent place to find information, support, education and friendship. A listing of memory loss support groups is available from the Alzheimer's Association MN – ND’s 24/7 Information Helpline.

**Telephone Support/Reassurance:**
Some hospitals, faith communities, and nonprofit agencies offer services in which volunteers call seniors at home daily to check on their well-being, or seniors call at specific times each day to let a volunteer know that they are okay.

**Transportation Services:**
There are several methods to provide transportation for older adults. Metro Mobility is a door-to-door public transportation service in the Twin Cities metropolitan area. Also some hospitals, clinics and health insurance providers offer rides. A number of private, for-profit companies offer transportation as well.

**Veteran's Benefits:**
County Veteran Service Centers provide information regarding available health services.
Web Resources:  
Dementia Services and Information

www.alzmndak.org  
The Alzheimer's Association, Minnesota-North Dakota web site which offers information and resource listings for local services for individuals with dementia and their professional and family care partners. Also provides information regarding upcoming events, family and professional education.

www.alz.org 
The National Alzheimer's Association web page can be accessed here. This web site includes tip sheets and general information as well as research updates and a link to the Greenfield Library for access to printed resources.

http://www.tcaging.org  
Information regarding the MAAA & Senior LinkAge Line is available via this web page.

www.MinnesotaHelp.info  
Created by the Minnesota Board on Aging, the Minnesota Department of Health and other partners this web page offers a directory of community resources.

www.aoa.gov/alz  
The Administration on Aging offers a resource page with information specifically regarding Alzheimer’s disease. This includes information on caregiving as well as professional tools and care management guidelines.

www.alzforum.org  
This link is for the Alzheimer’s Research forum.

www.alzheimers.org  
The National Institute on Aging’s Alzheimer’s Disease Education and Referral Center (ADEAR) can be accessed via this web address.

www.elderCare.gov  
The Eldercare Locator is a service of the United States Administration on Aging and connect older Americans and their care partners with information on senior services.

www.agelessdesign.com 
Ageless Design is an Alzheimer’s focused, free newsletter, the web site also includes a feature “Talking to an Expert” and an online chat room.

www.mnaging.org  
Minnesota Board on Aging web site which provides general caregiver information.

http://www.caregiver.org/caregiver/jsp/home.jsp  
Family Caregiver Alliance –National Center on Caregiving
About Alzheimer’s Disease

Alzheimer’s (AHLZ-high-merz) disease is a progressive brain disorder that gradually destroys a person’s memory and ability to learn, reason, make judgments, communicate and carry out daily activities. As Alzheimer’s progresses, individuals may also experience changes in personality and behavior, such as anxiety, suspiciousness or agitation, as well as delusions or hallucinations.

In late stages of the disease, individuals need help with dressing, personal hygiene, eating and other basic functions. People with Alzheimer’s die an average of eight years after first experiencing symptoms, but the duration of the disease can vary from three to 20 years.

Although there is currently no cure for Alzheimer’s, new treatments are on the horizon as a result of accelerating insight into the biology of the disease. Research has also shown that effective care and support can improve quality of life for individuals and their caregivers over the course of the disease from diagnosis to the end of life.

Causes of Alzheimer’s disease

Alzheimer’s disease has no known single cause, but in the last 15 years scientists have learned a great deal about factors that may play a role.

Late-onset Alzheimer’s, which chiefly affects individuals over age 65, is the more common form of the illness that is most often associated with the term “Alzheimer’s disease.” The greatest known risk factors for late-onset Alzheimer’s are increasing age and a family history of the disease. The likelihood of developing late-onset Alzheimer’s approximately doubles every five years after age 65. By age 85, the risk reaches nearly 50 percent. Scientists have so far discovered one gene that increases risk for late-onset disease.

Rare, familial types of Alzheimer’s found in a few hundred families worldwide have been linked to specific genes. Individuals who inherit these genes are virtually certain to develop the disease, usually before age 65, and sometimes as early as their 30s or 40s.

Researchers are working to discover other factors that affect Alzheimer risk. Some of the most exciting preliminary evidence suggests that strategies for general healthy aging may also help reduce the risk of developing Alzheimer’s. These measures include controlling blood pressure, weight and cholesterol levels; exercising both body and mind; and staying socially active.

How Alzheimer’s disease affects the brain

Scientists believe that whatever triggers Alzheimer’s begins to damage the brain years before symptoms appear. When symptoms emerge, nerve cells that process, store and retrieve information have already begun to degenerate and die. Scientists regard two abnormal microscopic structures called “plaques” and “tangles” as the hallmarks of Alzheimer’s disease. Amyloid plaques (AM-uh-loyd plaks) are clumps of protein fragments that accumulate outside of the brain’s nerve cells. Tangles are twisted strands of another protein that form inside brain cells. Scientists have not yet determined the exact role that plaques and tangles may play.

Diagnosing Alzheimer’s disease

Although Alzheimer symptoms can vary widely, the first problem that many people notice is forgetfulness severe enough to affect performance at home, at work or in favorite activities. Sometimes the decline in memory may be more obvious to a family member or close friend than to the affected individual. Other common symptoms include confusion, getting lost in familiar places and difficulty with language. The Alzheimer’s Association encourages everyone who notices these symptoms in themselves or someone close to them to consult a physician.

A skilled physician can diagnose Alzheimer’s disease with 90 percent accuracy. Because there is no single test for Alzheimer’s, diagnosis usually involves a thorough medical history and physical examination as well as tests to assess memory and the overall function of the mind and nervous system. The physician may ask a family member or close
friend about any noticeable change in the individual’s memory or thinking skills.

Most diagnostic uncertainty arises from occasional difficulty distinguishing Alzheimer’s disease from a related disorder.

Alzheimer’s is the leading cause of dementia, a group of conditions that all gradually destroy brain cells and lead to progressive decline in mental function. Vascular dementia, another common form, results from reduced blood flow to the brain’s nerve cells. In some cases, Alzheimer’s disease and vascular dementia can occur together in a condition called “mixed dementia.” Other causes of dementia include frontotemporal dementia, dementia with Lewy bodies, Creutzfeldt-Jakob disease and Parkinson’s disease.

One important goal of the diagnostic workup is to determine whether symptoms may be due to a condition other than dementia. Depression, medication side effects, certain thyroid conditions, excess use of alcohol and nutritional imbalances are all potentially treatable disorders that may sometimes impair memory or other mental functions. Even if the diagnosis is dementia, timely identification enables individuals to take an active role in treatment decisions and planning for the future.

**Treating Alzheimer’s disease**

Alzheimer medications approved by the U.S. Food and Drug Administration (FDA) may temporarily delay memory decline for some individuals, but none of the currently approved drugs is known to stop the underlying degeneration of brain cells. Certain drugs approved to treat other illnesses may sometimes help with the emotional and behavioral symptoms of Alzheimer’s.

One important part of treatment is supportive care that helps individuals and their families come to terms with the diagnosis; obtain information and advice about treatment options; and maximize quality of life through the course of the illness.

**Impact on caregivers**

Alzheimer’s has a major impact on those who help care for an affected individual. More than 70 percent of people with Alzheimer’s live at home, where family and friends provide most of their care. As the disease progresses, it places physical, emotional and financial stress on caregivers as they assume growing responsibilities that may include meeting physical needs, managing daily routines and making important medical and legal decisions.

**Impact on society**

Alzheimer’s takes an enormous toll on society. The Alzheimer’s Association and National Institute on Aging estimate that current direct and indirect costs of caring for the 4.5 million Americans with Alzheimer’s disease are at least $100 billion annually. By 2030, when our entire baby boom generation is over 65, the number of Americans with Alzheimer’s will soar to levels that may exceed our ability to absorb the added cost.

**Hope for the future**

As the pace of research accelerates, scientists funded by the Alzheimer’s Association, the pharmaceutical industry, universities and our federal government have gained detailed understanding of basic disease processes at work in the Alzheimer brain. Experts believe that several of these processes may offer promising targets for a new generation of treatments to prevent, slow or even reverse damage to nerve cells. Many experts are also convinced that ongoing research will soon clarify the role of cardiovascular factors or other aspects of risk that individuals may be able to influence through lifestyle. A strategy to delay the onset of Alzheimer’s by five years could halve the number of affected individuals over the next 50 years.

For more information about Alzheimer research, treatment and supportive care, please contact the Alzheimer’s Association.

**Alzheimer’s Association Minnesota – North Dakota**

24/7 Information Helpline: 1-800-232-0851
Website: [www.alzmnndak.org](http://www.alzmnndak.org)
Minneapolis / Duluth / Rochester / St. Cloud / Fargo / Bismarck
Contact the Information Helpline for Regional Contact Information
Alzheimer’s Disease and Related Dementias

What is Dementia?
Dementia is a loss of mental function in two or more areas such as language, memory, visual and spatial abilities, or judgment severe enough to interfere with daily life. Dementia itself is not a disease but a broader set of symptoms that accompanies certain diseases or physical conditions. Well-known diseases that cause dementia include Alzheimer’s disease, multi-infarct dementia, Parkinson’s disease, Huntington’s disease, Creutzfeldt-Jakob disease, Pick’s disease, and Lewy body dementia. Other physical conditions may cause or mimic dementia, such as: depression, brain tumors, head injuries, nutritional deficiencies, hydrocephalus, infections (AIDS, meningitis, syphilis), drug reactions, and thyroid problems. Individuals experiencing dementia-like symptoms should undergo diagnostic testing as soon as possible. An early and accurate diagnosis helps to identify reversible conditions, gives patients a great chance of benefiting from existing treatments, and allows them and their families more time to plan for the future.

Alzheimer’s Disease:
Alzheimer’s disease (AD) is the most common cause of dementia affecting as many as 4 million Americans. AD is a degenerative disease that attacks the brain, begins gradually, and progresses at a variable rate. AD results in impaired memory, thinking, and behavior and can last from 3 to 20 years from the time of onset of symptoms. Warning signs of AD are memory loss that affects job/home skills, difficulty performing familiar tasks, problems finding the right words, disorientation as to time and place, poor or decreased judgment, difficulty with learning and abstract thinking, placing things in inappropriate places, changes in mood and personality, and marked loss of initiative. In the last stage of AD, patients are unable to take care of themselves. Recent research has shown links between particular genes and Alzheimer’s disease, but in about 90% of AD cases, there is no clear genetic link. With the help of standardized diagnostic criteria, physicians can now diagnose AD with accuracy of 85-90% once symptoms occur. However, a definitive diagnosis of Alzheimer’s disease is possible only through the examination of brain tissue at autopsy.

