

# Guide for Choosing a Residential Care Community

## for Dementia Care



Ascension Living

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WE EMPOWER AND EDUCATE

Developed by Ascension Living,  
Alzheimer's Association Greater Missouri Chapter and  
VOYCE, the Long Term Care Ombudsman Program serving Greater St. Louis and Northeast Missouri



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# Forward

More and more families of those with dementia are facing the difficult decision of a move into a residential care community. To meet this growing need, Ascension Living, the Alzheimer’s Association Greater Missouri Chapter and VOYCE, The Long Term Care Ombudsman Program serving Greater St. Louis and Northeast Missouri, joined together to develop this dementia\* specific guide to help families understand the special home needs of those with dementia.

Families often do not know what kinds of specialized care community environments enhance the physical, emotional, intellectual and spiritual wellness of those living with dementia. Once their loved one becomes a resident, families may not know how best to assure that their loved one receives quality care, as well as a life of wellbeing.

How do I choose a residential care community (home) for someone with dementia? How can I effectively interact with my loved one when I visit? What can I do to help care for the person I love when they are living in a residential care community? How do I know if my loved one is receiving good care? How can I appropriately address any care concerns I may have? What are the rights of a person with dementia? How is my loved one’s life any better living in a residential care community? These are just a few of the questions that the Alzheimer’s Association and the Long Term Care Ombudsman Program deal with daily.

This guide is designed to help families through the process of selecting a residential care community (also referred to in this guide as a home) that has the right fit and to help them understand how to preserve the rights and dignity of someone with dementia and improve the quality of their loved one’s life when living in a residential care community.

It is our hope that this guide will help you to participate fully in the life of your loved one when they need to live in a residential care community.

*Ascension Living,  
Alzheimer’s Association Greater Missouri Chapter and  
VOYCE, the Long Term Care Ombudsman Program  
Serving Greater St. Louis and Northeast Missouri*

*(\*The word dementia, which will be used throughout the guide, includes Alzheimer’s disease as well as the many other different forms of dementia.)*



# When A Residential Care Community Is Needed

While you may feel that no one can provide care to your loved one as well as you can, try to look at the situation objectively. How can you continue to provide loving care when you are drained physically and emotionally, and you are faced with significant health and safety issues with your loved one?

There were days when her mother would seem fine and Mary Ann thought that she was taking a turn for the better--but she wasn't. She got worse. Mary Ann couldn't leave her mother alone, and the round-the-clock disruptions were taking its toll on her and her family. "I couldn't sleep at night, and I was exhausted. All I dreamt about was having just five minutes of peace. I was desperate. I knew that I needed help. But a home? How could I do that to my mother? I should be able to take care of her."

## Making the Decision

You may be overwhelmed by emotion by the enormity of the decision to have a loved one with dementia move into a residential care community. It's a decision you don't really want to make, but know that you must. You may experience self-blame by thinking that if you were really a good person you would try harder to provide care, or you may question if your decision was selfish. Then, there is the guilt. How could you remove someone you love from their home--someone who may not understand?

Dementia-specific environments that use a person-centered approach are proven to make a positive difference in the lives of those with dementia.





Exhibit A



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alz.org/greatermissouri

Guide for Home Placement

Use the following questions as a guide in determining when a move to a residential community may be appropriate. It may be necessary to evaluate the individual’s needs on a frequent and regular basis. Any sudden changes could mean potential health problems. Consult a physician for further evaluation.

One or more “Yes” answers in a category may indicate a need to change living arrangements.

Health/Safety Considerations

Is the individual:

- Uncooperative or combative?  

\_\_\_\_\_ Yes

\_\_\_\_\_ No
- No longer able to recognize family and/or their surroundings?  

\_\_\_\_\_ Yes

\_\_\_\_\_ No
- In need of personal care services that are too difficult or demanding for you physically, such as turning, lifting, bathing or toileting?  

\_\_\_\_\_ Yes

\_\_\_\_\_ No
- In need of special nursing services such as tube feeding or special skin care that you are unable to do and/or feel uncomfortable providing?  

\_\_\_\_\_ Yes

\_\_\_\_\_ No
- Regular disturbing the sleep of others by calling out, needing care or wandering at night?  

\_\_\_\_\_ Yes

\_\_\_\_\_ No
- Experiencing nutritional problems such as excessive weight loss or difficulty in swallowing or chewing?  

\_\_\_\_\_ Yes

\_\_\_\_\_ No
- Placing excessive needs on the primary caregiver and/or putting their own health at risk?  

\_\_\_\_\_ Yes

\_\_\_\_\_ No

- Living in a home that would require significant modifications to provide an adequate environment for the individual, such as wheelchair accessibility or an accessible bathroom?  
☐ Yes ☐ No
- Unable to continue with the help from a primary caregiver because he/she is no longer available and/or able to provide the necessary care?  
☐ Yes ☐ No
- Unable to continue receiving assistance from family and/or home health agencies/day care settings? Is the assistance no longer available or inadequate to ensure the safety and physical well-being of the individual?  
☐ Yes ☐ No

### Time and Energy

- Does the individual need someone to care for him/her at all times?  
☐ Yes ☐ No
- Must clothing or bed linens be changed and laundered so frequently that care becomes an excessive demand?  
☐ Yes ☐ No
- Do you have responsibilities for care of other family members that result in split loyalties or emotional overload?  
☐ Yes ☐ No

### Family Considerations

- Does the individual interfere with the running of the household?  
☐ Yes ☐ No
- Has the loss of privacy become a problem for the adult members of the household?  
☐ Yes ☐ No
- Is there excessive conflict with younger adults and teenagers because of the individual?  
☐ Yes ☐ No

# Selecting a Care Community for Someone with Dementia

When a loved one needs the 24-hour care provided by a residential care community, you will want to select one that will support their special needs, provide individualized care to enhance their lives and be committed to helping them through all of the stages of the disease as it progresses. You want to feel confident that your loved one with dementia is receiving the best care possible with or without your presence. This is not an easy task. Although the following information may seem overwhelming, it is important because it reflects the growing awareness among caregivers about what home environments work best for those with dementia. You may not be able to find everything described below in the communities you visit, but the items discussed can help guide you in evaluating the features in the homes you consider.

While all residential care communities have to meet government standards for providing needed care and protection for their residents and adhere to a basic set of “resident’s rights,” some provide better care than others. The staff to resident ratio will be different from place-to-place as well as the knowledge and training of the staff caring for persons with dementia, the nature of the activity programs and the types of environments where care is provided.

In an ideal world, you would have your choice of many outstanding homes that provide the special care needed for those with dementia and you would be able to spend as much time as you felt was needed in choosing that new home.

Many times, however, a move into residential care is made on an urgent basis when the already stressed caregivers face yet another stressful and difficult decision – deciding what will be best for their loved one without having time to do as much research as they would like. And depending on where you live, you may not have many choices.

## How to Begin

Start by calling your local chapters of the Alzheimer’s Association and VOYCE, who operates the local Long Term Care Ombudsman Program.

Staff at the Alzheimer’s Association can answer your questions about care communities that provide dementia specific care.

- Has the staff had special training in dementia and dealing with the challenges of those with Alzheimer’s disease or related dementias?
- Is it ongoing?

They can also help you through issues regarding transitioning your loved one into living in a residential care community and refer you to local support groups.

*(For more information about how the Alzheimer’s Association can help, please see the Appendix.)*

Staff at the Long Term Care Ombudsman Program can give you information about a particular residential care community. Has the Ombudsman received complaints about it? What were the nature of the complaints? What did the home do to correct the problems? They can also tell you if that community has an Ombudsman. Not all places do. While they are not allowed to recommend one community over another, they can refer you to websites to help you find survey information and provide some information about the care community’s complaint history. They can also answer questions you may have and give you general advice on what to look for when you visit various Assisted Living and Skilled Care communities.

*(For more information about how your Long Term Care Ombudsman can help, please see the Appendix.)*

# When You Visit

If possible, visit several communities before making a choice. And, if you can, visit more than once and at different times of the day and week. Ask questions. Don't be intimidated by the newness of the situation. Remember--you are interviewing them.

Use your intuition and your senses. How do you feel being there? Is the overall atmosphere comfortable? Does the home look and smell clean? Are the residents clean, dressed appropriately, and do they seem relaxed and content? Do the connections made between staff and residents and visitors seem warm, friendly and meaningful?

A friendly tour guide and the marketing brochure may not tell the entire story.

# Things to Look for That Will Support the Special Needs and Enhance the Lives of Those with Dementia

One goal of dementia care is to make it possible for the person with dementia to do as much as they can for as long as they can. Both the physical environment and the engagement of purposeful and meaningful activity can have long range benefits on the mental, physical and spiritual well-being of residents. Well-designed environments and programs can accommodate behaviors, maximize functional abilities, promote safety, encourage independence and enhance the quality of residents' lives.

Don't choose the home you would want for yourself – choose one that resembles your loved one's home and previous lifestyle. *(For instance, did their home have a cozy, lived-in look or a formal, elegant look?)*

# What are the dementia care policies and procedures of the home?

## Questions to Ask

- Do you have a mission statement that addresses the unique needs of persons with dementia? *(Ask to see a copy.)*
- What is your approach to dementia care? *(Providing simple directions, limiting choices and "cueing" are several answers to listen for to determine if the staff has an understanding and knowledge of the unique needs of persons with dementia.)*
- Do you adapt your care and services to fit the schedule the resident is accustomed to, or do you expect that person to adapt to yours?
- How do you work with challenging behaviors? *(What is their policy on using physical restraints to control movement and/or chemical/medical restraints to control behavior?)*
- How are adequate nutrition and hydration assured?
- What assistance is provided specifically for persons with dementia? *(Does the staff encourage residents*

*to do things independently such as feed and dress themselves, walk around and explore their living space, etc.?)*

- Do they provide a continuum of care for all stages of the disease, or will progression of the disease result in a need to move out of that care setting?
- What type of care is provided for persons with late-stage dementia?
- Does the care setting serve only persons with dementia, or is it a diverse population of elders living in one space? *(Think about which type of setting would be best for your loved one. Some would find a large area confusing, or they may be too disruptive to live in a diverse environment, or they may become isolated because they “can’t keep up with the others” living around them.)*
- How are changes of condition monitored and addressed? *(Examples include falls, injuries, illness and changes in behavior, nutritional intake and medications.)*
- How and when are families notified of care needs and changes? Are families invited to all care plan meetings, including ones required for change of status?
- How are issues and concerns resolved? *(Listen for the role the family plays in problem solving.)*
- How does the home encourage caregiver participation in their routine and programs? Are families encouraged to become part of their loved one’s lives within the community?

