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## Planning for Residential Dementia Care

In planning for the future needs of a loved one with dementia, family caregivers often avoid including a dementia-care residential option. Many people have a negative opinion of “nursing homes” and feel that this type of care cannot match their own standards of quality. Some feel that providing one-on-one care to their loved ones is their own obligation and feel guilty accepting help from professionals. Some have even made a promise to their loved ones of “never to put them in a nursing home.”

On the other hand, people affected with progressive dementia may reach a point in the disease requiring extensive 24/7 care. Late-stage dementia care includes complex medication and nutritional management, incontinence monitoring and dressing, cognitive and ambulatory enhancing activities, aspiration prevention, fall control, transferring and ambulation assistance. Family members who often have already spent years in monitoring and dedicated care may find the additional requirements of late-stage care overwhelming. The cumulative stress of caregiving may result in severe safety and health hazards for both patients and caregivers.

Families can extend the potential for advanced dementia care in the home by hiring professional in-home assistance. There are several in-home care agencies in our area specialized in dementia care and management that can greatly enhance the quality of care in the home and provide much needed respite to family members. Their services can be contracted on an as-needed basis and range from a few hours per week companion care to as much as 24/7 intensive



care. As dementia progresses, the level of required assistance rises, and so does the cost of professional in-home care.

Preparing for the day when it is no longer safe or financially possible to continue care in the home is an important part of a care plan. Knowing ahead of time who to contact, where to go and how much it costs will best ensure the patient’s safety, give you peace of mind and potentially save you a lot of money.

### Dementia Changes Everything

We now live 30 years longer than people in the early 1900s. Elderly care has changed much in the past four decades, and we have long abandoned the old concept of institutionalization. Retirement communities today are sought-after options for seniors.

However, when addressing the special needs of advanced dementia patients, most available retirement options are inappropriate.

Progressive dementia, such as in Alzheimer’s disease, are health conditions that require proper treatment and management. In many cases, the appropriate man-

agement can be best delivered in Residential Care Facilities for the Elderly (RCFEs), with special settings equipped to care for dementia patients.

RCFEs are not nursing homes or facilities that provide skilled nursing care. RCFEs are non-medical facilities that provide room, meals, housekeeping, supervision, storage and distribution of medication, and personal-care assistance with basic activities like hygiene, dressing, eating, bathing and transferring for residents 60 and older. Their services are not limited to dementia patients, but whenever offering dementia care, RCFEs must meet additional licensing requirements.

The best modern dementia care RCFEs are specially designed to provide a safe and soothing environment, where residents are attended to and monitored around the clock, but still have the feeling of being at home. Staff is trained to be personable, patient and alert to any signs of discomfort or distress. Activities are planned taking in consideration

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## Caregiver Tips

### Ways to ease the transition when moving to a dementia care facility:

-  Prepare in advance as much as possible.
-  Personalize your family member's room. Pictures, familiar objects and furniture will give a sense of continuity.
-  Give staff a list of likes and dislikes, as well as personal interests, history and achievements.
-  Attend care plan meetings.
-  Allow time for your loved one to build new relationships with staff and other residents.
-  Build relationships with staff.
-  After an initial adaptation period, join in facility activities with your family member.
-  Encourage family and friends to visit.
-  Acknowledge your own feelings and share your experience with others. Join a support group.

**Long-Term Care Ombudsman Services**  
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individual needs and strengths, promoting the preservation of basic independent skills and reducing health hazards. RCFEs are not required to have an in-house medical staff, but a medical team is often assisting and guiding the staff's activities.

These highly specialized homes also encourage family visits and participation, so residents continue to feel included and appreciated.

Although some dementia care settings may appear plain and dull to most healthy people, those affected with dementia thrive in them. Soon after placement, with proper attention and expert care, residents often get better, develop new friendships and experience contentment in their daily activities.

Every family caring for a loved one with dementia should take the time to study local options and identify the most appropriate dementia care residential facility. Even if you do not foresee placement in the near future, it will help you to better understand the complexities of dementia care and avoid getting caught in an emergency situation without a backup plan.

### Learn About Your Options

Here are some steps you can take to learn about local dementia care facilities:

- ◆ **Contact your local Alzheimer's Association** office for information on dementia care resources.
- ◆ **Consult a placement specialist in your area.** They can be extremely helpful in narrowing down available care facilities options to just the ones that fit your family's needs.
- ◆ **Not all facilities provide dementia care.** Make sure that the facility you are considering has experience in dementia and meets all of the state licensing standards to provide dementia care.
- ◆ **Consult the Long Term Care Ombudsman.** The local Ombudsman office keeps records of all citations RCFEs have received and other reports from licensing, so families can review the reports for any facilities they are considering. Also, ask for a RCFE checklist, which lists the things to look for when touring a facility.
- ◆ **Visit several homes and speak to the administrators.** The administrator is also the heart of the facility and sets the standards of care for the entire staff. Make sure you share the same values and adopt similar approaches of care.
- ◆ **Enquire about Hospice Waivers.** Some RCFEs have permission to care for people on hospice, which means residents will not have to move out as their condition worsens.

◆ **Enquire about costs.** Supplemental Security Income (SSI) has extremely limited funding for qualifying residents. Medicare and Medi-Cal will not cover residential dementia care costs. Most RCFEs are private pay only and will work with your long-term care insurance. Make sure you are informed of all incurring costs, assessment costs, additional care fees and non-returnable deposits. Ask for a written description of what the fees cover.

◆ **Enquire about staff ratios.** Because licensing does not stipulate a specific staff-to-resident ratio, numbers of qualified staff on the premises vary between RCFEs.

◆ **Enquire about activities.** Make sure the provided activities options are appropriate for the interest and cognitive levels of your loved one.

◆ **Join a support group.** Support groups are where families speak candidly about their ongoing experiences in caregiving and are a great source of current information about available services and resources.

◆ **Take your time to review admission agreements.** Before signing an agreement, read and study it carefully. An admission agreement is a legal contract and may vary widely from one facility to the next. Consider having the document reviewed by an attorney.

### Preparing Ahead of Time is the Key to Success

As you can expect, there are many considerations families need to ponder before they are ready to make an informed decision. Families that don't study their options in advance incur the likely risk that an unforeseen event precipitates the need for a quick placement. Such events may be a sudden change in the progression of the dementia, an unrelated but aggravating new health condition, a family emergency or a health-related condition affecting the closest caregiver.

When a quick placement becomes a necessity, families are constricted to limited placement options and may select a facility that does not fit the individual needs of the patient. Families are then forced to rethink their selection after a few weeks, facing additional financial losses and emotional distress.

The best time to educate yourself about residential dementia care is long before you need it. If you are caring for a loved one with dementia, make sure your long-term care plan includes the possibility for placement and you are informed about your options. This knowledge will give you power.

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### Helpful Resources:

**Booklet: What You Need to Know About Residential Care Facilities,** California Advocates for Nursing Home Reform, available at <http://www.canhr.org/index.html>