Multi-infarct Dementia:
Multi-infarct dementia (MID), or vascular dementia, is a deterioration of mental capacity caused by multiple strokes (infarcts) in the brain. These events may be described as mini strokes, where small blood vessels in the brain become blocked by blood clots, causing the destruction of brain tissue. The onset of MID may seem relatively sudden, as it may take several strokes for symptoms to appear. These strokes may damage areas of the brain responsible for a specific function as well as produce general symptoms of dementia. As a result, MID is sometimes misdiagnosed as Alzheimer’s disease. MID is not reversible or curable, but detection of high blood pressure and other vascular risk factors can lead to a specific treatment that may modify MID’s progression. MID is usually diagnosed through neurological examination and brain scanning techniques, such as a computerized tomography (CT) scan or magnetic resonance imaging (MRI).

Parkinson’s Disease:
Parkinson’s disease (PD) is a progressive disorder of the central nervous system that affects over one million Americans. In PD certain brain cells deteriorate for reasons not yet known. These cells produce a substance called dopamine, which helps control muscle activity. PD is often characterized by tremors, stiffness in limbs and joints, speech difficulties, and difficulty initiating physical movement. Late in the course of the disease, some patients develop dementia, Alzheimer’s or some other dementia. Conversely, some Alzheimer’s patients develop symptoms of Parkinson’s. Medications such as levodopa, which converts dopamine inside the brain, and deprenyl, which prevents degeneration of dopamine-containing brain cells, are used to improve diminished or reduced motor symptoms in PD patients but do not correct the mental changes that occur.
Huntington’s Disease
Huntington’s disease (HD) is an inherited, degenerative brain disease that causes both physical and mental disabilities and usually begins in mid-life. Early symptoms can vary from person to person but include involuntary movement of the limbs or facial muscles, difficulty concentrating, and depression. Other symptoms include personality change, memory disturbance, slurred speech, and impaired judgment. Children born to a person with HD have a 50% chance of inheriting the gene that causes HD. Today a genetic test is available to confirm a diagnosis of HD and to identify carriers of the HD gene. It is recommended that anyone considering genetic testing talk first with family and/or appropriate medical and counseling professionals. There is no treatment to stop the progression of HD, but the movement disturbances and psychiatric symptoms can be treated with medication.

Creutzfeldt-Jakob Disease:
Creutzfeldt-Jakob disease (CJD) is a rare, fatal brain disorder that causes rapid, progressive dementia and other neuromuscular disturbances. CJD is cause by a transmissible agent. Research suggests that the agent differs significantly from viruses and other conventional agents. This newly discovered pathogen is called a “prion”, short for “proteinaceous infectious particle,” because it consists of protein and transforms normal protein molecules into infectious ones. The disease can be inherited, but the majority of cases are not. Early symptoms of CJD include failing memory, changes in behavior, and lack of coordination. As the disease advances, usually very rapidly, mental deterioration becomes pronounced, involuntary movements (especially muscle jerks) appear, and the patient experiences severe difficulty with sight, muscular energy, and coordination. Like Alzheimer’s disease, a definitive diagnosis of CJD can be obtained only through examination of brain tissue at autopsy.

Pick’s Disease:
Pick’s disease (also know as Fronto-temporal dementia) is also a rare brain disorder, characterized by shrinkage of the tissues in the frontal and temporal lobes of the brain and by the presence of abnormal bodies (Pick’s bodies) in the nerve cells of the affected areas of the brain. Pick’s disease usually begins between the ages of 40 and 60. The symptoms are similar to Alzheimer’s disease, with a loss of language abilities, skilled movement, and the ability to recognize objects or people. Initial diagnosis is based on family history (Pick’s disease may be inherited), symptoms, tests, and ruling out other cause of dementia. A definitive diagnosis of Pick’s disease is usually obtained at autopsy.

Lewy Body Dementia:
Lewy body dementia (LBD) is an irreversible form of dementia associated with abnormal protein deposits in the brain called Lewy bodies. Symptoms of LBD are similar to Alzheimer symptoms and include memory loss, confusion, and difficulty communicating. Hallucinations and paranoia also become apparent in the earlier stages of the disease and often last throughout the disease process. Although initial symptoms of LBD may be mild, affected individuals eventually develop severe cognitive impairment. At this time, there is no treatment available for Lewy body dementia.

For further information about Alzheimer’s disease or a related dementia, please contact the Alzheimer’s Association.

Alzheimer’s Association Minnesota – North Dakota
24/7 Information Helpline: 1-800-232-0851
Website: www.alzmnndak.org
Minneapolis / Duluth / Rochester / St. Cloud / Fargo / Bismarck
Contact the Information Helpline for Regional Contact Information
Tips for Communicating with a Person with Alzheimer’s Disease or Other Memory Loss Problems

Families and other care partners often discover communication problems as Alzheimer’s disease progresses. As with anything else in life, people learn new ways to compensate for those losses.

Initially, it may not seem like the person with Alzheimer’s disease is experiencing communication difficulties. Common things, like daily routines, may be remembered enough to talk about until the middle phase of the illness. In some instances, the ability to chat or make small talk will diminish, or may be all that a person can do.

Changes in the brain make selecting appropriate words, matching objects to their use, or following the simplest of instructions difficult. Changes in language ability can cause withdrawal from social situations because the person becomes self-conscious of those losses. This can be a frustrating time for families because the medical information they get does not always address these common changes in communication.

Some caregivers create new patterns of communication easily. Other families need more practice. Remember, we still need communication as the bond that holds us together. We just need to change the way we mix the cement!

When a person with Alzheimer’s disease is having difficulty expressing themselves and understand others. They may:

- Have difficulty finding the right words
- Use familiar words repeatedly
- Invent new words to describe familiar objects
- Frequently lose their train of thought
- Experience difficulty organizing words logically
- Revert to speaking in a native language
- Curse or use offensive words
- Speak less often
- Rely on nonverbal gestures

The following pages include a variety of tips to help enhance your communication with your loved one with Alzheimer’s disease or a related dementia

When having a conversation...

- Do not startle by approaching from behind. Begin conversations by identifying yourself, calling the person by name and orienting them to the situation. Stand in front or in the direct line of vision of the person with Alzheimer’s. Touch an arm or shoulder gently to get or keep attention. Show your interest by sustaining eye contact throughout the conversation.

- Avoid questions whenever possible. Not knowing the answers embarrasses the person. It may be helpful to cue the person with the necessary information such as supplying a name or a place. When you do use questions, ask one question at a time and use only those that call for a yes or no answer
whenever possible. Do not offer choices that make decisions difficult, or that are not acceptable to you.

- Tone of voice and facial expressions (non-verbal communications) are just as important as the actual words you use when communicating with a person with dementia. Use a normal tone of voice in a calm manner. Do not express excitement with your voice.

- Speak slowly and simply. Do not expect a quick response. Present only one idea at a time. Use short sentences, giving simple messages and use direct statements to initiate actions. Let’s get dressed now.” Give the person time to process the information. Discuss only concrete actions and objects because the person cannot relate to abstract concepts and avoid using pronouns and identify people by their names.

- If it is necessary to repeat statements, use the same words. Do not rephrase sentences or use different words. You may wish to ask the person to repeat what you have said. This may help the person understand. Be prepared to repeat yourself time and again until your loved one understands what you are saying.

- Use gestures and visual cues or aides to clarify your message. Try using more than one of the senses to communicate, such as touching as well as talking. Do not use gestures which threaten the person.

- Be aware of your own behavior. Try to remain calm and gentle, and avoid showing signs of frustration and anger. Persons with dementia often mirror the behavior they see modeled. If they show anger or hostility toward you, try not to take it personally. Don’t argue. If the person says something you don’t agree with, let it be.

- Encourage the person to continue to express thoughts even if he or she is having difficulty. Encourage non-verbal communication as well. Be careful not to interrupt.

- Communicate with the person as much as possible, although a constant stream of conversation is neither helpful nor necessary.

**Show Compassion**

- Be patient and supportive. Let the individual know that you’re listening and trying to understand what is being said.

- Avoid criticizing, correcting, and arguing. Avoid using negative statements and quizzing (i.e. “You know who that is, don’t you?”)

- Don’t talk about the person as if he or she wasn’t there

- Have patience, flexibility, and understanding. Give the person time, let them think about and describe what is wanted.

- Validate the emotions the person feels. The person you care for may express frustration over communication problems. Let her know that you understand and will be there to help.

- Don’t place unreasonable demands on the person. Don’t expect them to perform lost skills. Instead encourage activities that the person can still perform and enjoy. (i.e. Walking, listening to music, looking at photos etc.) Do not assume that the person can understand and act on messages, either written or verbal. You will need to observe him/her to know. Try to be aware of the changing abilities and inabilities of the individual.
• Be aware that the person with Alzheimer’s has lost the ability to keep track of time. This may cause anxiety and frustration. A person may feel deserted when only a few minutes have elapsed. Reassure as much as possible.

• Remember that for those with dementia their world can be confusing and frightening.

Coping Strategies to Respond to Lost Abilities:

• Use song lyrics or prayer verses to communicate since these are easier to remember and understand.

• Reminiscence about the previous good times to give your loved one something to talk about that he/she will remember.

• Use touch and music to substitute when conversation is too difficult to carry.

• Understand that the person with Alzheimer’s may say one word and mean another. Listen and try to find the meaning in what is being said. You may have to guess at the correct meaning. Try to clarify your guess with the person. You could be wrong. Focus on feelings, not facts. Tone of voice and actions may help you understand how the individual is really feeling. Limit distractions. Find a place that is quiet.

• Use objects to help the person understand what you are telling them. (i.e. Bring their jacket if you are suggesting that you talk a walk.)

• Simplify complex tasks by breaking them into manageable steps. Encourage the person to take one step at a time, and talk through each step. (i.e. Brushing teeth involves many steps, take one at a time)

• Help the person get adequate exercise.

• Write things down. Sometimes a visual aide is helpful.

• In many cases you will have to work around the behavior because you will not be able to change it.

Other Communication Tips to Keep in Mind:

• If the person starts to walk away while you are talking, don’t try to stop them right away. Move along with them and keep talking. If you are met with resistance, it may be best to stop and try again later.

• Avoid situations which bring about frustration and anger. Try to anticipate problems and prevent them from happening.

• Encourage persons to participate in activities which are adult and provide pleasure to them. Be aware though, that they may have short attention spans. Find out what activities they have enjoyed in the past and may continue to be rewarding.