Purposeful and meaningful activities promote independence, maintain retained abilities and support resident functioning for as long as possible.

## Purposeful and Meaningful Activity

It is important for persons with dementia to engage in activities throughout the day that provide pleasure, trigger memories of familiar activities from their past and create a sense of usefulness. Activities should consist of more than just structured group activities. Does staff encourage “spontaneous activity?” Are staff allowed by the leadership to spend the time needed to engage residents in meaningful living? Are the activities provided in small groups so that each individual can become engaged?

Successful activity programming should be designed to encourage the person to utilize their existing abilities. However, emphasis is no longer placed on “being able to do something,” as it was in the past. Good activities focus on sensory cues that evoke past memories that make an elder feel good about themselves. It also encourages the residents to become involved in daily living that has meaning to them. Successful dementia-specific activity need to be done beyond “activity for activity’s sake.”

Activity programming helps residents with dementia express themselves in ways that still work for them. They don’t want to be reminded of what they can’t do. Meaningful activities have a purpose - the resident understands why he is doing them. Meaningful activities are not forced (the resident can say “no”) and are appropriate for the resident’s age and experience. They take advantage of what the resident can still do, promise success and make the resident feel good right away by giving just enough help for them to complete an activity successfully.

Letting staff know about past experiences of the resident can help them develop personalized activities.

Questions to Ask

- Is there a “life story” that is used to determine appropriate individualized activity throughout one’s lifetime? If not, are the families asked questions that will help staff determine appropriate activity?
- How do you individualize activities to meet the specific needs, interests and abilities of each individual?
- What opportunities are there to participate in familiar activities from the past, such as household work that is meaningful to the resident? *(For example, access to a kitchen area, a sewing machine, yard work tools, opportunities to set the table and fold laundry, etc.)*
- Does the individual have the opportunity to engage in meaningful activities involving music and other expressive arts that were important to them in their past? Is this provided individually and daily?
- Do activities range from small to larger groups?
- Do they offer varied activities for residents every day of the week and at night for those residents who are unable to sleep?

Some Things to Look For

- An activity schedule with regularly scheduled events throughout the day and evening *(Be aware that dementia specific programming is flexible and is not necessarily done according to specific times. A monthly calendar is not required in dementia specific programs. However, a daily list of activities that will be offered is required.)*
- Residents appearing to be engaged in and enjoying activities
- Residents sitting in small groups or clusters engaged in some type of stimulating activity rather than grouped around the nurse’s station not receiving any stimulation
- All elders need some alone time and a place to go that is free from noise. But, elders should not be sitting alone in their room for excessive amounts of time, unless it is their choice or is best for their individual well-being.
- Outdoor areas that are well-utilized.

It is the staff who put the “special” into dementia specialized care programs. Nothing can replace the person-to-person sensitivity of a dedicated staff caregiver.

Staffing

The quality of care provided to your loved one rests on the individuals providing that care. Be cautious of a “beautiful building.” It does NOT necessarily mean your loved one will receive better care. You will want the caregiver staff to not only be kind and friendly but also skilled and knowledgeable about how to care for someone with dementia. If you feel comfortable, talk to the caregiver staff when you visit. This can be very helpful. It is important to remember, however, that the staff you see today may not be there in a few weeks. Because the work is hard, it is difficult for residential care communities to attract and keep qualified staff, keeping care for your loved one consistent.

Questions to Ask

- What special training in dementia care does the staff receive?



- Who provides the training, and how often does it take place?
- What percentage of staff is full-time as opposed to agency (temporary) or “prn” (occasional- as needed) staff?
- How many residents are each of the direct care staff members responsible for? *(It is generally accepted that the more staff available to work with residents the higher the quality of care will be and the more individual attention your family member may receive. For optimal well-being, residents with dementia need more time from staff than residents in the general population in order to encourage using their current abilities and for enhancing their life engagement.)*
- Does the staffing plan allow for continuity of care by having the same staff members assigned to the same residents (called designated care staff--no use of “floaters”)?

While specific staff-to-resident ratios have not been established in many states, in 1987, the Office of Technology Assessment suggested 1:6 for specialized dementia programs. Based on focus groups conducted with experienced dementia caregiver staff, the ideal ratio was 1:5. Staff mentioned that a ratio of 1:7 was the maximum with experienced staff to provide good care, and a ratio of 1:8 was impossible. When you see an aide sitting and holding a resident’s hand that sends a strong message about the sensitivity of the care.

### Some Things to Look For

- Do staff members communicate with confused residents through talking, smiling and touching?
- Does the staff appear friendly towards you, residents, visitors and each other?
- Does the staff appear content (not unhappy or stressed)?

## Environment

The environment and layout of the home can do much to support persons with dementia by accommodating behaviors, maximizing functional abilities, creating opportunities for meaningful activities, promoting safety and encouraging independence of residents.

### Things to Look For:

- Places for visiting, things to do and see--both indoors and out--that foster conversation and interaction
- Personal recognizable memorabilia on the door or close to the doorway entrance to increase the resident’s ability to independently locate his/her room
- Clutter-free paths and walkways that encourage exploration and strolling and allow visual access to interest points such as activity rooms, a fish tank or a window
- Lighting throughout the living space, including the residents’ personal space, should be adequate to limit falls and discourage inappropriate behavior. Look around to see if there are dark shadows, shiny spots on the floor from sun glaring through the windows, strange designs created from sconces on the walls, etc. The lighting could be causing a problem.
- Comfortable places to sit and observe the activities around them, both indoors and outdoors
- Furniture groupings that encourage stopping and visiting with others. There should not be chairs in a straight line along a wall.

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- Workstations--both inside and outside--with interesting items to look at or hold
- An environment that promotes independence and helps the resident to know where they are and where they are going. *(Examples include cues in the environment that help individuals locate key areas, such as a picture of a toilet on the bathroom door; use of color or artwork to make the hallways look different.)*
- A quiet and pleasing atmosphere in the dining area, where staff are engaged in the dining experience with the elder
- Personal belongings decorating resident rooms
- Residents moving about freely in a safe area
- Pleasant smells
- An appropriate noise level that won't cause increased agitation *(e.g., overhead speakers, buzzers, televisions on regardless of anyone watching them)*
- Do confused residents have an adequate safe place to wander indoors?
- Do confused residents have an adequate, safe place to wander outdoors that is limited, such as an enclosed courtyard?
- Do confused residents have easy access to this outdoor space? *(In some facilities, residents can only go outdoors when accompanied by a staff member, which limits the time they can spend outdoors.)*

Indoor workstations might include things such as a hat rack with a variety of hats to try on, a desk with an assortment of magazines, catalogs, files and papers to look at and sort. An outdoor workstation might be a garden plot. These should be determined according to the interests of the residents within that living space.

#### Questions to Ask:

- What safety measures are in place for persons with dementia to provide a safe and secure environment that protects them from self-harm and harm from others, such as agitated residents? What are the policies on the use of medication for "behavior management?" Are alternative approaches used BEFORE medication is ordered? What is the understanding and implementation of best practices regarding the concept that "behavior is communication?"
- Does the community provide direct access to an outdoor space for people who are living in a dementia-specific area?
- Are all outdoor spaces constructed specifically to ensure safety as one is exploring the outdoor space for enjoyment?
- Are doors to the outside secure-fitted with alarms so residents can't wander outside unless it is to a safe area? Are exits placed appropriately so residents can go outside when they choose, even without direct supervision?
- Is registration in the Alzheimer's Association MedicAlert + Safe Return program encouraged?

The environment includes more than just the physical look of the setting. A safe environment is equally, if not more important, for persons with dementia.

MedicAlert + Safe Return is a national program of the Alzheimer’s Association that assists in the identification and safe, timely return of individuals with Alzheimer’s who wander and become lost. More information about the program and a partnering organization can be found at: <https://www.alz.org/care/dementia-medic-alert-safe-return.asp>.

## **The Home Looks Nice but How Do You Know It Provides Good Care?**

This is very hard to judge. You can’t pick a home based only on how nice the entrance is or how perky your tour guide was. You need to know how well they provide care. The physical appearance of the building, the activity schedule and the survey history are only pieces that tell a part of the story. Even if everything looks good at the time of one visit, the situation can change overnight--the ownership may change, or the staff may change.

A grand piano, silk flowers and a chandelier do not provide good care--people do.

At the end of your visit, ask to see the most recent state survey report. This report is very technical and detailed, but the main thing to keep in mind is that it details how the community did on its last survey, not how it is doing today. You may see all sorts of deficiencies on the report. While they are important to note, you’ll especially want to ask staff how they were corrected. This is called the “Plan of Correction.” If you have any unanswered questions or concerns about the report, call your local Long Term Care Ombudsman office.

Residential care communities can’t operate unless they are licensed by the state in which they are located, and they can’t receive Medicare or Medicaid funding unless they are certified as meeting federally mandated standards. These standards reflect beliefs about minimally acceptable standards of providing care.