• Remember that the person may have lost the ability to judge between safe and unsafe conditions. Evaluate each situation and do not let the person be in a potentially dangerous position.
Links to Clinical Guidelines

http://www.aan.com/professionals/practice/guideline/index.cfm
American Academy of Neurology Practice Guidelines

http://www.alzla.org/medical/CAguidehtml.html
California Guidelines for Alzheimer’s Disease Management

Guidelines for Alzheimer’s Disease Management, California Workgroup on Guidelines for Alzheimer’s Disease Management – Final Report

Kaiser Permanente Dementia Guidelines
Tools for
Early Identification, Assessment, and Treatment
for People with
Alzheimer’s Disease
and
Dementia

A publication of the Chronic Care Networks
for Alzheimer’s Disease initiative
# Tools for Early Identification, Assessment, and Treatment for People with Alzheimer’s Disease and Dementia

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Chronic Care Networks for Alzheimer’s Disease: About the Initiative

Between 1998 and 2003 national and local partnerships of the Alzheimer’s Association and National Chronic Care Consortium (NCCC) members demonstrated that networks of integrated care, support, and education can be developed to incorporate the range of services needed by people with dementia and can function under risk-based managed care financing or traditional Medicare. Furthermore, these networks result in high levels of satisfaction on the part of participating patients, family caregivers, primary healthcare providers, and Alzheimer’s Association chapter staff. (See latest evaluation reports at http://www.nccconline.org.)

The national and local partners are committed to ongoing dissemination of user-friendly products, materials, tools, program descriptions, and other innovations developed through the demonstration. The materials that follow are current as of the date at the bottom of this page. Changes can and will be made to these materials as the experience of initiative implementation and evaluation suggests improvements.

Unless otherwise noted, the tools and information in this publication were developed by the Care Management Advisory Group and the Education and Support Advisory Group of the Chronic Care Networks for Alzheimer’s Disease (CCN/AD) initiative. Duplication for educational and clinical purposes is authorized without prior written approval if acknowledgment is given to the National Chronic Care Consortium and the Alzheimer’s Association as the source. Notification of use and suggestions for improvement are appreciated. Contact the National Chronic Care Consortium, 8100 26th Avenue South, Suite 120, Bloomington, MN 55425.

The latest version of these tools along with descriptive material about the conduct of the initiative and its research results can be found on the NCCC Web site at http://www.nccconline.org.

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Kathryn Borgenicht, M.D.; Kenneth Brummel-Smith, M.D.; Susan Denman, M.D.; Peter Engel, M.D.; Alan Lazaroff, M.D.; Katie Maslow; Jon Mertz; Cheryl Phillips, M.D.; Elizabeth Pohlmann; John Selstad

Education and Support Advisory Group (1997 development period)
Pauline Bourgeois, D.S.W.; Wayne Caron, Ph.D.; Helen Ann Comstock; Elizabeth Edgerly, Ph.D.; Katie Maslow; Elizabeth McKinney; Linda Mitchell; Kim Peloso; Theresa Polich, Ph.D.; John Selstad
Tools for Early Identification of Dementia

Dementia is very prevalent among the elderly but is often overlooked even by skilled clinicians. Clues to the presence of dementia may be subtle and nonspecific. Unrecognized dementia may lead to iatrogenic illness, unnecessary workups driven by vague symptoms, inappropriate and costly utilization of hospital and emergency room care, and poor outcomes. Improving our ability to recognize dementia is a key first step toward improving this widespread situation.

The Chronic Care Networks for Alzheimer’s Disease early identification process uses two tools to identify people who may have dementia and should receive a full assessment. The flowchart on the next page illustrates the early identification process.

**Tool 1: Education and Awareness Materials—Triggers**

The early identification process is based on recommendations from the Agency for Health Care Policy and Research (AHCPR) Clinical Practice Guideline, *Early Identification of Alzheimer’s and Related Dementias.* This clinical practice guideline recommends the use of triggers to identify people with possible dementia.

The CCN/AD initiative uses separate but somewhat overlapping sets of triggers from three sources. These are:

- The Alzheimer’s Association publication, *Ten Warning Signs of Alzheimer’s Disease*
- A list of patient behavior triggers for clinical staff developed by the Care Management Advisory Group of the CCN/AD
- The triggers recommended in the AHCPR Clinical Practice Guideline, *Early Identification of Alzheimer’s and Related Dementias*

The triggers should be used creatively in training sessions to increase awareness of dementia among all care system staff, health plan enrollees, and families. Useful strategies will vary in each health plan and clinic but may include training physicians and other staff, sending regular publications to enrollees, and displaying posters and pamphlets in clinic waiting areas.

**Tool 2: Family Questionnaire**

Family members are likely to be aware of signs and symptoms of possible dementia that are not readily apparent to clinical staff.

People who are identified as possibly having dementia by the triggers (Tool 1) and/or the Family Questionnaire should receive an Initial Dementia Assessment.

**Note:** Until February 2001 CCN/AD used a third tool that has been removed from the CCN/AD model based on the rational on page 11.

Medical office staff and health plan enrollees and their families recognize signs and symptoms of possible dementia based on triggers from the Alzheimer’s Association’s “Ten Warning Signs,” the list of patient behaviors for clinical staff, and the AHCPR guidelines.

Family Questionnaire indicates possible dementia

Initial Dementia Assessment

- Negative workup
- Uncertain results
- Delirium or depression

Monitor by reassessing triggers and administering MMSE every 6 months

Treat and reassess

Use care management tool and family support tool

Diagnosis of dementia
Early Identification Tool 1
Alzheimer’s Association Ten Warning Signs

The Alzheimer’s Association developed the following checklist of common symptoms. (Some of them also may apply to other dementing illnesses.) Individuals with several of these symptoms should see a physician for a complete examination.

1. **Memory loss.** One of the most common early signs of dementia is forgetting recently learned information. While it’s normal to forget appointments, names, or telephone numbers, those with dementia will forget such things more often and not remember them later.

2. **Difficulty performing familiar tasks.** People with dementia often find it hard to complete everyday tasks that are so familiar we usually do not think about how to do them. A person with Alzheimer’s may not know the steps for preparing a meal, using a household appliance, or participating in a lifelong hobby.

3. **Problems with language.** Everyone has trouble finding the right word sometimes, but a person with Alzheimer’s disease often forgets simple words or substitutes unusual words, making his or her speech or writing hard to understand. If a person with Alzheimer’s is unable to find his or her toothbrush, for example, the individual may ask for “that thing for my mouth.”

4. **Disorientation to time and place.** It’s normal to forget the day of the week or where you’re going. But people with Alzheimer’s disease can become lost on their own street, forget where they are and how they got there, and not know how to get back home.

5. **Poor or decreased judgment.** No one has perfect judgment all of the time. Those with Alzheimer’s may dress without regard to the weather, wearing several shirts or blouses on a warm day or very little clothing in cold weather. Individuals with dementia often show poor judgment about money, giving away large amounts of money to telemarketers or paying for home repairs or products they don’t need.

6. **Problems with abstract thinking.** Balancing a checkbook may be hard when the task is more complicated than usual. Someone with Alzheimer’s disease could forget completely what the numbers are and what needs to be done with them.

7. **Misplacing things.** Anyone can temporarily misplace a wallet or key. A person with Alzheimer’s disease may put things in unusual places: an iron in the freezer or a wristwatch in the sugar bowl.

8. **Changes in mood or behavior.** Everyone can become sad or moody from time to time. Someone with Alzheimer’s disease can show rapid mood swings—from calm to tears to anger—for no apparent reason.

9. **Changes in personality.** People’s personalities ordinarily change somewhat with age. But a person with Alzheimer’s disease can change a lot, becoming extremely confused, suspicious, fearful, or dependent on a family member.

10. **Loss of initiative.** It’s normal to tire of housework, business activities, or social obligations at times. The person with Alzheimer’s disease may become very passive, sitting in front of the television for hours, sleeping more than usual, or not wanting to do usual activities.

Source:
Alzheimer’s Disease and Related Disorders Association, Inc. 2003. *Ten Warning Signs of Alzheimer’s Disease.* This tool can be accessed at [http://www.alz.org/AboutAD/10Signs.htm](http://www.alz.org/AboutAD/10Signs.htm).
Early Identification Tool 1
Patient Behavior Triggers for Clinical Staff

Individuals with undiagnosed dementia may exhibit behaviors or symptoms that offer a clue to the presence of dementia and can be observed by physicians, nurses, and other clinical and office staff. Educational sessions and discussions with all office staff can create an awareness on everyone’s part that general decline or change of the nature listed below on the part of a patient is worthy of note to a clinician for further attention.

Some examples:

The patient

✔ Is a “poor historian” or “seems odd”
✔ Is inattentive to appearance, inappropriately dressed for the weather, or dirty
✔ Fails to appear for scheduled appointments or comes at the wrong time or on the wrong day
✔ Repeatedly and apparently unintentionally fails to follow instructions (e.g., changing medications)
✔ Has unexplained weight loss, “failure to thrive,” or vague symptoms (e.g., weakness or dizziness)
✔ Seems unable to adapt or experiences functional difficulties under stress (e.g., the hospitalization, death, or illness of a spouse)
✔ Defers to a caregiver—a family member answers questions directed to the patient

In addition to failure to arrive at the right time for appointments, the clinician can look for difficulty discussing current events in an area of interest and changes in behavior or dress. It also may be helpful to follow up on areas of concern by asking the patient or family members relevant questions.

All of the above needs to be modified to an office’s own patient panel and can be strengthened with case examples.
Early Identification Tool 1
Symptoms That May Indicate Dementia

Many older adults suffer from dementia. Positive answers to the following questions can help to identify possible dementia.

Does the person have increased difficulty with any of the activities listed below? If the answer is yes, he or she should receive a dementia assessment from a doctor.

_____ Learning and retaining new information. Is more repetitive; has trouble remembering recent conversations, events, appointments; frequently misplaces objects.

_____ Handling complex tasks. Has trouble following a complex train of thought or performing tasks that require many steps, such as balancing a checkbook or cooking a meal.

_____ Reasoning ability. Is unable to respond with a reasonable plan to problems at work or home, such as knowing what to do if the bathroom is flooded; shows uncharacteristic disregard for rules of social conduct.

_____ Sense of direction. Has trouble driving, organizing objects around the house, finding his or her way around familiar places.

_____ Language. Has increasing difficulty with finding the words to express what he or she wants to say and with following conversations.

_____ Behavior. Appears more passive and less responsive, is more irritable than usual, is more suspicious than usual, misinterprets visual or auditory stimuli.

Experience from the CCN/AD Initiative Sites
Even though sites found significant overlap between this AHCPR (now AHRQ) list and the Alzheimer’s Association’s “Ten Warning Signs,” they found both to be useful in different applications. The authority and medical source for the AHCPR symptoms list seemed especially important in physician training sessions. Other office staff, patients, and family members seemed to respond better to the “Ten Warning Signs.”

Source:

Revised May 2003
Early Identification Tool 2
Family Questionnaire

We are trying to improve the care of older adults. Some older adults develop problems with memory or the ability to think clearly. When this occurs, it may not come to the attention of the physician. Family members or friends of an older person may be aware of problems that should prompt further evaluation by the physician. Please answer the following questions. This information will help us to provide better care for your family member.

In your opinion does ___________________ have problems with any of the following?  
Please circle the answer.

1. Repeating or asking the same thing over and over?  
Not at all  Sometimes  Frequently  Does not apply

2. Remembering appointments, family occasions, holidays?  
Not at all  Sometimes  Frequently  Does not apply

3. Writing checks, paying bills, balancing the checkbook?  
Not at all  Sometimes  Frequently  Does not apply

4. Shopping independently (e.g., for clothing or groceries)?  
Not at all  Sometimes  Frequently  Does not apply

5. Taking medications according to instructions?  
Not at all  Sometimes  Frequently  Does not apply

6. Getting lost while walking or driving in familiar places?  
Not at all  Sometimes  Frequently  Does not apply

Relationship to patient ____________________________  
(spouse, son, daughter, brother, sister, grandchild, friend, etc.)

This information will be given to the patient’s primary care provider. If any additional testing is appropriate, he or she will let you know. Thank you for your help.
Early Identification Tool 2
Use of the Family Questionnaire

The Family Questionnaire is designed to help us identify patients with memory problems that might otherwise go unnoticed. It consists of five simple questions. A family member or friend of the patient can complete the questionnaire in less than a minute.

When to Use the Family Questionnaire
• If the patient has no prior diagnosis of dementia
• If the patient is aged 65 or older
• If the patient comes to the clinic in the company of a family member or friend
• If the questionnaire has not been completed in the past year

We encourage the use of the Family Questionnaire for all patients who meet all of these criteria.

How to Use the Family Questionnaire
First, find out if a family member or friend has come in with the patient.

When you are checking vital signs and collecting other screening information, tell the patient you have a brief questionnaire for his or her family member or friend that will help us find out if the patient has trouble remembering or thinking clearly. Explain that these symptoms may not come to our attention unless we ask about them and that the information will help us take better care of the patient. Show the questionnaire to the patient if he or she asks to see it. Be sure the patient consents, then present the questionnaire to the family member or friend.

Use the information on the questionnaire itself when you explain it to the family member. Ask the family member to return it to you once it is complete; score the questionnaire, and attach it to the patient’s chart.

Scoring: Not at all = 0
Sometimes = 1
Frequently = 2

Total Score: ____________

Score Interpretation: A score of 3 or more should prompt the consideration of a more detailed evaluation.

Experience from the CCN/AD Initiative Sites
Although some staff at CCN/AD sites were concerned that patients might become upset when their family members or friends were asked to complete the Family Questionnaire, this problem did not occur at any of our sites.
Rationale for the Removal of the High-Risk Screening Tool

When the CCN/AD model was designed, we believed that use of the triggers and the Family Questionnaire would identify many individuals with possible dementia and that healthcare organizations would want to reduce the total number of individuals who went on to receive a full diagnostic assessment. Therefore, we created what we believed would be a very difficult brief mental status test by taking the most difficult items from the Mini Mental State Examination (MMSE) and adding the Clock Drawing. The test we created, the High-Risk Screening Tool, was intended to be used after individuals were identified on the basis of the triggers and/or the Family Questionnaire, and it was intended to rule out individuals who were very unlikely to have dementia. We set a very high score—individuals would have to score perfectly on the test to be ruled out. We reasoned that individuals with dementia would be very unlikely to score perfectly on this difficult mental status test.

After the CCN/AD sites began implementing the model, we heard about three kinds of problems with the use of the High-Risk Screening Tool:

- Staff at some sites said they were not using it due to resistance of physicians and other clinical staff.
- Staff at some sites were completing the High-Risk Screening Tool as a required activity, but they were completing it after they had already decided to proceed with the Initial Dementia Assessment. That was not the intended use of the High-Risk Screening Tool. Moreover, since the MMSE is part of the Initial Dementia Assessment and since the MMSE and the High-Risk Screening Tool include two identical items (name and remember three objects and spell “world” backwards), using both results in duplication of effort for clinicians and individuals with possible dementia.
- Staff and clinicians at some sites used or were thinking about using the High-Risk Screening Tool to screen for possible dementia in individuals who had not been previously identified on the basis of the triggers or the Family Questionnaire. That was not the intended use of the High-Risk Screening Tool, and it is probably a very poor tool for that purpose. As noted above, we created the High-Risk Screening Tool to be used after someone has indicated concern about the individual on the basis of the triggers or the Family Questionnaire, and we created what we thought would be a very difficult test that would identify only those individuals who are very unlikely to have dementia even though someone had identified them on the basis of the triggers or the Family Questionnaire.

All screening tests have the same two potential problems: false positives (that is, situations where the test indicates the person has the condition, but he or she really doesn’t) and false negatives (that is, situations where the test indicates the person does not have the condition, but he or she really does). We believe that the High-Risk Screening Tool used as a screening test for individuals who have not been previously identified on the basis of the triggers or the Family Questionnaire will produce many false positives. False positives result in

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1 Two comprehensive literature reviews show that the items we selected from the MMSE are the most difficult items on the MMSE [Tombaugh, and McIntyre, 1992. Journal of the American Geriatrics Society 40(9):922–35.] and that one of the items we selected from the MMSE and the clock drawing are two of the four most difficult items on any of the widely used brief mental status tests. [Siu, A. L. 1991. “Screening for Dementia and Investigating Its Causes.” Ann. of Intern. Med. 115:122–32.]
unnecessary work for staff. More importantly, false positives create unnecessary fear and time-consuming tests for individuals and their families. (False negatives are probably less of a problem with the High-Risk Screening Tool because the test is so difficult, but we have no data to support that idea.)

Other brief mental status tests (for example, the MMSE and the 7-Minute Screen) are probably less likely than our High-Risk Screening Tool to produce large numbers of false positives when used for screening purposes in a general population because they include some less difficult questions, and they do not require perfect scores as our High-Risk Screening Tool did. On the other hand, research suggests that all brief mental status tests are likely to result in false positives. In addition, as many of our sites found, individuals who score above the usual cutoff score on the MMSE (for example, 24–29) may nevertheless have dementia. For these reasons a committee of Alzheimer’s experts formed by the Agency for Health Care Policy and Research recommended against screening for dementia in general populations of elderly people. An international consensus group of Alzheimer’s experts also recommended against screening for dementia in general populations of elderly people, concluding that “cognitive testing should occur for older patients when there is a reason to suspect dementia. Testing may occur in an individual considered to be at risk because of an informant history of cognitive or functional decline, clinical observation, or, sometimes, very old age.” In November 2000 the Medical and Scientific Advisory Council of the Alzheimer’s Association reaffirmed its recommendation against screening for dementia in general populations of elderly people.

2 In 1980–81 the federal government sponsored a large-scale survey, the Epidemiologic Catchment Areas (ECA) study in five sites in the United States. In all sites, a probability sample of adults was interviewed using the MMSE and other tests. Thus, the MMSE was used in the general population—not just people who are suspected for some reason to have dementia. In the East Baltimore site subjects whose scores on any of the tests indicated that they might have a cognitive or psychiatric disorder were then interviewed by a psychiatrist who used standardized clinical methods to make a clinical diagnosis based on DSM III criteria. Of those aged 65 and over who scored below 24 on the MMSE (the usual cutoff score for the MMSE), only 26.4 percent had dementia; 5 percent had delirium; others had other psychiatric disorders, and 33.1 percent had no diagnosable cognitive or psychiatric disorder. Thus, the use of the MMSE in this general population generated a very high rate of false positives. [Folstein, et al. 1985. *Journal of the American Geriatrics Society* 33(4):228–35.]


Initial Dementia Assessment for Primary Care Providers: Three Levels of Investigation

Attached is the approach to dementia assessment developed by the Care Management Advisory Group of the Chronic Care Networks for Alzheimer’s Disease initiative. These recommendations are based upon the Advisory Group’s evaluation of currently available practice guidelines regarding dementia assessment and work by Siu. The guidelines were developed for implementation in primary care-driven, managed care settings. In such settings where there may be more opportunities for practicing population-based care and using non-physician personnel, the detection and workup of dementia is likely to be different than in fee-for-service settings. In developing the recommended assessment, the Advisory Group considered both comprehensiveness and cost effectiveness.

The approach to dementia assessment recommended by the Advisory Group assumes that people with possible dementia have been identified using case finding methods such as provider education about signs and symptoms of possible dementia, use of a family questionnaire, or other health risk assessments. It is not expected that all parts of the assessment will necessarily be implemented in one visit, rather two or three visits could be required.

The results of the Initial Dementia Assessment (IDA) support both the physician’s diagnosis and the development of a care plan and management of care over time.

The Advisory Group recommends a three-step approach to assessment. The examinations and tests listed in Level 1 should be done for all clients. We estimate that 65 percent of clients will need no more than this level of assessment. Level 2 examinations and tests should be done for all clients unless there is relative certainty about the diagnosis based upon the Level 1 information, or the results of a Level 2 test would not change the care plan. We estimate that virtually all remaining clients will be in this category. Level 3 interventions are rarely needed in the routine assessment and management of dementia in primary care settings. However, if onset is early (age < 65), if course is atypical, or if diagnostic uncertainty is high, they may be helpful.

Sources:
Veterans Health Administration. 1977. Dementia Identification and Assessment: Guidelines for Primary Care Practitioner. U.S. Dept. of Veterans Affairs.

This tool was developed by the Care Management Advisory Group of the Chronic Care Networks for Alzheimer’s Disease initiative and is the joint property of the National Chronic Care Consortium and the Alzheimer’s Association. The primary author is Kenneth Brummel-Smith, M.D. Duplication for educational and clinical purposes is authorized without prior written approval if acknowledgment is given to the National Chronic Care Consortium and the Alzheimer’s Association as the source. Notification of use and suggestions for improvement are appreciated. Contact the National Chronic Care Consortium, 8100 26th Avenue South, Suite 120, Bloomington, MN 55425.

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Initial Dementia Assessment
Level 1—For All Patients

Note: This workup assumes that the patient has met early identification criteria indicating the need for assessment or that the patient or caregiver has requested an in-depth assessment.