The survey is meant to ensure that the facilities meet minimum federal and state requirements. It does not necessarily imply that residents are receiving quality care. In regards to staffing, state regulations require the community to go beyond the minimal requirements if care needs indicate a need for increased staffing.

A home can have a very good survey and still not provide warm, compassionate care.

When a Residential Care Community is Needed

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Another source of information is the Nursing Home Compare database at Medicare’s website: <https://www.medicare.gov/nursinghomecompare/search.html?> It gives you information about every Medicare- and Medicaid-certified skilled care home in the country and the results from their latest federal survey. You can search for homes by geographic area and then get side-by-side comparisons about such quality of care issues as weight loss, dehydration, skin breakdown, behavior problems and falls and fractures experienced by residents in a particular home. This is only for skilled care communities. Assisted Living communities are not regulated by CMS (Center for Medicare and Medicaid Services) because they are not funded with Medicare or Medicaid dollars.

The Nursing Home Compare website can also be used as a guide to talking to the staff about the quality of care being provided and help you monitor the care being provided to your loved one after they are living in the community.

This website does have some limitations. It may be hard to interpret because an overall rating isn’t provided; it doesn’t show the facility’s plan of correction, and it may not be up to date. The survey may be at least a year old, and conditions may have changed considerably for better or for worse since that time.

A goal for us all is to advocate for consumer satisfaction ratings.

The Pioneer Network is a group that promotes a culture of person-centered dementia care in long term care. For more information you may want to log onto <http://www.pioneernetwork.net>.





# What is Memory/Dementia Care?

Some homes have “Special Care Units” that provide environments and programs specifically designed to meet the needs of residents with dementia. New terminology is used to describe these specified areas as Dementia Care or Memory Care Neighborhoods. The goal of these neighborhoods is to enable people living with dementia to remain as independent and self-sufficient as possible while being in a protective environment with a specially trained staff. Typically, they are self-contained living spaces in existing homes with separate and enhanced dining and activity programs. These neighborhoods are usually secured by some kind of an alarm system. These spaces often have enclosed outdoor courtyards with circular paths to accommodate the tendency of those with dementia who want to walk and explore their surroundings without the need of supervision.

## Memory Care: How It Differs From Assisted Living

Memory care goes beyond what is traditionally offered in an assisted living setting. Housekeeping, laundry and meal preparation services are provided, as in Assisted Living, but the level of assistance with activities of daily living is increased. In a memory care community the daily activities are designed specially to help the individual to reconnect with favorite hobbies, interests and past memories.

Scheduled, structured activity, such as what is offered through activity programming in Assisted Living communities is often not very effective for those with fluctuating cognitive changes. In a memory care community, activities are initiated spontaneously to build on the strengths and current abilities of the individual.

Some memory care communities are stand-alone facilities. Or, in the case of a continuing care community, the memory care community may be a designated neighborhood of a long-term care community, designated solely for residents requiring memory care. Often, these communities incorporate design elements that research has shown to lower stress in individuals with Alzheimer’s or dementia. These elements include increased natural lighting and a circular neighborhood design that allows for the need for safe walking and browsing. Because an estimated six in 10 people with Alzheimer’s will explore their living space, memory care communities are designed to minimize the risk of elders leaving their neighborhood, whether employing quiet security alarms on doors or performing more frequent safety checks by staff.

Because research has shown that seniors with Alzheimer’s and dementia can become easily stressed and disoriented, memory care communities are designed to create a relaxing setting, and therefore, special features that may be available in an assisted living community, such as an ice cream parlor or indoor swimming pool, are purposefully not found.

Spaces are themed and used for specific reasons. Residents need to have the opportunity to live in different areas beyond the dining room!

Elders experiencing the progression of memory loss usually have reverted back to the experiences of their younger years, losing all reference to their most recent years. Therefore, all environmental and programming design in a Memory Care neighborhood must have purpose, meaning and provide a familiarity with residents’ younger years (mostly the years of their teens, 20s and early 30s), while focusing on the dignity and respect of individuals as adults.

Communities typically have a secured courtyard that allows residents the opportunity to walk outside or garden without the risk of leaving the building or getting lost. Many outdoor spaces provide opportunities to have family functions, including areas designed for visiting grandchildren.

Small indoor gathering places, such as a TV lounge or library, are also common features. To create a more intimate setting for residents, apartments may be clustered around shared common areas. Hallways lead back to common areas in order to assist individuals with way-finding.

Most memory care apartments now offer single bedrooms to provide private space and reduce anxiety of “a stranger” living in the person’s space. However, there might be some apartments that allow for companions to reside together, for those who become afraid to be alone. In companion spaces, the bedroom would be a private space, while a common area in the apartment can be designed for companion living.

Amenities are minimal—again, in the effort to reduce stress. To assist in wayfinding, memory care neighborhoods might provide a shelf or memory box filled with mementos from the resident’s life outside each apartment door or an identifying cue (such as a wreath with a name on the door). Apartments should have a clear, identifying apartment number on or next to the door. Hallways are designed with familiar “stop-and-look” decor to encourage memory stimulation.

Areas in the bathrooms (not named “spas”- elders of today do not recognize that term) should provide space for complete and comfortable individual bathing, dressing and washing hair (maybe a salon washing bowl) and applying makeup/jewelry ( such as a vanity with a chair and mirror).

Dining is designed as a social engagement activity--not merely as an activity of daily living, focusing on nutrition maintenance. Dining rooms typically feature family-style dining so residents can gather together for mealtimes, although all styles of dining are available to support an individual’s preferred way to dine. Providing appropriate finger foods throughout the day and evening (through resident-prepared themed activity and food carts) help support the individual’s need for constant “food grazing” to maintain weight while socializing.

Some dining rooms feature a tropical fish tank, as studies have shown that watching fish can increase appetites. Attention is placed on creating a contrast between the food’s color and the plate so residents can better see the food.

Activities are specially designed around a resident’s past lifestyle choices so residents may reconnect with their memories; expressive arts and normal daily home activities are usually offered, along with (updated) exercise classes and “walking clubs.” As research shows elders with dementia need sunshine and fresh air to reduce anxiety and improve cognition, memory care communities need to provide regular outings and outdoor activity. Many elders did volunteer work, so providing ways for individuals to continue their “charity work” is important. Meaningful connections to their community need to be explored and pursued. Activities are used as the way to create connections with others. Meaningful sensory cues throughout the neighborhood are a daily and constant necessity in developing appropriate life-engaging activity.

Specialized education for the staff is a must in order to provide a quiet home-like environment for people with dementia. Particular emphasis is needed in understanding behavior, such as triggers causing catastrophic reactions and emotions, and how to minimize over-stimulation to provide a quiet living environment.

Staffing needs to be consistent and must allow for the increased time to provide a calm, supportive environment. Appropriate staff-to-resident ratios are needed to avoid being rushed and to factor in the time needed to provide encouragement, as well as personal care support.

A memory care neighborhood is an ENHANCED environment and should contain MORE staff and individual, familiar, spontaneous, home-style meaningful activity programming than is typically offered in a traditional Assisted Living.



In some states, there are special regulations regarding “Special Care Units” that are detailed in a Special Care Unit Disclosure form, which defines the services that make them unique. Missouri and Illinois are mandated by the state regulations to have this disclosure. In other states, there are no special requirements, and these dedicated spaces just have to meet minimum state and/or federal standards. You can always request to see the disclosure if you are considering a secured dementia-specific neighborhood. (Although the language is changing to meet person-centered care best practices, the state still refers to these spaces as “special-care” units at this time.)

Because these neighborhoods are expected to have more staff who have been well trained in dementia care and have an enhanced environment that encourages people to be as independent and engaged in their lives as possible, you can expect them to be more expensive.

## Does My Loved One Need to be Placed in a “Dementia Specific Memory Care Neighborhood?”

An individual may need to live in a dedicated dementia-care neighborhood if his/her memory loss is causing difficulty in negotiating the environment and keeping the person from being able to structure their day independently. For individuals who have a need to wander (particularly in others’ rooms or out of the building) or those who are becoming isolated because of their inability to “keep up with others,” a specialized care neighborhood would be beneficial to their well-being, while accommodating these particular needs.

## Is it Really Specialized Care or Just a Space with a Lock?

Some homes may just offer an area that is secured with a locked door and call it a “Special Care Unit” or simply have it labeled as “Memory Care.” Don’t let looks deceive you. It is important that you learn what is “special” about this unit.

### What to Look For

- Can staff clearly state the benefits your relative or loved one will receive if they move in there?
- Ask what the criteria are for moving someone into the “special-care” living space.
- Is the most common diagnosis in the neighborhood Alzheimer’s disease and other dementias, or mental illness such as schizophrenia?
- Do other residents in this type of specialized neighborhood have capabilities similar to those of your loved one?
- Are there written guidelines that determine when residents would be moved in or out of this neighborhood? Ask for them.
- Does the specialized neighborhood include those who have late-stage dementia and/or a debilitating illness?
- Will changes in your loved one’s condition or abilities cause them to have to move out of the neighborhood? Ask for examples.
- Is the staffing ratio significantly higher in the dedicated neighborhood than in the rest of the community?
- Is staff training in dementia significantly greater than in other areas of the home? Ask to see what kind of training the staff has received.
- How do activities here differ from activities offered to residents in the rest of the community? Are they designed to meet the individual needs of the elders living there?

- Do staff other than scheduled activity staff provide activity opportunities? Do all staff seem to be engaged with the residents who are living there?
- Does the neighborhood have the ability to support all of the care needs of your loved one?
- Is the environment calm and pleasurable?
- Do the residents appear engaged and content or bored and lethargic?
- What are the practices for addressing disruptive or difficult behavior of residents? *(Some answers to listen for include finding out what is triggering the behavior, using distractions, props, snacks, walks or one-on-one conversations.)*

### Exhibit

#### Situation:

Ever since Mr. Anderson was transferred to a “Special Care Unit” due to his increasing dementia, his family has noticed that his behavior problems have increased. He’s very agitated and sometimes gets aggressive towards other residents and staff. When his family visits during the day, the staff seems very attentive. However, in the late afternoon and evening, residents are pretty much left to themselves to stare at the TV in the living room.

#### Discussion:

People with dementia have a need to work out their physical and psychological energy. Activities are a positive way to channel these energies. However, even good residential care facilities sometimes forget that residents with dementia need activities throughout the day and evening, during normal waking hours--not just during the day shift. Not providing appropriate activities for these residents is a way of neglecting their need for stimulation. Families need to discuss this with staff and the administrator and insist that activities be available throughout the entire day for residents and that staff be educated about their importance and be scheduled so that the activities can occur. Families can help the facility by volunteering their time to provide these activities.



# The Move-In Process

You have found a home, filled out the application and they have a place for your loved one to live. Now, you are faced with a very trying time for both you and your family member – the move-in process. There is a great deal of paper work to fill out. There are forms to read, things to do and consider and some difficult feelings to experience and manage.

First, recognize that this will be a big adjustment for your loved one. It is not uncommon for people living with dementia to have difficulty getting used to a new environment. It could take weeks for your loved one to become familiar with and comfortable in his/her new living space. It is possible that you might see an increase in anxiety and frustration. So, be patient, and understand that the adjustment may come in small steps.

The following are some suggestions that may help ease the transition to a home for both of you.

## Getting Prepared for Move-In Day

- Share information about the new home and the upcoming move based on the person’s ability to handle stress and understand what is happening.
- Involve the person (*when appropriate*) with things such as packing to help make them feel more in control.
- Visit the home with your family member (*if possible*) to see the room, meet their potential roommate and have a meal there together.
- Ask what personal possessions, such as a favorite chair and loved memorabilia, can be taken to the home and take as many important things as possible.
- Select washable, durable clothing that is easy to get on and off like pants you can pull on. Avoid buttons.
- Label all clothing (*including shoes*) with a permanent laundry marker. (*State regulations require that labeling not be visible when clothing is worn.*) Label all other possessions, including furniture, books, pictures, and glasses. Inventory what you bring.
- Involve another family member or friend to accompany you on move-in day. If at all possible, don’t do this alone.
- Ask whether your loved one’s doctor will make visits to the home. If not, select a physician who will visit the community or arrange for the care community doctor to see them.
- Have your family member’s insurance cards and social security card ready to take with you on move-in day. Also, have copies of any Durable Power of Attorney for Health Care or Living Wills (Advance Directives) so they can be placed in the medical chart and in the family member’s file in the business office. Keep the originals yourself.

### Will My Loved One's Advance Directives Be Honored?

Before moving in, show a copy of the Advance Directives, and make your wishes and your family member's wishes clear to the person who is working with you on the move-in process. Ask if it will be honored. You don't want to wait until the time comes when it needs to be active and find out that it will not be honored by the home. If your family member is to be cared for by the staff doctor, make a phone call as soon as possible to discuss Advance Directives, and inquire about the doctor's history of honoring them.

- Ask if the home will allow you to move your loved one's possessions before your family member moves in so you can have furniture arranged, pictures hung and clothing unpacked before you arrive. Arrange the room as close to the previous room arrangement as possible so the space will feel a little more familiar. Bring the familiar bedding, curtains, etc. if possible. Don't purchase new items for the room until your loved one becomes familiar with his/her new space.

### Life Story

Information about a person's life – their Life Story – honors their uniqueness. It lets staff know what is special about them – their social history, likes, dislikes or interests and important life routines. The Life Story can help the staff begin to develop a relationship with new residents by helping them find ways to communicate with them and honor their uniqueness. It can take on many forms: a biographical sketch, scrapbook, collage or memory box.

- You may want to type a biographical sketch (Life Story) to give to staff and also hang inside the closet of your loved one's new room to help the staff get to know them and their routines.
- Consider bringing a photo album or making a memory scrapbook, collage or box to further help the staff to get to know more about your loved one and to give you and your loved one the pleasure of viewing treasured memories.

### The Life Story Album

"When my mother was in a home, I made her a collage of pictures of our family with the names of each person below their picture and their relationship to my mother. I feel that this collage was very helpful to my mom and the staff. My mother would look at the pictures in between our visits and it helped her to remember who we all were. It was also an easy reference for the staff because they could tell at a glance what relation each of us was to my mother. Also, sometimes when I visited, my mom and I would look at the pictures and share stories about each person that we would point out on the collage."

"My mother would look at the pages of the scrapbook every day. When I visited, we would go through the book together and tell stories about the things the pictures reminded us of. I even found one of the nursing assistants sitting next to my mother sharing my mother's 'Life Story' album. It warmed my heart."

# What to Tell Your Loved One About the Move--There Are No Simple Answers

- “The doctor says we both need some rest and help. We are going to a place that can provide that.”
- “We are going someplace special where you will get care. I’ll continue to care for you, too.”
- “I’m not happy about this, but we are going to try out a home for you.”
- “I’m doing the best I can for both of us and I love you, but I need some help. So we are going to try another living arrangement.”

There are no simple answers or “perfect” explanations for this difficult journey. Provide only as much honest, yet neutral, information as the person can absorb. Try to remain calm and non-defensive. Be aware of the feelings your loved one is expressing, and validate the feelings. This is more important than telling information.

## Move-in Paperwork

Signing the papers usually takes at least several hours. Many people don’t allow enough time for the move-in process and, overwhelmed by all of the paperwork involved, begin signing papers without reading them just so they can get finished.

Don’t feel pressure to sign anything immediately. You have the right to set the pace for the meeting so that you have time to read and understand what you are signing.

If you do not have a Durable Power of Attorney for Health Care or Guardianship, ask for all the papers your family member will have to sign. Read through these to see if you have any questions and so you can provide guidance to your family member, if needed, before they sign any forms.

When there are papers for you to sign you will be asked to sign as either the “responsible party” or as “agent.” Ask for a definition of these terms before deciding how you will sign.

Do not leave without a copy of everything you signed. Also, get copies of important documents such as the billing policy and the “bed hold” policy.

The “bed hold” policy will tell you if the home will hold a space for your family member while he or she is in the hospital at no charge, or whether the home expects you to pay for the time your family member is in the hospital at a full or reduced rate.

Because the daily rate usually does not include all charges, you will want to know what is included in the rate and what extra charges to expect.

Read everything carefully. Take time to process the information. If there is something you are not sure of, ask questions.

## Move-in Day

- Plan to spend part of the day with your loved one.
- On the day of move-in, check with the home about a preferred time for moving, and try to match your relative’s “best” time of day with their schedule. Many families find bringing their family member in midmorning, before lunch, helps with the initial adjustment. This also gives you time to fill out the



paperwork, see the new room and tour the building with your family member before they start a structured activity such as lunch. After mealtime is a good time to leave your family member to get adjusted to the routine of their new home. Try to avoid coming during a change in shift when staff may be too hurried to talk in depth with you. *(Shift changes in many homes occur at 7 a.m., 3 p.m. and 11 p.m.)*

- Tell the person where you are going if they can understand.
- When arriving, meet staff members and learn as many names as you can.
- Tell the staff stories about your loved one, and tell them about their routines: bathing/shower schedule, bedtimes, waking times, coping styles, stresses, significant others and roles in the family. *(Decision-maker, loner, socially active, passive, leader, what makes them happy or sad, favorite foods, favorite colors, activities they enjoy, nicknames, occupation(s), personality and behavior patterns. Any behavior pattern you noticed at home will very likely occur in their new home.)*
- This is the time to give the staff the “Life Story” form, if you have not already provided it. If you have given the life story to someone before moving in, be sure that the staff caring for your loved one has received it.

If the home does not have a resident handbook, ask to see their policies and procedures.

- Ask the home to mark dentures.
- Don’t leave money, expensive jewelry or other valued items that other confused residents might be attracted to.
- Monitor how your presence is affecting your family member.
- The nursing staff or friend you brought along may be helpful to you at this point.
- Take a tour of the home with your loved one if possible.

Every day at 5 p.m., Mary got agitated and screamed, “Where’s John?” She was looking for her husband who used to come home from work then. Because the staff knew this, they were able to distract Mary during times such as this or reminisce about John and married life.

### **Educate the staff about the resident.**

Educating staff about your loved one is an ongoing process. Educate them little by little during and after move-in in positive ways.



# What to Tell Your Loved One About Where They Are

It’s generally not necessary to lie to your loved one and tell them they are in a hospital or hotel. It might be easier for you, but that will only increase their confusion. The family member will expect to go home in a few days and will get upset and angry when staff tells him or her that the place you left them is their new home. The adjustment process will go faster and more smoothly if you sit with your family member in their new room and explain this is their new residence or a place where they can always get help and care. Remember to validate their feelings rather than try to change the way they feel.

## How Long to Stay

Use your own judgment about when it’s time to go. Consider how your presence is affecting your family member. Is it a calming influence or a source of agitation? Parting will be difficult no matter how long you stay. Prepare yourself for how wrenchingly painful it will be if you hear your loved one cry, “I want to go home,” or “Don’t leave me.” You may want to consider saying things like, “They’ve prepared a meal for you. Stay for a while.” Or, the staff may offer a distraction to your loved one, like an activity, to make it easier for you to leave.

## Adjusting to the Separation

There will be some difficult days and nights ahead. It takes time for residents, family and staff to adjust to one another and to the resident’s new life in a home.