Interview (should be corroborated with family or caregiver)
• Focused history—Patterns of losses, behavioral issues, current functioning, safety concerns, onset of memory and other cognitive problems
• Past medical history—Risk factors, head trauma, neurological conditions
• Geriatric review of systems—Continence, driving, falls, constipation, vision and hearing, dental, depression, neurologic symptoms
• Social and family history
• Review of medications—Prescriptions, OTC
• Review of preventive interventions—Immunizations, appropriate cancer screening
• Advance healthcare directive status—Expressed wishes, chosen surrogate

Family Interview (without patient present)
• Caregiver strain—Reports by caregivers of negative consequences of caregiving for their: health, relationship with care receivers, non-caregiving social activities, and perceived ability to function effectively in the caregiver role. MBRC Caregiver Strain Instrument (Attachment 5)
• Caregiver perceptions of patient’s cognitive and behavioral symptoms—Caregiver reports of common symptoms of dementia. Cognitive Incapacity & Problem Behaviors Assessment (Attachment 6)

Examination
• Physical exam—Hearing and vision screens, orthostatic blood pressure
• Neurologic exam—Cranial nerves, muscle strength and tone, tremor, localized findings, deep tendon and pathologic reflexes
• Functional status—Functional Activities Questionnaire (FAQ) and Activities of Daily Living (ADL) (Attachments 3 and 4)
• Mental status assessment—Mini-Mental State Examination (MMSE)* (Attachment 1)
• Depression assessment—Geriatric Depression Scale and Single-Item Depression Indicator (Attachment 2)

Laboratory Tests (prior laboratory studies should be sufficient if done within a relatively recent time frame)
• CBC • Serum electrolytes • TSH
• Glucose • BUN/creatinine • Drug levels (e.g., digoxin)

Therapeutic “Diagnostic” Tests
• Remove possible offending medications
• Treat depression

*Use of the MMSE is required in the Chronic Care Networks for Alzheimer’s Disease sites. Other instruments mentioned in this section are highly recommended.
The MMSE was a required part of the Initial Dementia Assessment for the CCN/AD initiative and was previously included in the Tools for Early Identification, Assessment, and Treatment for People with Alzheimer’s Disease and Dementia document. Due to copyright restrictions that took effect after the CCN/AD tools document was developed, we can no longer reproduce the MMSE. MMSE sources are listed at the bottom of this page. Copyright and purchasing information is listed below.

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Sources:
**Initial Dementia Assessment**

**Attachment 2—Geriatric Depression Scale (GDS) and Single-Item Depression Indicator**

**Geriatric Depression Scale**

1. Are you basically satisfied with your life? ................................. Yes  No
2. Have you dropped many of your activities and interests? ............... Yes  No
3. Do you feel that your life is empty? ............................................ Yes  No
4. Do you often get bored? .............................................................. Yes  No
5. Are you in good spirits most of the time? ................................. Yes  No
6. Are you afraid that something bad is going to happen to you? ........ Yes  No
7. Do you feel happy most of the time? .......................................... Yes  No
8. Do you often feel helpless? ......................................................... Yes  No
9. Do you prefer to stay at home, rather than going out and doing new things? ................................................................. Yes  No
10. Do you feel you have more problems with memory than most? ........ Yes  No
11. Do you think it is wonderful to be alive now? .......................... Yes  No
12. Do you feel pretty worthless the way you are now? ..................... Yes  No
13. Do you feel full of energy? ......................................................... Yes  No
14. Do you feel that your situation is hopeless? .............................. Yes  No
15. Do you think that most people are better off than you are? .......... Yes  No

**Score: __________ (number of “depressed” answers)**

Five or more depressed responses warrants further evaluation.

The following question could be used instead of the GDS (see Mahoney, et al., 1994) or in addition to the GDS. If using both, consider asking the Single-Item question *not* in direct sequence with the GDS.

**Single-Item Depression Indicator**

1. Do you often feel sad or depressed? Yes  No

**Sources:**


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Revised October 2000
Initial Dementia Assessment
Attachment 3—Functional Activities Questionnaire (FAQ)

The FAQ is an informant-based measure of functional abilities. Informants provide performance ratings of the target person on ten complex higher-order activities.

Individual Items of the FAQ
1. _____Writing checks, paying bills, balancing checkbook
2. _____Assembling tax records, business affairs, or papers
3. _____Shopping alone for clothes, household necessities, or groceries
4. _____Playing a game of skill, working on a hobby
5. _____Heating water, making a cup of coffee, turning off stove
6. _____Preparing a balanced meal
7. _____Keeping track of current events
8. _____Paying attention to, understanding, discussing a TV show, book, magazine
9. _____Remembering appointments, family occasions, holidays, medications
10. _____Traveling out of neighborhood, driving, arranging to take buses

Total _______

The levels of performance assigned range from dependence to independence and are rated as follows.

- Dependent = 3
- Requires assistance = 2
- Has difficulty, but does by self = 1
- Normal = 0

Two other response options can also be scored.

- Never did (the activity), but could do now = 0
- Never did, and would have difficulty now = 1

A total score for the FAQ is computed by simply summing the scores across the 10 items. Scores range from 0 to 30. A cutpoint of 9 (dependent in 3 or more activities) is recommended.

Source:

Revised April 1999
# Initial Dementia Assessment

## Attachment 4—Activities of Daily Living (ADL)

Please circle the response that you feel best represents the person’s ability to do each of the following activities of daily living.

<table>
<thead>
<tr>
<th>Activity</th>
<th>Needs no assistance or supervision</th>
<th>Needs some assistance or supervision</th>
<th>Totally dependent/cannot do at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eating</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Toileting</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Bathing (sponge, shower, or tub)</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Dressing</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Grooming (combing, shampooing hair; shaving; trimming nails)</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Transferring</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

**Total Score _________________**

Source:

Revised June 2000
A primary caregiver is the family member or friend who gives the most help to someone with a health problem. The following items refer to how a caregiver feels and behaves as a result of providing care.

Please use the following scale to answer questions 1–14. There are no right or wrong answers.

- Strongly agree = 3
- Agree = 2
- Disagree = 1
- Strongly disagree = 0

During the past four weeks, because of helping the patient, I felt:

1. _____unsure whether he/she was getting proper care.
2. _____uncertain about how to best care for him/her.
3. _____that I should be doing more for him/her.
4. _____that I could do a better job of caring for him/her.
5. _____that he/she tried to manipulate me.
6. _____that my relationship with him/her was strained.
7. _____that he/she made requests over and above what he/she needed.
8. _____resentful toward him/her.
9. _____angry toward him/her.
10. _____my physical health was worse than before.
11. _____downhearted, blue, or sad more often.
12. _____more nervous or bothered by nerves than before.
13. _____I had less pep or energy.
14. _____bothered more by aches and pains.

Caregiver Mastery Score _________________ (Sum of items 1–4)

Relationship Strain Score _________________ (Sum of items 5–9)

Health Strain Score _________________ (Sum of items 10–14)

Continued on page 20.
Please use the following scale to answer questions 15–19. There are no right or wrong answers.

- Less often = 2
- The same = 1
- Strongly disagree = 0

During the past four weeks, because of helping the patient, I:

15. ____ participated in church or religious activities.
16. ____ visited with friends or family.
17. ____ participated in group or organized activities.
18. ____ engaged in volunteer activities.
19. ____ went out to dinner, the theater, or a show.

Activity Restriction Score _________________ (Sum of items 15–19)

No exact cutting points for heightened caregiver risk have been determined for this tool. Answers can help caregivers describe difficulties they are experiencing, and with repeated administrations, it can be used to assess change in the care situation over time. However, scores greater than 8 for mastery, greater than 10 for relationship strain or health strain, or greater than 5 for activity restriction may indicate heightened risk and may warrant further clinical investigation.

Sources:
Initial Dementia Assessment
Attachment 6—Cognitive Incapacity & Problem Behaviors Assessment

A primary caregiver is the family member or friend who gives the most help to someone with a health problem. Primary caregivers may help with personal care (e.g., bathing, dressing), instrumental daily activities (e.g., housekeeping, laundry, shopping), or health-related decisions (e.g., when to seek care, what types of treatments to select). Because of this help, caregivers can give important information about possible symptoms that may not be noticed during a visit to the doctor or other care provider.

Please indicate the best response for each behavior listed using the following scale. There are no right or wrong answers.

- Most or all of the time = 3
- Often = 2
- Sometimes = 1
- None of the time = 0

How often in the past four weeks did the patient:

1. ____ act confused?
2. ____ talk or mumble to him/herself?
3. ____ repeat the same thing over and over?
4. ____ hear or see things that were not there?
5. ____ forget the names of his/her family or close friends?
6. ____ forget the right words to use?
7. ____ yell or swear at people?
8. ____ interfere or offer unwanted advice?
9. ____ act restless or agitated?
10. ____ act fearful without good reason?
11. ____ complain about or criticize things?
12. ____ show inappropriate sexual behavior?
13. ____ wander outside the house?
14. ____ refuse to be left alone?

Cognitive Score _________________ (Sum of items 1–6)
Behavior Score _________________ (Sum of items 7–14)

No exact cutting points for heightened caregiver risk have been determined for this tool. However, cognitive symptom scores greater than 7 may indicate heightened risk of caregiving problems and may warrant further clinical investigation. The presence of any behavior symptoms may warrant further investigation, with values greater than 2 indicating heightened risk.

Source:

Revised June 2000
Initial Dementia Assessment
Level 2—For Most Patients

Note: These tests are always worth considering as part of the assessment. If one decides not to do them there should be good justification.

Laboratory Tests
- Liver function tests
- B12 and folate levels
- VDRL (some argue FTA instead)
- Calcium

Brain Imaging*
CT scanning without intravenous contrast will detect hydrocephalus and most clinically significant mass lesions, infarcts, and subcortical ischemic changes (see note below). This study is suitable for most patients who require brain imaging. For individuals over age 75 with a classic history of Alzheimer’s disease and normal neurological examination, CT scanning is unlikely to produce any clinical benefit. For those patients, brain imaging is not essential for appropriate diagnosis and treatment.

Note: No controlled studies compare the diagnostic sensitivity of non-contrast CT with contrast CT or CT with MRI in the evaluation of patients with dementia.

*Sources:
Initial Dementia Assessment
Level 3—For Some Patients

Note: These examinations and tests are rarely needed in routine assessment and management of dementia in primary care settings. However, if onset is early (age < 65), if course is atypical, or if diagnostic uncertainty is high, they may be helpful.

Consultation
Neurology or psychiatry

Neuropsychological Evaluations
Neuropsychological testing is of value in confirming the presence of dementia when the diagnosis is in doubt, in clarifying dementia type, and in differentiating dementia from mental illness, including depression.

Laboratory Tests
• Genetic testing (e.g., CAG triple repeat for Huntington’s disease)
• Heavy-metal screen
• Copper, ceruloplasmin for Wilson’s disease

Studies
• Lumbar puncture (e.g., if there is a positive syphilis history or screening exam, meningitis history, mixed dementia/delirium, unusual presentation with varying course)
• EEG (if partial or generalized seizures are a consideration)
• SPECT, diffusion MRI (These are primarily research tools, rarely needed for clinical management.)