After the move, your loved one may become more confused and agitated and be at a higher risk for falls. This should pass as they adjust to the new environment. Also, the emotional turmoil and your feelings of guilt will usually lessen over time as you and your loved one become used to the new home, the staff and the routines.

“I wasn’t prepared for how hard the separation would be. When I left my mother in the home, my insides were in knots. I couldn’t drive. I just sat in my car and wept.”

## Dealing With Feelings About Moving a Loved One Into a Residential Care Community

This will be a very emotional time--a time of grieving for the loved one you feel you are losing. Allow yourself and your loved one ample time to adjust to the move and know that a certain amount of sorrow is involved with this decision and that you may experience a range of chaotic feelings. The adjustment will possibly take longer than you would think.

Friends, faith communities, professionals and support groups may be of help to you at this time.

When you are no longer required to provide the constant care that has overwhelmed your every waking moment, you may experience feelings of loss, grief and anxiety about your changing role. There will be a hole in your life because you aren’t busy doing what you used to do. And, you may have conflicting emotions. You may grieve and at the same time feel relieved that someone else is helping you provide care for your loved one. And, you may be anxious about or overly critical about the care staff provide or overlook.

Remember – Your caregiver role does not stop at the door to the home. You are still your loved one’s caregiver--it’s just that the nature of your daily responsibilities has changed. Someone else is now providing round-the-clock care. You are their historian, communicator and bridge to the staff.

Don’t let these feelings undermine your focus-the compassionate care of your loved one.

To fill this empty space, move forward by defining a new caregiver role for yourself – an expanded role where you find ways to support and help staff in caring for your loved one and become your loved one’s advocate to make sure their needs are met.

## **Family Involvement is a Key Component of Compassionate Dementia Care**

Those with dementia especially benefit from a family-centered approach to care where family members continue to have a vital role in the resident’s care. Being involved in the life of the home brings you into closer contact with the caregiver staff who have now become a part of your loved one’s “extended family.”

Ask about and attend care plan meetings so the staff will know you want to be involved. Help the staff get to know your loved one. You are an ongoing source of information about your loved one’s life, times and personal experience. And, help the staff figure out ways to connect with your loved one to assure the best possible personalized care.

## **Volunteer**

Consider volunteering to help with home activities-reading to residents, calling bingo and helping with the craft program or the afternoon social. By volunteering you will meet other family members, residents and staff. These kinds of activities can help you cope with the difficult feelings associated with moving a loved one into their new home. Also, when there is a concrete task or commitment associated with visiting, the visit is often easier, and you may be inclined to visit more often.

## **Things to Do For Yourself after the Move-in**

- It’s important that you take care of yourself. Not taking care of yourself can snowball and negatively affect you, your family, your relationship with the home and your ability to participate in your loved one’s care.
- Find support from friends, family and by attending an organized support group.
- Remember, realistically, what events forced you to make this decision.

Make yourself a priority--it isn’t selfish. If you neglect yourself you may become incapable of being there for those you love.

- Realize that this was the best choice under the circumstances and accept it. Ask other family members and friends to share positive thoughts about the move with the person and with you.
- Think of the advantages the move will provide to you. With your loved one in a home, you now have help and assurance that your loved one is receiving care when you’re not able to be there.

- Think about the advantages the move may provide to your loved one. Some residents with dementia look and feel better with the structured, predictable routines and abilities-oriented program offered by a good home. There is 24-hour supervision, meals are balanced, family can share caregiver responsibilities with the staff, staff may be better at coping with some behaviors, and there are social and recreational opportunities. Your relationships may improve since you are no longer exhausted by the demands of caregiving. In fact, relieved of the pressure of daily caregiving, you may find it's easier to be with and do things with and for your loved one.
- Think about your new role and determine how you want to stay involved in your loved one's care (visit at meals, attend religious services together, participate in activities together or volunteer at the home).
- Do things that you enjoy. Live in the moment. Create moments of joy. Massage, long baths or lunch with a friend has worked for others.
- Rest.



# Know Your Loved One’s Rights To Care And Treatment In A Home

## The Right to Individualized (Person-Centered) Care

A federal law known as the Nursing Home Reform Act requires that communities participating in either the Medicare or the Medicaid program “provide services and activities to attain or maintain the highest practicable physical, mental and psychosocial well-being of each resident in accordance with a written plan of care.” (*Residents don’t have to have their care paid for by Medicare or Medicaid to get the protections of the law.*)

Although assisted living communities do not receive Medicaid funding, they are still required by state regulations for licensure to provide individualized care that focuses on a person’s abilities and choices to ensure their highest level of well-being.

Individuals, including those with dementia, do not lose basic rights as citizens when they enter a home. Instead, they gain additional rights related to being in the home. Further, residents with dementia are protected from discrimination by their caregivers under the Americans with Disabilities Act and other federal civil rights laws.

There may be times when you have to speak up and let the home know you know your loved one’s rights.

## The Right To Make Decisions

Elders living in residential care communities have a right to make their own decisions--even “bad” ones--unless deemed mentally incompetent to do so or they have made legal arrangements (*guardianship*) for someone else to make those decisions.

### Forced Treatment

If an aide tells a resident, “You have to take a bath,” and the resident says “no,” the aide has to stop. If the aide persists, even though they may have been well meaning, the aide is ignoring the resident’s right to refuse. And, by forcing the resident, they may accidentally injure the resident. They will be expected to make other attempts, maybe using a different approach, to eventually provide the needed care. But, no means “**no**,” even for people living with dementia.

## Advance Directives

Advance Directives protect the resident’s right to accept or refuse medical care if they are physically or mentally unable to choose or communicate their wishes. There are two types of Advance Directives. One or both may be used.

- **Living Will** – A written document that tells others what kind of life-sustaining treatment your loved one wants or does not want when death is imminent.



- **Durable Power of Attorney for Health Care (DPA)** – Names a person (an agent) your loved one wishes to make health care decisions when they can no longer speak for themselves.

Guardianship is a legal proceeding where, based upon medical evidence, a court finds that a person is legally incompetent (in the case of dementia because of cognitive impairment) and unable to make decisions relating to his or her care and management of assets. Some costs are involved. Once an individual is found incompetent, the court appoints a guardian to make care decisions for him or her. With that said, a guardian can make executive decisions. But an elder can still make decisions, based on capacity, for day-to-day choices.

Because laws vary from state to state, it is important that you obtain legal advice and services from an attorney who practices in the area of elder law to find out how to implement these processes and learn what your powers are.

*The Alzheimer's Association can provide you with referrals to legal services. Please call (800) 272-3900.*

People often assume that since they have been married for years they have the legal authority to speak on behalf of their spouse when their spouse becomes incompetent. That is not true. You must have a Durable Power of Attorney (DPA) for Health Care or Guardianship.

### Exhibit

#### Situation:

"I feel that my mother and the home staff had difficulty understanding Durable Power of Attorney (DPA) for Health Care. My father gave me that power instead of my mother because he knew that she was under a tremendous amount of stress dealing with his dementia, and he didn't want her to bear the responsibility for his medical decisions. My mother visited him every day, so the home staff was more familiar with her and always honored her verbal wishes over my legally documented ones. The best example that I can give is that of physical restraints. I was adamant that restraints not be used on my dad and had expressed this to the home staff promptly upon move-in. While my mom was visiting one day, he slid out of his chair and onto the floor. My mom told the nurse that she wanted a vest restraint used on dad so he wouldn't fall out of the chair again, and the restraint was immediately placed on him."

#### Discussion:

First you need to make sure your DPA is in effect. There are different versions of this document and in some, your father would have to be declared incompetent before it goes into effect. Then, you need to see if the document actually specifies "no restraints." Having DPA does not mean that you can make every decision. You can only make those specified in the document. Once you have clarified what authority the document gives you, show a copy of it to the Director of Nursing and Administrator and tell them that you expect them to honor your request. If this does not work, you will need an attorney to tell them they must comply with your legal rights.

# Make Their Decisions – Not Your Decisions

If your loved one did not provide a living will or DPA and his or her condition has deteriorated to a degree that it is no longer possible for him or her to participate in the decision-making process, you need to make decisions in a manner that respects the intentions of your loved one as much as possible as you understand them.

## The Right to a Thorough Assessment

You and your loved one have the right to participate in the thorough assessment, which homes must make of every new resident’s needs and abilities within one to two weeks of move-in.

The staff must consider what activities give him or her pleasure, comfort, a sense of creativity and feelings of success.

The assessment is very broad. It includes medical status and needs, cognitive abilities, conduct such as wandering or aggression, physical strengths and weaknesses, and nutritional needs including eating habits, preferences and special diet requirements. The assessment also describes customary routines in daily life, such as preferred times for rising, eating, bathing and going to bed. It records how your loved one related to others, his or her past interests and things that make him or her happy. For individuals with dementia, this personal history and profile are essential to helping the staff understand your loved one so a personalized plan of care can be developed. In many communities this is referred to as a “Life Story.”

While residents with dementia should participate in the assessment as much as possible, families can provide information that the person with dementia may have forgotten or is unable to communicate to the staff. In addition to providing a detailed history, family members can help the home by describing approaches that work best to manage behaviors.

For someone with Alzheimer’s disease, strengths, preferences and needs will change as the illness progresses. Whenever your loved one experiences a significant change in his or her health, ability to care for themselves, their mood or behavior, the staff must reassess their needs and abilities. A change in mood or behavior, for example, might indicate the presence of a health problem, such as a urinary tract infection. After the information in the assessment is analyzed, a care plan is developed.

If you see a significant change, you should ask for a new assessment if the staff has not undertaken one on its own.

## The Right to Participate in the Plan of Care

The care your loved one receives in the home is based on a care plan in which you and your loved one have a right to participate.

The plan is a written description of the strategies the staff will use to help a resident reach specific care goals, such as helping them maintain their current level of functioning. It is very specific and clinical and includes objectives for the person (*e.g., Mrs. Davis will maintain a weight of 110-115 pounds*), and methods of achieving that goal (*e.g., Mrs. Davis will be served at least two foods she likes at each meal*).



The overall objective of the plan is to help your loved one to function physically, mentally and emotionally as best as they can by building on their strengths and preferences.

The plan is prepared using information from the assessment, from your loved ones, your own and other family members’ ideas about what they want and what care they need, and from observations and ideas of various staff members. It is prepared by staff whose skills and services are most necessary to meet their needs, including the physician and nurse responsible for them. For residents with dementia, social services staff and the activities director will also be involved in writing the care plan.

The home must provide services identified in the care plan such as activities, social services, nursing, therapies, special diets, pharmacy, and physician’s services. Your loved one has the right to refuse any treatment or approaches included in the care plan, and the staff must then try alternative solutions to the problem the treatment was intended to address.

Because the abilities and needs of the person with dementia change throughout the disease process at a rate and in a way that are highly individual to that person, it is essential that care planning be an ongoing, evolving process that is responsive to changes in condition and is focused on current needs. *(Encourage the home to include the staff that know your loved one best in the care planning.)*

Family members can play an important role in helping the home know who the person now living with them is.

**What Are Care Plan Meetings**

At a care plan meeting, staff, residents and families talk about life in the home--meals, activities, therapies, personal schedules, medical and nursing care, and emotional needs. All staff who work with the resident should be involved--nurses, nursing assistants, activities, dietitian, social services, and occupational and physical therapists. Ideally, families are to be invited to the care plan meeting. You will need to be vigilant to assure this occurs.

**When Are Care Plan Meetings Held**

In communities participating in Medicare or Medicaid, care plan meetings are conducted within three weeks of move-in, within seven days of a new assessment, every three months to see if the plan is working and if any changes are needed, when there is a major change in a resident’s physical or mental health that might require a change in care, or whenever the resident or family requests one. If your loved one is living in an assisted living community, care plans are required within seven days of move-in, every six months, and if there is a significant change in your loved one’s needs. If you feel your loved one’s care plan is not being followed, or is not working, or that your loved one’s needs have changed and require a new care plan, you can request a care plan meeting.

Prepare for the meeting by thinking about your concerns and what outcomes your loved one and you would like to have occur. Write these down. While you have a right to take as much time as you need during the meeting and ask any questions you have and then request changes that might make the plan more effective, be considerate of staff time constraints. Families also have a right to call their local Ombudsman office to request that an Ombudsman be at the meeting. *(The number of your local Long Term Care Ombudsmen should be displayed in the facility.)*

# What Is Discussed During the Meeting

This is a time when you can bring up any concerns that you have with the care and to communicate wishes and needs to the staff. For example, if your mother has been going to Bingo and you know she doesn't like it, let the staff know. "Mom doesn't like Bingo. She likes to play cards. Please make sure that she has an opportunity to play cards each week." At the same time, be open to the staff's observations about any of your loved one's changing interests.

If there are any problems and concerns, it is a time for group problem solving. Even if your loved one has dementia, involve him or her in the planning to the extent possible. Always assume she or he can understand and communicate at some level.

You may request a copy of the care plan for your records. Review it regularly so you can see how it is being followed. If it is not being followed to your satisfaction be persistent about your concerns. Request outside consultation from an Ombudsman if necessary.

# The Right to be Free of Restraints

Your loved one has a right to receive care without use of either physical restraints or chemical restraints (*drugs*) that are not needed to treat their medical condition.

Physical restraints are devices or equipment that restrict movement and that the individual cannot easily remove. Drugs may become chemical restraints when they are used inappropriately for staff convenience. Ask the nurse, physician or pharmacist questions about medications that are being used and whether they are necessary for treatment.

Before placement in a home you should ask what the restraint policy is. Some homes may tell you it is against the law to restrain. Although the regulations are moving away from allowing the use of any restraints in residential care communities, the use of restraint is still legal in very special situations. Many communities have written policies against the use of any physical and/or chemical restraint. It may be the community's policy not to restrain, but it is not the law. However, the law is very strict about when a resident can be restrained. For example, a resident can't be restrained because they wander too much and the staff can't keep track of them, because they won't sit still long enough for the staff to get them to eat or because they won't stay in bed, or because the person is at risk of falling.

In order to legally restrain a resident there has to be a medical condition requiring restraints with a doctor's order, and then the resident is monitored very closely throughout the duration of the restraint period.

Restraints can cause falls, incontinence, loss of muscle tone, pressure sores, loss of ability to move independently causing depression, decreased appetite and a "breaking of one's spirit" because of the loss of their control of their wishes. Staff has an obligation to try alternatives to restraints, such as diversions for aggressive behavior or safe places to wander. Even if restraints may be needed to treat a specific medical condition, staff must talk to your loved one and you about alternatives before using them. Restraints cannot be used without a physician's order and without your loved one's consent. If they are unable to consent, staff must consult with you or another family member with authority to make decisions for him or her.

### An Example of Restraint-Free Care

People with dementia often spend hours walking in a seemingly aimless manner, making home staff fearful for their safety (especially if they “wander” outside the home.) By law, the staff is prohibited from tying such individuals down with vest restraints in wheelchairs to prevent their wandering. Instead, the home must have a safe place for such individuals to move around independently; staff must be trained in the care of people with dementia; and they must try to determine the cause or risks of the individual’s movement and design care alternatives. A woman trying to leave the home early in the morning might be remembering an earlier life pattern of going off to her job in a floral shop. Staff can redirect her energy by setting up a place for her to work with flowers and plants and make sure it is available for her early in the morning.

## The Right to File Grievances

There may be times when you believe the home is not giving your loved one the care they need or is not paying attention to their preferences and wishes. If you feel you can’t solve the problem informally by problem solving with the staff, you have the right to file a formal grievance.

The home must have a procedure for you and your loved one to express such grievances and must act promptly to resolve them. It is important that you know what that procedure is. The procedure should be in your move-in packet. If you do not find it there, contact social services or the administrator for a copy.

The home must allow your loved one and you to talk to the state or local home Ombudsman. This is a person whose job it is to speak up for residents and to support residents and family members in speaking up for themselves. The home must give you the Ombudsman’s telephone number.

Remember: At any time, you have the option of calling your local Ombudsman office for assistance.

It must also allow your loved one, yourself and other family members to participate in *resident and family councils*, in private space with staff present only if you want them to be.

Routine participation in councils is a good way to keep abreast of the goings on at the care community. Moreover, the councils provide a channel to present grievances to the home. Working together with other residents and their family members may feel safer and more comfortable to you than filing a grievance by yourself.

If these methods of solving problems do not work, you may call the state agency that regulates care communities. That agency must investigate your complaint. The Ombudsman can help tell your story to the complaint investigator. Informing the state agency when things are not going right for your loved one can solve problems for them, as well as making regulators aware that others in the home may be having the same problem.

The home must make available the name, address, and telephone number of the state agency that regulates the home. The home must also provide your loved one (although not you) with a private area to use a telephone.

## The Right to Protection against Transfer or Eviction

Care Communities may ask residents to either leave the home (discharge them), or move somewhere else within the community. In the case of those with dementia, they may want to move these individuals into a dementia-specific location if they believe it would be of benefit to them. Alternatively, they may ask individuals to leave these dementia-specific locations when staff determines the individual no longer benefits from the program.

Your loved one's legal rights differ according to whether the proposed move is within the community where he/she is currently living or to another home. There are informal steps you can take in both cases. Ask for a new assessment and a care plan meeting. If something is serious enough for the community to want your loved one to move, they most likely have experienced a physical or mental change that warrants attention. These situations rarely occur suddenly. So, in most cases you should be aware of the evolving situation. If necessary, seek help from the family council or Ombudsman.

But what if you do not want your loved one to leave their living space? By understanding how the move-out process works, you will be in a better position to make educated decisions about your loved one's rights and how to act on those rights. (The move-out process only applies if the resident has been in the home for 30 days.)

Once a home has decided to move your loved one out, they must send a notice that details its reasons and what your loved one can do if he or she doesn't want to leave.

When you receive the notice, you must decide if you want to appeal the decision or if you would rather move to a home in a new location. If you choose to move, you can move your loved one to the location stated in the letter, or you can find another home you would prefer.

When your loved one is being asked to move to a different home, he or she has the following rights:

- **The home can only ask them to leave if:**
  1. The home cannot meet their needs,
  2. Their health has improved so they no longer need the home's services,
  3. The safety of others in the home is endangered,
  4. The health of others in the home would be endangered if they stayed,
  5. Payment is not being made on their behalf to the home, either by themselves or family; or by Medicare or Medicaid; or the home is closing.
- **The home must send a move-out notice that includes the following:**
  1. It must be a 30-day prior written notice,
  2. It must state the reason for the need to move out,
  3. It must have the effective date,
  4. There must be a location stating where the resident is going to be moved (It is the responsibility of the home, not the family, to find a replacement.),
  5. Information on your right to a hearing to appeal and question the home about the decision to have your loved one move out

6. How to ask for the hearing and how soon they must do so with the name and address where the appeal should be mailed; the name, address and number of your local Regional Ombudsman Program; and of advocacy organizations that can help prepare for the hearing, and
7. There should be a line saying that if you wish to appeal the decision you will be allowed to stay in the home until the appeal has been heard.

If the letter doesn't include all the above, it is not valid and should be returned to the home requesting the correct information with a new date.

- **The hearing is called a “fair hearing,” and the person judging the case will be an employee of the state, not the home.**
- **At the hearing, the home must show that its reasons for wanting your loved one to leave are valid. You or someone else, including an attorney, can ask questions and present information on behalf of your loved one. You may want to present information about what services are necessary to meet your loved one's needs and how the home can best care for them.**
- **If the hearing decision says your loved one must leave the home, the home has to give them time to move and must help to ensure that the move is safe and orderly.**

If the move is within the home--to a different room or location in the home--your loved one must be notified. Although they may not have a right to a hearing (in some states they do), they can ask not to be moved.