A rationale should be recorded when Level 3 examinations or tests are used.
Care Management Blueprints for Alzheimer’s Disease

This tool provides information and a basic structure that healthcare organizations and partnerships should use to establish their own approach to care management, consistent with their organizational structure(s) and care practices. The attached grids show desired outcomes, assessment procedures, goals, and possible interventions for medical and non-medical care management in three phases of disease (initial identification, longitudinal monitoring and treatment, and end-of-life) and for six important domains of care:

Domain 1. Patient Function
Patient functioning at maximum level of independence consistent with physical potential and patient and caregiver wishes.

Domain 2. Caregiver Support
Caregiver(s) identified and given information and support to best balance his or her caregiver role and personal life in accordance with caregiver needs and wishes.

Domain 3. Medical Care
Patient receives optimal medical care consistent with accepted standards of care and patient and caregiver preference.

Domain 4. Psychosocial
Patient and caregiver understand monitoring parameters to assess mood and behavioral concerns and are satisfied with management strategies employed.

Domain 5. Patient Nutrition
Patient is in targeted body weight range, and patient and caregiver are satisfied with diet and nutritional status.

Domain 6. Advance Directives Planning
Patient and caregiver understand purpose of Advance Directives/Living Will/Durable Power of Attorney for Health Care (DPOAHC), enact them according to personal values and needs, and ultimately see wishes followed.

Experience from the CCN/AD Initiatives Sites
CCN/AD sites found that this comprehensive tool was useful in training and in building relationships among the partnering organizations at each site. Shorter, less complex tools for day-to-day care management were developed at some sites, and several of these tools are available at http://www.nccconline.org.

This tool was developed by the Care Management Advisory Group of the Chronic Care Networks for Alzheimer’s Disease initiative and is the joint property of the National Chronic Care Consortium and the Alzheimer’s Association. The primary authors are Susan Denman, M.D., and Jon Mertz, M.H.A. Duplication for educational and clinical purposes is authorized without prior written approval if acknowledgment is given to the National Chronic Care Consortium and the Alzheimer’s Association as the source. Notification of use and suggestions for improvement are appreciated. Contact the National Chronic Care Consortium, 8100 26th Avenue South, Suite 120, Bloomington, MN 55425.
## Domain 1
### Patient Function

<table>
<thead>
<tr>
<th>Pathway Outcome</th>
<th>Initial Identification Phase</th>
<th>Longitudinal Monitoring and Treatment Phase</th>
<th>End-of-Life Phase</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Patient functioning at maximum level of independence consistent with patient/caregiver wishes</td>
<td>Patient maintaining targeted functional levels</td>
<td>Patient/caregiver satisfied with approaches being used to address functional needs</td>
</tr>
</tbody>
</table>
| Assessment      | • Assess patient/caregiver concerns regarding functional abilities  
• Obtain baseline information regarding ADL, IADL, continence, falls, driving, safety, assistive devices | • Assess for new patient/caregiver concerns regarding functional abilities  
• Evaluate for new safety concerns such as falls, wandering  
• Evaluate for medical complications related to functional decline (skin breakdown, weakness, weight loss, side effects) | • Evaluate patient/caregiver concerns regarding functional decline  
• Assess degree of functional dependency  
• Determine if current approaches used to meet functional needs are satisfactory to caregiver  
• Evaluate for medical complications related to functional dependencies |
| Goal Formation  | • Establish functional goals in conjunction with patient/caregiver, aiming for the most satisfactory level of independence in self-care, mobility, and continence  
• Maximize safety  
• Specify time frames for reaching goals | Adjust functional goals as appropriate in conjunction with patient/caregiver | Adjust functional goals in conjunction with patient/caregiver to maximize satisfaction, comfort, and dignity |
| Interventions   | Consider:  
• OT, PT referrals  
• Exercise program  
• Driving evaluation  
• Educational materials regarding home safety  
• Home safety assessment  
• Medication adjustment  
• Toileting program  
• ID bracelet | Consider:  
• Previous interventions | Consider:  
• In-home nursing/assistance/aides  
• Hospice referral  
• Support groups |
| Response        | • Assess goal attainment  
• Adjust goals or strategies if goals not met | • Assess goal attainment  
• Adjust goals or strategies if goals not met | • Assess goal attainment  
• Adjust goals or strategies if goals not met |

Supporting documents might include functional assessment tools (Barthel Index, Katz ADL Scale), safety checklist, educational materials, and medical alert information.
## Domain 2
### Caregiver Support

<table>
<thead>
<tr>
<th>Pathway Outcome</th>
<th>Initial Identification Phase</th>
<th>Longitudinal Monitoring and Treatment Phase</th>
<th>End-of-Life Phase</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Caregiver(s) is identified and given information and support in accordance with his or her needs/wishes</td>
<td>Caregiver(s) is supported to enable him or her to maximize caregiving role(s) while maintaining appropriate balance in personal life</td>
<td>Caregiver(s) achieves maximum satisfaction with his or her role(s)</td>
</tr>
</tbody>
</table>

| Assessment       | • Identify current and potential caregivers  
• Record contact information in patient chart  
• Assess caregiver concerns, agenda, needs, availability  
• Assess caregiver knowledge  
• Assess caregiver role with ADLs/IADLs  
• Assess caregiver perception of patient’s living environment (appropriateness and safety) | • Update caregiver information  
• Follow up on status of previous caregiver concerns and needs  
• Assess for new issues and burdens  
• Assess caregiver role with ADLs/IADLs  
• Assess caregiver perception of patient’s living environment (appropriateness and safety) | • Assess caregiver comfort/concerns with end-of-life issues  
• Assess burden of caregiver tasks and need for respite  
• Evaluate caregiver perception of patient’s environment regarding appropriateness for meeting end-of-life needs |

| Goal Formation   | • Provide caregiver with information, referrals, and resource materials  
• Establish caregiver role(s) as appropriate in conjunction with patient/caregiver | • Review/revise caregiver roles as appropriate according to changing needs in conjunction with patient/caregiver  
• Provide caregiver support to maximize ability to fulfill role with appropriate balance and satisfaction | Adjust caregiver roles by providing additional support services as needed to achieve maximum caregiver satisfaction |

| Interventions    | Refer to Alzheimer’s Association and consider:  
• Educational materials  
• Counseling referral  
• Social work referral  
• Support group  
• Respite services/aide services  
• Family meeting  
• Other community referrals  
• Home nursing referrals  
• PT/OT/SLP referrals  
• Chaplaincy referral | Refer to Alzheimer’s Association and consider:  
• Previous interventions  
• Chaplaincy referral | Refer to Alzheimer’s Association and consider:  
• Previous interventions  
• Hospice referral |

| Response         | • Assess goal attainment  
• Adjust goals or strategies if goals not met | • Assess goal attainment  
• Adjust goals or strategies if goals not met | • Assess goal attainment  
• Adjust goals or strategies if goals not met |

Supporting documents might include information from the Alzheimer’s Association chapter, community services, and educational materials. (Caregiver Support Planning Tool is attached, see page 31.)
## Domain 3
### Medical Care

<table>
<thead>
<tr>
<th></th>
<th>Initial Identification Phase</th>
<th>Longitudinal Monitoring and Treatment Phase</th>
<th>End-of-Life Phase</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Pathway Outcome</strong></td>
<td>Patient receives optimal medical care consistent with accepted standards of care and patient/caregiver preferences</td>
<td>Patient receives optimal medical management with emphasis on 2° and 3° prevention consistent with accepted standards of care and patient/caregiver wishes</td>
<td>Patient/caregiver satisfied with medical management of symptoms</td>
</tr>
<tr>
<td><strong>Assessment</strong></td>
<td>• Perform (review) dementia and general assessment (see second component)</td>
<td>• Evaluate status of previous symptoms</td>
<td>• Evaluate status of all symptoms</td>
</tr>
<tr>
<td></td>
<td>• Record assessment results in chart including medical problem list, medications, pertinent physical exam, MMSE, vision/hearing screen, laboratory results</td>
<td>• Assess for new symptoms since last visit</td>
<td>• Review medications for effectiveness, compliance, and potential side effects</td>
</tr>
<tr>
<td></td>
<td>• Prioritize symptoms in conjunction with patient/caregiver</td>
<td>• Review medications for effectiveness, compliance, and potential side effects</td>
<td>• Perform focused physical exam based on symptoms/concerns</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Repeat MMSE every 6 months or sooner as appropriate until patient scores 10 or less</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Perform focused physical exam based on symptoms/concerns</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Update medical problem list</td>
<td></td>
</tr>
<tr>
<td><strong>Goal Formation</strong></td>
<td>• Establish treatment goals to optimize health and function for the patient in conjunction with patient/caregiver</td>
<td>• Review previous goals and establish new goals in conjunction with patient/caregiver</td>
<td>• Establish treatment goals to achieve greatest patient/caregiver satisfaction regarding symptom management</td>
</tr>
<tr>
<td></td>
<td>• Specify time frames for reaching goals</td>
<td>• Specify time frames for reaching goals</td>
<td>• Specify time frames for reaching goals</td>
</tr>
<tr>
<td><strong>Interventions</strong></td>
<td>Consider:</td>
<td>Consider:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Additional diagnostic testing</td>
<td>• Previous interventions</td>
<td>• Previous interventions</td>
</tr>
<tr>
<td></td>
<td>• Specialty referrals</td>
<td></td>
<td>• Hospice referral</td>
</tr>
<tr>
<td></td>
<td>• Medication changes</td>
<td></td>
<td>• Chaplaincy referral</td>
</tr>
<tr>
<td></td>
<td>• Educational materials</td>
<td></td>
<td>• Social work referral</td>
</tr>
<tr>
<td></td>
<td>• Audiology referral</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Home nursing referral</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• PT/OT/SLP referrals</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Response</strong></td>
<td>• Assess goal attainment</td>
<td>• Assess goal attainment</td>
<td>• Assess goal attainment</td>
</tr>
<tr>
<td></td>
<td>• Adjust goals or strategies if goals not met</td>
<td>• Adjust goals or strategies if goals not met</td>
<td>• Adjust goals or strategies if goals not met</td>
</tr>
</tbody>
</table>

Supporting documents might include dementia assessment tool, MMSE, sample forms for medical problem/medication lists, and flow sheets.
# Domain 4
## Psychosocial