Your loved one's physician may be able to state that a move will be harmful, especially if he or she orients themselves by people or places that are particular to their own floor or room. Asserting these positions may have some bearing on the decision to move them.

## **The Right to Be Free From Abuse**

Those with Alzheimer's disease and related dementias are at special risk of being neglected and/or abused due to memory and language impairments and physical limitations.

Both the Alzheimer's Association and the Long Term Care Ombudsman Program offer training for care community staff on ways to avoid situations that might trigger neglect or abuse.

Persons with cognitive losses are among those most frequently abused and or neglected in a care community setting.

While not the norm, neglect and abuse can occur in many forms in care communities. Some general categories are: failure on the part of the home to provide the treatment, care, goods and services necessary to care for the resident; failure to carry out the physician's plan of treatment; failure to report changes in a resident's health; failure to meet the physical needs of the resident, such as bathing and toileting; and failure to protect residents against abusive behavior from staff, other residents or visitors.

Specific types of abusive behavior include: physical abuse, misuse of restraints, verbal/emotional abuse, physical neglect, medical neglect, verbal/emotional neglect, and theft or misuse of personal property.

Abuse that occurs in a care community is often not detected or reported. Residents may not report abuse because they feel they are at the mercy of the health care staff and are afraid of retribution. Or, if they are suffering from Alzheimer's disease or other forms of dementia they may be unaware that they are being abused, or they may be too confused to report it. And, family members may not report suspected abuse



because they may not feel sure their suspicions are justified, or they may not know how or to whom to report it, or they may worry that a loved one will be treated badly if they cause any “trouble.”

**When You Suspect Elder Abuse**

If any abuse is suspected, do not be afraid to ask questions, to investigate it, and, if the answers are unsatisfactory, to report it. Contact your local Long Term Care Ombudsmen Program, the Adult Protective Service Agency, the state licensing agency, or call the Eldercare Locator for a referral to the appropriate agency in the community to report the suspected abuse.

*A List of Resident Rights can be found in the Appendix.*

**Families Have Rights Too**

Families have a right to be involved in the resident’s assessment and to attend the care plan meeting.

The family has a right and should be notified within 24 hours of any accident involving the resident; any significant change in the physical or mental needs of the resident; of the need to change medical treatment of the resident; if there is a decision to move the resident and the reason for this action; of a change in room or roommate; and/or any change in resident rights.

Family members and legal guardians have the right to privacy when visiting. They also have a right to meet with the families of other residents and to join or address family councils in an area provided by the home. The home must designate a staff person who is responsible for acting upon grievances and/or recommendations of the family council.

**Families Have a Right to Access the Residents Inventory List, to Add or Delete Property Brought Into or Removed From the Home.**

Immediate family members have a right to unlimited access to the resident in a Medicaid/Medicare bed no matter what time of day or whether or not it is during posted visiting hours as long as the resident agrees to see them.

Families have a right to a copy of the bed hold policy after a resident has entered the home.

*(Note: A written copy of this policy must be provided within 24 hours of the resident being transferred to the hospital from the home. This only applies to those residents in a Medicaid bed.)*

# Visiting

Visiting a loved one in a home can be very difficult. In some places, the institutional environment may make you feel like a foreigner in a strange land. Visiting someone with dementia can sadden or frustrate you, depending on the response of your loved one and your own expectations. Visiting can be particularly painful if your loved one no longer remembers you and rarely understands the things you say.

It is important to realize and accept that your loved one and your relationship with your loved one may no longer be the same as in the past. You will need to give up that relationship and reestablish a new one. Enjoy the moments when meaningful communication or interaction occur. Enjoy and love who they are today. Continue to make loving connections that evoke emotional responses rather than trying to relay information.

## Things You May See When Visiting

When visiting a dementia-specific area of the home, be prepared for the unexpected: Spitting, repetitive actions, wandering, cursing, shouting, hyper-sexuality, and physical aggression. You may also find another person with dementia in your loved one's room who may not remember where their room is. They may even be wearing your loved one's clothes because they may not know which clothes belong to them.

Having an objective can help you gain your bearings. One way to do this is to think about how your loved one seems to be responding to the care plan. If an objective of the care plan was to help him or her maintain their weight, and they are losing weight, visit at meal times so you can see if they appear to be enjoying the meal. If you have any concerns, plan to talk with the care staff.

When you are with your loved one, you want that time to be meaningful and enjoyable--even joyful--for both of you, but you may feel unsure about what to say and do. The following are some things that may help:

- Look beyond the limitations of your loved one to see the person inside. Remember there is more to a person than their memory or ability to do things.
- Keep things simple. Don't overwhelm the person with too many activities or too many people.
- Try to limit distractions and excess noise in the environment by finding a quiet place to spend time together. There are often underutilized areas in the home.
- Remember, your loved one may respond differently each time you visit. This is part of the disease process and not anything you said or did. Live in the moment.
- Be flexible. You may need to do different activities each time you visit. What worked well one day may not work the same way on another day.
- If your loved one becomes angry or upset with you, don't take it personally. When a person is having an unpleasant reaction to something, they may be trying to communicate a need.
- Don't overreact. Keep a sense of humor and respond in ways that are not overly serious.
- Don't try to make your loved one understand. This usually results in an argument resulting in bad feelings for you and your loved one.

# Suggestions for Positive Communication With Your Loved One

Try to always approach them from the front and smile. Greet them by name. Introduce yourself and give them a hug and a warm hello. Establish and maintain eye contact at a face-to-face level. Speak in a low-pitched, soft voice. Give brief, one-step directions and break down tasks. Give your loved one enough time to respond to questions or directions. Don't rush them. Offer comfort, reassurance and understanding. Praise successes and emphasize the positive. Use nonverbal communication including nods, smiles, pats, gestures and props. Use familiar words. Remain calm and reassuring even if your loved one becomes agitated. Don't become impatient or force them to talk. Take a break and try again in a few minutes. Use good emotional memories and sensual cues to stimulate connections with your loved one during a visit.

The Alzheimer's Association can help with ideas for enjoyable visits.

## Activity Suggestions

When you are visiting, think about activities that have meaning for your loved one and use their senses. Be creative.

### Music is Magical

- Find music that your loved one used to enjoy and play it during your visit.
- Use music to bring about discussion of memories.
- Music can also make your loved one want to move or dance. Encourage them as long as it is safe.
- Encourage singing and sing-alongs if your loved one liked that kind of activity in their past. Don't worry if you or your loved one "can't sing."
- Remember, not everyone likes music! Be sure your loved one is NOT included in music entertainment/sing-alongs if this group activity is disturbing to them.

### Touch is Healing

- Give your loved one a hand massage with a lotion scented with a smell they like. *(This is a chance to hold their hand, look into their eyes and convey your love and care.)*
- Scratch their back. People usually love having their back scratched. They may even want to scratch your back too!
- Rub their shoulders to relieve tension and encourage relaxation.
- Brush, comb or style their hair.
- Pamper them with a manicure.
- Give them hugs.

## Vision is Stimulating

- Bring mementos to show and discuss.
- Look at magazines that have lots of colorful pictures.
- Try drawing or painting together.
- Have a grandchild bring or send along artwork or school papers.
- Bring a video to enjoy together.

## Reminiscing Triggers Memories

- Use props like hats, fabrics or mementos.
- Remind your loved one of fond memories of the past, such as a job that they loved, a special family event or a time with a beloved pet.
- Bring in family photos and talk about them.

At some stages of the disease reminiscing can be painful. When the person with dementia looks at pictures of people they no longer remember or hear stories they don't recognize, they may feel very alone and afraid.

## Spirituality Inspires and Touches Their Inner Being

- Read from the Bible or other religious books that are familiar to your loved one.
- Play or sing spiritual music/songs.
- Celebrate religious traditions together.
- Involve your loved one in something that gave them spiritual comfort (*e.g. sitting outside in nature, smelling flowers, hearing beautiful poetry, hearing moving and inspirational music beyond religious music, petting an animal, etc.*)

## From the Heart

- Don't worry that your loved one won't remember what you said--say it anyway! Be sincere and honest.
- Thank your loved one for something they have said to you or they did for you in the past and tell them how much it meant to you.
- Tell your loved one about how they have inspired you, either because of something they did in the past or are doing now.
- Share your love for that person and how much they mean to you.
- Bring your loved one a small gift--something you know that they will enjoy (*e.g., a small plant or flowers, perfume, a stuffed animal to hug or a food item that they love to eat.*)
- Give the person a personal inspirational card or quote that has significance or gives them hope.
- Listen to your loved one. Really listen and empathize with them. You don't always have to try to fix them or make them all better.
- Honor the feelings they have at the moment. Reassure them. If they say, "I'm afraid," tell them, "It's okay to be afraid. I'm here to help you."
- Laugh with them. Have fun. Be playful.

# Frequency of Visits

## “How often should I visit?”

This is a personal choice but, you must use good judgment when making this decision. Your loved one isn’t going to benefit from you being there 8-10 hours a day when it wears you out and leaves you with a multitude of unfinished business. It doesn’t help you or your loved one if your family is suffering because you aren’t there for them. Don’t try to be at the community every waking moment. Visit your loved one and spend quality time with them, and then let the staff do their job. Some families say that their loved one can’t adjust and that is why they are always there. In fact, the resident will never have the opportunity to adjust until the family leaves and gives them the chance. It’s not the length of the visit that is important. What is important is to try to make the visit meaningful. Shorter, frequent visits are usually best. And, try to visit during a week day when the staff who spend the most time with your loved one are there so you have an opportunity to interact with them and receive feedback about how your loved one is doing.