<table>
<thead>
<tr>
<th>Pathway Outcome</th>
<th>Initial Identification Phase</th>
<th>Longitudinal Monitoring and Treatment Phase</th>
<th>End-of-Life Phase</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient/caregiver understand monitoring parameters to assess mood and behavioral concerns</td>
<td>Patient receives optimal management of depression, disruptive behaviors consistent with patient/caregiver wishes</td>
<td>Patient/caregiver satisfied with management strategies used to address moods/behaviors and adjustment to end of life</td>
<td></td>
</tr>
<tr>
<td><strong>Assessment</strong></td>
<td>• Assess patient/caregiver concerns regarding mood, depression, sleep patterns, disruptive behaviors, agitation, aggression, wandering, etc.</td>
<td>• Evaluate current status of previously identified moods and behavioral problems</td>
<td>• Assess patient/caregiver satisfaction regarding management of moods/behaviors</td>
</tr>
<tr>
<td></td>
<td>• Administer depression scale (GDS)</td>
<td>• Review available behavior logs/diaries/reports for response to interventions and for new problems</td>
<td>• Update previous assessment</td>
</tr>
<tr>
<td></td>
<td>• Assess patient/caregiver priorities regarding quality-of-life issues</td>
<td>• Reassess for signs of depression</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Evaluate environmental factors affecting moods/behaviors</td>
<td>• Update relationship of environment, activity, and other symptoms to moods/behaviors</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Evaluate relationship of activities/schedule to moods/behaviors</td>
<td>• Reassess patient/caregiver priorities regarding quality-of-life issues</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Evaluate relationship of other symptoms to moods/behaviors</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Goal Formation</strong></td>
<td>• Establish methods/parameters to monitor moods/behaviors</td>
<td>Select management strategies to improve targeted symptoms, moods/behaviors in conjunction with patient/caregiver</td>
<td>Select management strategies to maximize end-of-life comfort regarding moods/behaviors in conjunction with patient/caregiver</td>
</tr>
<tr>
<td></td>
<td>• Establish treatment goals for targeted moods/behaviors</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Interventions</strong></td>
<td>Consider:</td>
<td>Consider:</td>
<td>Consider:</td>
</tr>
<tr>
<td></td>
<td>• Diary/behavior log</td>
<td>• Previous interventions</td>
<td>• Previous interventions</td>
</tr>
<tr>
<td></td>
<td>• Social work referral</td>
<td>• Behavior management techniques</td>
<td>• Hospice referral</td>
</tr>
<tr>
<td></td>
<td>• Psychology referral</td>
<td>• Changes in medications</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Support group</td>
<td>• Changes in schedule/activities</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Respite care</td>
<td>• Changes in environment</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Home aide</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Medications</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Family meetings</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Educational materials</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Chaplaincy referral</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Response</strong></td>
<td>• Assess goal attainment</td>
<td>• Assess goal attainment</td>
<td>• Assess goal attainment</td>
</tr>
<tr>
<td></td>
<td>• Adjust goals or strategies if goals not met</td>
<td>• Adjust goals or strategies if goals not met</td>
<td>• Adjust goals or strategies if goals not met</td>
</tr>
</tbody>
</table>

Supporting documents might include educational materials, depression scales, and behavior monitoring tools.
## Domain 5
### Patient Nutrition

<table>
<thead>
<tr>
<th>Pathway Outcome</th>
<th>Initial Identification Phase</th>
<th>Longitudinal Monitoring and Treatment Phase</th>
<th>End-of-Life Phase</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient in ideal body weight range</td>
<td>Patient maintaining targeted body weight</td>
<td>Patient/caregiver satisfied with diet and nutritional status</td>
<td></td>
</tr>
<tr>
<td>Assessment</td>
<td></td>
<td>Evaluate for change since last assessment</td>
<td>Adjust goals to maximize patient/caregiver satisfaction</td>
</tr>
<tr>
<td>• Evaluate patient/caregiver status and wishes regarding nutritional status</td>
<td>• Evaluate how food is obtained and prepared</td>
<td>• Evaluate for change since last assessment</td>
<td></td>
</tr>
<tr>
<td>• Evaluate diet and nutritional status</td>
<td>• Obtain history of weight changes</td>
<td>• Reassess Advance Directives regarding feeding/nutritional issues with patient/caregiver</td>
<td></td>
</tr>
<tr>
<td>• Assess eating function</td>
<td>• Measure weight</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Evaluate for edema and hydration</td>
<td>• Evaluate dentition</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Evaluate pharmaceutical/nutrient interactions</td>
<td>Goal Formation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Establish weight/nutritional goals in conjunction with patient/caregiver</td>
<td>Adjust weight and nutritional goals as appropriate, in conjunction with patient/caregiver</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Establish home monitoring parameters in conjunction with patient/caregiver</td>
<td>• Evaluate for change since last assessment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Specify time frame for reaching goals</td>
<td>• Reassess Advance Directives regarding feeding/nutritional issues with patient/caregiver</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interventions</td>
<td>Consider:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Swallowing evaluation</td>
<td>• Swallowing evaluation</td>
<td>• Previous interventions</td>
<td></td>
</tr>
<tr>
<td>• Dietician referral</td>
<td>• Dietician referral</td>
<td>• Previous interventions</td>
<td></td>
</tr>
<tr>
<td>• Nutritional supplements</td>
<td>• Nutritional supplements</td>
<td>• Feeding tube (only if consistent with patient/caregiver wishes and goals)</td>
<td></td>
</tr>
<tr>
<td>• Diet changes</td>
<td>• Diet changes</td>
<td>• Hospice referral</td>
<td></td>
</tr>
<tr>
<td>• Home delivered or other meals program</td>
<td>• Home delivered or other meals program</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Social work referral</td>
<td>• Social work referral</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Caregiver educational materials</td>
<td>• Caregiver educational materials</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Dental referral</td>
<td>• Dental referral</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Response</td>
<td>• Assess goal attainment</td>
<td>• Assess goal attainment</td>
<td></td>
</tr>
<tr>
<td>• Adjust goals or strategies if goals not met</td>
<td>• Adjust goals or strategies if goals not met</td>
<td>• Adjust goals or strategies if goals not met</td>
<td></td>
</tr>
</tbody>
</table>
# Domain 6
## Advance Directives Planning

<table>
<thead>
<tr>
<th>Pathway Outcome</th>
<th>Initial Identification Phase</th>
<th>Longitudinal Monitoring and Treatment Phase</th>
<th>End-of-Life Phase</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assessment</td>
<td>Patient/caregiver understand purpose of Advance Directives/ Living Will/Durable Power of Attorney for Health Care</td>
<td>Patient/caregiver enact Advance Directive as legally allowed according to cognitive status</td>
<td>Patient/caregiver wishes regarding end-of-life care are followed</td>
</tr>
<tr>
<td>Goal Formation</td>
<td>Provide information/documents to patient/caregiver according to identified needs</td>
<td>Obtain copies of Advance Directive statements regarding treatment wishes, limitations for chart(s)</td>
<td>Resolve any conflicts among patient/caregiver/ family members</td>
</tr>
</tbody>
</table>
| Interventions   | Consider:  
- Educational materials  
- Social work referral  
- Chaplaincy referral  
- Psychology referral  
- Legal counsel  
- Support group referral | Consider:  
- Previous interventions | Consider:  
- Previous interventions  
- Hospice referral |
| Response        | • Verify that information/documents are received and reviewed  
• Adjust goals or strategies if goals not met | • Verify that documents are on chart  
• Adjust goals or strategies if goals not met | • Assess goal attainment  
• Adjust goals or strategies if goals not met |

Supporting documents might include copies of Advance Directives, legal information regarding Advance Directives/Living Will/Durable Power of Attorney for Health Care, and educational materials.
Living with Dementia:
Caregiver Support Planning Tool

This tool was designed to help healthcare organizations and partnerships of organizations improve their readiness to assist and support family caregivers of people with Alzheimer’s disease and related dementias. The tool uses a conceptual framework that was developed by Wayne Caron, Ph.D., and his colleagues at the University of Minnesota. The framework defines phases of caregiving in terms of the tasks and challenges faced by families as they experience the progressive changes in a person with these conditions. The six phases of caregiving in the Caron framework are: (1) prediagnostic, (2) diagnostic, (3) role change, (4) chronic caregiving, (5) transition to alternative care, and (6) end of life (see note below).

The CCN/AD Caregiver Support Planning Tool includes a brief description of each of the six phases of caregiving from the Caron framework and general interventions for that phase. A grid for each phase lists specific objectives CCN/AD sites hoped to achieve for family caregivers in that phase.

In developing this tool, the CCN/AD Education and Support Advisory Group considered using a conceptual framework based on stages of Alzheimer’s disease or other dementias. The Advisory Group chose the Caron framework instead because it reflects an awareness that the tasks and challenges for family caregivers do not necessarily follow the same time sequence as stages of the disease. Some families face the task of getting a diagnosis when the person is in a very early stage of his or her disease, while others do not face this task until much later in the person’s disease. Likewise, the tasks and challenges of transition to alternative care occur for some families at a much earlier point in the person’s disease than for other families. The tool is intended to identify programs and materials that meet family caregivers’ needs regardless of the person’s stage of disease.

Many different kinds of interventions may be useful to family caregivers in each phase of caregiving. The CCN/AD sites have used the grids to identify information, programs, and services that are available in their communities and to decide which of the partnering organizations (for example, the Alzheimer’s Association chapter or healthcare system) will be responsible for providing them or referring people to them. Most CCN/AD sites were able to fill most of the cells in each grid, but the grids have also been useful in identifying gaps for which new materials and programs are needed.

Note: Wayne Caron and his associates at the University of Minnesota use their model, including the phase framework, to guide family therapy and support services for caregivers. Their application of the model reflects its foundation in family systems theory and collaborative family healthcare models. For further information about their model and its application, please contact Wayne Caron, Ph.D., L.M.F.T, at the University of Minnesota, College of Human Ecology, Department of Family Social Science, (612) 625-1790, or e-mail wcaron@tc.umn.edu.


This tool was developed by the Education and Support Advisory Group of the Chronic Care Networks for Alzheimer’s Disease initiative and is the joint property of the National Chronic Care Consortium and the Alzheimer’s Association. Distribution for educational and clinical purposes is authorized without prior written approval if acknowledgment is given to the National Chronic Care Consortium and the Alzheimer’s Association as the source. Notification of use and suggestions for improvement are appreciated. Contact the National Chronic Care Consortium, 8100 26th Avenue South, Suite 120, Bloomington, MN 55425.
Experience from the CCN/AD Initiative Sites

In the CCN/AD initiative, the partnering healthcare organizations and Alzheimer’s Association chapters at each site completed the grids by identifying available programs, materials, and services that could be used to meet each objective and noting which of the partnering organizations would be responsible for providing or referring family caregivers to these programs, materials, and services. The sites found that this exercise was very useful as an initial cross-training exercise because it increased each organization’s awareness and understanding of the capabilities and resources of the other organization. By completing the grids, sites also became aware of gaps in available programs, materials, and services, and organizations at some sites were able to take steps to fill the identified gaps. Despite the usefulness of completing the grids for cross-site training and gap identification, the sites found that the completed grids were not an effective tool for day-to-day practice. For this purpose, a shorter list of programs, materials, and services is essential, and project staff at the sites developed such lists for their communities. The sites also found that the conceptual value of the Caron framework was often lost in the work of identifying specific programs, materials, and services. As a result of their experience with the Caregiver Support Planning Tool, the sites have made the following recommendations:

1. The Caron framework should be used for initial and ongoing training to emphasize the concept that the tasks and challenges faced by family caregivers of a person with dementia do not necessarily follow the same time sequence as the stages of the person’s disease.

2. For cross-training purposes, partnering organizations should complete at least a few rows on each grid to increase understanding of the capabilities and resources each organization brings to the partnership.

3. Partnering organizations should develop a relatively short list of available programs, materials, and services to be used for day-to-day referrals.

In the CCN/AD initiative, some of the objectives listed in the grids were used for evaluation purposes: in telephone interviews, family caregivers were asked questions intended to determine whether the services offered through CCN/AD had achieved these objectives. The particular objectives that were used in this way were those identified as most important by site-level project staff; they are marked with a double asterisk.
Six-Phase Model for Helping Families with Alzheimer’s Disease

Phase 1. Prediagnostic
During this time there is a growing awareness that something is wrong. Both the family and the person with dementia are trying to decide how seriously they should take memory lapses, functional impairments, or periods of confusion. This phase may last for years. A major task for the family is to monitor things over time to see if they get better, stay the same, or get worse. The primary issue during this time is arriving at a realistic understanding among family members about the illness.

Suggested Intervention
Provide information that is helpful in resolving the ambiguity, educational materials on Alzheimer’s disease containing clear information to help families understand their situation, and concrete steps that families can take.

Phase 2. Diagnostic
Sooner or later, as symptoms of cognitive impairment accumulate or a single, critical event occurs—making it impossible to believe nothing is wrong—families will obtain a diagnosis. The family must deal with the emotional issues of fear, sadness, anger, and denial that will be present and begin to process the meaning of the diagnosis. They must decide whom to tell about the diagnosis and find a way to maintain family morale and hope in the face of lost dreams for the future.

Suggested Intervention
Offer a one-session family consultation, the purpose of which is not to give the family more information, but rather to offer family members the opportunity to process information they have already received and to facilitate family communication and processing of the diagnosis.

Phase 3. Role Change
With the progression of impairment, the person with dementia changes from a competent, independent adult into a person who requires help with all activities of daily living. Family roles also change as the caregiving system is organized and the family begins to take greater control over the elder’s life. Tasks must be assigned to different family members with a means to monitor and encourage each to take a fair share. The family must understand what the person with dementia can and cannot do and adapt situations to maximize his or her participation. Both the person with Alzheimer’s and the family must deal with issues of significant loss.

Suggested Intervention
Provide educational programs, parallel support groups, and individual and family counseling to help families accept the losses of roles. Services for the person with dementia are critical to help him or her maintain a sense of self and morale.
Six-Phase Model for Helping Families with Alzheimer’s Disease (cont.)

Phase 4. Chronic Caregiving
With the continued loss of abilities, the person with dementia requires greater amounts of help with activities such as dressing, bathing, grooming, toileting, and feeding. The major challenge for the family is to stave off the physical and emotional exhaustion of caregiving. Support systems must be alert to signs of exhaustion, burnout, or depression among all family members, including the person with dementia, and plans must be developed to provide respite and maintain energy in daily life. Family members can be organized as case managers to help identify appropriate services in the community and develop the means for using these services with the least amount of stress on the primary caregiver and person with dementia. At this phase the disease crowds out normal family life.

Suggested Intervention
Provide psycho-educational programs for the entire family to minimize caregiver stress and connect caregivers with community services such as day care programs, support groups, and caregiver skills training programs to provide concrete guidance in caring for the person with dementia, the caregiver, and the family system.

Phase 5. Transition to Alternative Care
As caregiving resources are exhausted, it is often no longer possible to care for the person with dementia at home, necessitating placement in a nursing home or other care facility. The family must be provided assistance to help identify the point at which placement should occur, making sure to consider the needs of all family members. This traumatic event marks the end of personal caregiving and requires a shift into collaborative caregiving with appropriate role expectations.

Suggested Intervention
Offer services that address the demoralization families experience with placement, and facilitate development of collaborative care relationships between family and facility staff.

Phase 6. End of Life
Families are faced with many decisions regarding care and the treatment of potentially life-threatening illnesses. The family must not only witness but also participate in the dying of the person with dementia. Based upon the foundation of values and benefits unique to each family, the ethical dilemmas faced in making end-of-life treatment decisions must be resolved. The family must be helped to develop an image of a “good death,” including important rituals and legacies, which will help bring closure and meaning at the point of death.

Suggested Intervention
Support families as they anticipate death and multiple difficult decision-making situations. Involving the primary medical provider to educate the family on treatment options is crucial.
# Programs and Materials for People with Alzheimer’s Disease and Related Disorders
## Prediagnostic Phase

<table>
<thead>
<tr>
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<th>Program(s)*</th>
<th>Provided By</th>
<th>Appropriate Materials*</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.**</td>
<td>Know general information about dementia versus aging.</td>
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<td>2.</td>
<td>Know how to communicate with physician.</td>
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<td>3.**</td>
<td>Know steps for getting a diagnosis.</td>
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<td>4.</td>
<td>Have a positive attitude toward getting a diagnosis.</td>
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<td>5.</td>
<td>Discuss concerns openly with healthcare providers.</td>
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<td>6.</td>
<td>Believe options are available if diagnosis is irreversible dementia.</td>
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<td>7.</td>
<td>Have confidence in provider's ability to refer for information and services.</td>
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<td>8.</td>
<td>Call community agency with questions.</td>
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<tr>
<td>9.**</td>
<td>Know what educational and supportive services are available in the health plan and community.</td>
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</tbody>
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**These objectives were identified as most important by site-level project staff and were used for evaluation purposes (see page 32).
## Programs and Materials for People with Alzheimer’s Disease and Related Disorders
### Diagnostic Phase

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<tbody>
<tr>
<td>1.**</td>
<td>Obtain an accurate diagnosis. Know how to get a second opinion if necessary.</td>
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<tr>
<td>2.</td>
<td>Understand how the diagnosis was made.</td>
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<td>3.</td>
<td>Know how to approach the patient with news.</td>
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<td>4.**</td>
<td>Know what possible treatments exist.</td>
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<td>5.</td>
<td>Begin to accept the diagnosis and patient's limitations.</td>
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<td>6.**</td>
<td>Understand the need for proactive planning, including financial, legal, and care plans.</td>
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<td>7.</td>
<td>Seek out supportive services as needed (early-stage support groups, education sessions, etc.).</td>
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# Programs and Materials for People with Alzheimer’s Disease and Related Disorders
**Role-Change Phase**

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</tr>
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<tbody>
<tr>
<td>1.**</td>
<td>Understand the disease process. Know what changes to expect.</td>
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<td>2.</td>
<td>Know where to turn for information and support.</td>
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<td>3.</td>
<td>Anticipate the need for greater family involvement and support.</td>
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<td>4.**</td>
<td>Know how to talk with family about expected changes and necessary decisions (e.g., driving).</td>
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<td>5.</td>
<td>Know that all family members are experiencing grief.</td>
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<td>6.</td>
<td>Feel confident about potential family support and accept family limitations.</td>
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<td>7.</td>
<td>Feel confident about ability to provide care—caregiver self-efficacy.</td>
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<td>8.**</td>
<td>Use available services as needed.</td>
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<td>9.</td>
<td>Attend support groups.</td>
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<td>10.</td>
<td>Participate in research and clinical trials as desired.</td>
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# Programs and Materials for People with Alzheimer’s Disease and Related Disorders
## Chronic Caregiving Phase

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<tbody>
<tr>
<td>1.**</td>
<td>Use techniques for caregiving, including ways of managing difficult and dangerous behaviors.</td>
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<td>2.</td>
<td>Know ways of communicating with the patient.</td>
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<td>3.</td>
<td>Use appropriate medications for cognitive and behavioral symptoms.</td>
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<td>4.</td>
<td>Experience a caregiving partnership with physician and community agencies.</td>
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<td>5.**</td>
<td>Know how to enlist family members and others to help with caregiving.</td>
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<td>6.</td>
<td>Continue proactive planning for the future, including financial, legal, and care plans.</td>
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<td>7.**</td>
<td>Accept paid help with caregiving as needed, (e.g., aides, adult day care, respite services).</td>
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<td>8.</td>
<td>Use needed services, including skill training.</td>
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<td>9.</td>
<td>Begin grieving task without losing hope.</td>
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## Transition to Alternative Care Phase

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<th>Appropriate Materials*</th>
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</thead>
<tbody>
<tr>
<td>1.**</td>
<td>Know what alternative care options are available in the community.</td>
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<tr>
<td>2.</td>
<td>Explore care options before a crisis occurs.</td>
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<td>4.**</td>
<td>Discuss options with family.</td>
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<td>5.**</td>
<td>Know what kinds of financial assistance the patient may qualify for.</td>
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<td>6.**</td>
<td>Accept the need for alternative care, and feel positive about the process of selecting a provider.</td>
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<td>7.</td>
<td>Navigate the admission process, including knowing how to make the move easier for all.</td>
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<td>8.</td>
<td>Know how to create a new role for the family in collaboration with the care provider.</td>
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<td>9.</td>
<td>Acknowledge as a family that placement is a loss that will be associated with grief.</td>
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# Programs and Materials for People with Alzheimer’s Disease and Related Disorders

## End-of-Life Phase

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<th>Program(s)*</th>
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<th>Appropriate Materials*</th>
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<tbody>
<tr>
<td>1.**</td>
<td>Understand the end-stage process and physical care issues.</td>
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<td>2.**</td>
<td>Understand the key decisions that will have to be made by the family before an emergency.</td>
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<td>3.</td>
<td>Understand how to use any existing Advance Directives.</td>
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<td>4.</td>
<td>Understand methods of communication that may work well with the patient.</td>
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<td>5.**</td>
<td>Know how to access hospice care, if desired. Visit hospice programs if desired.</td>
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<td>6.</td>
<td>Feel a sense of peace about decisions that are made in this phase.</td>
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<td>7.</td>
<td>Know how to arrange an autopsy, if desired.</td>
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<tr>
<td>8.</td>
<td>Be aware of bereavement services available to the family after the patient’s death.</td>
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