# Monitoring The Care

Your involvement, at the beginning and throughout your loved one’s stay, may be the single most important factor in assuring that they receive quality care.

To monitor the care your loved one is receiving, visit the home often and at different times of the day. Let the staff know if you think anything is needed, and ask them what they need to best help your loved one. Be alert for any signs of mistreatment.

It’s especially important to be involved in dementia care because your loved one may not be able to self-advocate or report neglect or abuse.

## Neglect

Neglect is the most common way elders are mistreated. Neglect may not be intentional. A poorly trained, but caring aide may not know how to provide proper care. For example, the inability to recognize depression and other signs of physical and mental health can cause a host of untreated problems.

Some common examples of neglect, adapted from The National Citizens Coalition for Nursing Home Reform (NCCNHR) website, include:

- Incorrect body positioning (not moving or turning the resident can lead to limb contractures (shortened muscles) and pressure sores)
- No range of motion exercises or physical therapy (can lead to limb contractures)
- Lack of toileting or changing of disposable briefs (can result in incontinence, discomfort, loss of dignity and skin breakdown)
- Lack of assistance in eating and drinking (can lead to malnutrition and dehydration)
- Lack of assistance with walking (can lead to loss of mobility)
- Lack of bathing (can lead to indignity and poor hygiene)
- Lack of assistance in participating in activities of interest (can lead to withdrawal and isolation)
- Failure to help residents dress and groom themselves (can lead to indignity and sloppy appearance)
- No encouragement to retain independence (can lead to increased dependency and to loss of ability to eat, dress, walk, bathe, and get in and out of bed)
- Use of feeding tubes strictly for staff convenience when they aren’t needed
- Ignoring call bells or cries for help

## Exhibit

### Toileting:

Mrs. Jones has been diagnosed with Alzheimer's disease and several other medical problems. She has been a resident of Shady Oak Care Community for over a year. She isn't totally incontinent but she needs for staff to know her bowel and bladder routine to insure that she doesn't have accidents. If she goes to the bathroom within 30 minutes of eating, she is fine. If staff don't assist her to the toilet in that time frame, she almost always soils herself. Lately, the family has found Mrs. Jones with soiled underwear when they visit in the early evening.

### Discussion:

There are many medical conditions that can contribute to bowel and bladder problems with older people. People with dementia may not always have a sense of time or the ability to know when they need to be taken to the bathroom. The family should discuss this with the nursing staff and the attending physician. Simply doing a "scheduled two-hour change" may not address your loved one's individual needs. The staff needs to be educated about why this is so important to both the mental and physical health of Mrs. Jones. And the family must continue to monitor the situation to assure that unnecessary accidents do not occur; when staff doesn't pay attention to residents' individual needs, it is neglect.

## Inadequate Home Care

A 2003 study\*, *"Dementia Care in Assisted Living and Nursing Homes,"* funded and shaped by the Alzheimer's Association found that people with Alzheimer's disease and related dementias were experiencing the following:

- 54% had low food intake.
- 51 % had low fluid intake.
- 40% with recognized pain received no pain medication.
- 27% were experiencing depression, and of those, only 28% were receiving professional treatment.

## How Do You Know if Your Loved One Is Receiving Good Care

### Things to Look For:

- Do the daily activities in which your loved one engages relate to activities that have given meaning in the past?
- Does your loved one's 24-hour schedule in the home adapt to their desired or agreed upon schedule, based on past lifestyle choices?
- Does staff interact with residents through body language and tone of voice in a warm, non-threatening way?
- When you visit, does your loved one seem to feel at home-are they relaxed, free of anxiety or quietly content?

- Is there any evidence of pain or discomfort? (They tell you they hurt, show rigidity in body, make loud vocalizations or pace.)
- Does your loved have unexplained bruises, cuts, bedsores, torn or damaged skin or deformed joints?
- Does your loved one smell clean and are their fingernails clean? (If their nails are clean, they are most likely getting a bath.)
- Is their ability to function declining rapidly?

## Declines in Functioning

What if you think your loved one's abilities are declining? Before you get upset with the care at the home, you need to understand what is realistic for your loved one to accomplish, and you need to consider that the decline might be due to a progression of the disease, the onset of a new disease or condition or a decision to choose to refuse treatment.

Collect the facts before you react.

So you can realistically assess your loved one's situation, it is important to stay informed about how the disease progresses through the Alzheimer's Association, the home's social worker or other staff.

## Nutrition and Dehydration

Lack of proper nutrition and dehydration are serious problems for older adults who may have diminished thirst and altered taste due to disease or medication. Those with dementia are particularly susceptible to inadequate nutritional intake and dehydration because they may forget to eat or drink, may not be able to access water, may be unable to eat by themselves, may not recognize food or may be unable to interpret their own feelings of hunger or thirst. These problems worsen as the disease progresses.

### Things to Look For:

- Have they lost weight?
- Do they have interest in food? Can they recognize it?
- Can they use eating utensils?
- Are they experiencing swallowing or choking difficulties?
- Does there seem to be enough staff to assist each resident who requires help with eating? (*Visit at meal times so you can observe.*)
- Is mealtime pleasant or hectic?
- Does the staff interact with the residents during meals in an encouraging way?
- Is there a water pitcher and glass on the table in each room, and are they filled regularly?
- Does staff encourage residents to eat or drink if they are not able to do so?
- Are residents given time to eat all that they want or does staff take away their food because of their own time constraints?
- Are there adequate snacks of substance/satisfying drink offered throughout the day?

## Exhibit

**Dehydration:** is a red flag signaling that the resident may not be receiving attentive care.

Recently, Mr. Lane's family noticed that he seemed more confused and very weak. When they visited, he often asked for a drink of water. The family also noticed that the water pitcher next to his bed was often empty or missing from the room.

### Discussion:

Mr. Lane has some classic symptoms of dehydration. Homes are required to provide proper hydration since lack of water can cause serious problems for people. Lack of access to water is a clear form of neglect.

*Sometimes staff will collect water pitchers for cleaning but don't return them to the bedside. Other times, staff will not put water in the pitchers, or will move the pitchers or glass out of the reach of a resident so that the resident doesn't need to be assisted to the bathroom so often. And, some staff just don't understand the reasons why water is so important. The family should bring this to the attention of nursing supervisors and continually monitor the water intake of their father and check to see if his skin, mouth and eyes look as moist as they should. They should also encourage drinking fluids when they visit.*

*In many instances, elders with Alzheimer's disease cannot pour themselves water from a bedside water pitcher. If this kind of access to water is insufficient for consumption, be sure to address a different approach in the care plan.*

## Recognizing Fear, Pain or Physical Discomfort from Illnesses or Medications

Those with dementia, especially in the later stages of the disease, often have difficulty communicating their fear, pain or discomfort. However, there are some ways to recognize distress.

### Things to Look For:

- Physical signs such as a pale or flushed skin tone, dry or pale gums, mouth sores, vomiting, constipation, feverish skin, or swelling of any part of the body can indicate illness.
- Nonverbal signs and body language such as gestures, vocalizations, holding their stomach and facial expressions (*e.g., wincing*) may indicate pain or discomfort.
- Changes in behavior or abrupt changes in mood such as anxiety, restlessness, agitation, shouting, and sleep disturbances can all indicate pain or physical discomfort.
- Signs of depression such as crying, lack of interest in surroundings, withdrawal, unreasonable anger, loss of appetite and weight loss, a change in sleep patterns, seeming less alert, or repetitive questions or complaints.

# An Increase in Difficult Behaviors

If your loved one is displaying an increase in difficult behaviors it may be due to progression of the disease, environmental factors or staff approaches. These could include over stimulation-loud noises or a too busy environment, activities or chores that are too complicated and difficult for them to complete, feeling frustrated because they are unable to communicate effectively; medications; or they may be feeling alone and frightened.

Talk with the staff to try to determine what events (triggers) may have led up to the uncomfortable behaviors and how these might be prevented in the future. Working together, try to find ways to respond that soothe the resident.

Because of the changing nature of dementia, responses that worked in the past may not work in the present. New ideas are needed continually.

Be aware if staff are providing “behavior management drugs” as a first approach rather than finding other reasons for the behaviors. Behavior is a sign of the individual trying to communicate something they cannot voice.

When care concerns arise, share your concerns with the staff and ask them how they plan to help your loved one. Ask how you can help or support them in their efforts. Then watch for signs that the staff is doing what they said they would do, and look to see if there is an improvement.

# Long-Distance Care Giving

Long distance care giving for someone with dementia can be especially difficult. You may feel guilty because you can’t be there to support your loved one and you may have concerns about the care they are receiving and difficulty getting accurate information.

# There Are Some Things You Can Do

- Maintain regular communication with the care staff and visitors.
  - Agree on a time when you can call the appropriate staff, or the physician to get updates on your loved one’s condition and progress.
  - Call family, friends or members of his or her church and ask them to visit and let you know about the care your loved one appears to be receiving and how they are doing.
- Stay in touch with your loved one through telephone calls, cards or letters. Is staff reading mail to your loved one, and your loved one’s life-story to help them learn more about the person for whom they are caring?
- When you are able to visit, arrange to meet with the staff members who provide most of the care for your loved one.



# Staff and Family Communication

Family members and care community staff often have difficulties communicating because they have differing expectations and perspectives about caring for the resident. They may also possess different types of knowledge about dementia care.

## Unrealistic Expectations

Families need to have realistic expectations about the care that can be provided in a home and about how the progression of the disease will affect the abilities and behaviors of their loved one with dementia. It is possible for your loved one to have very good care and still experience the downward spiral of decline in ability to think and function.

Families understandably are most concerned about staff’s attentiveness to their loved one and often forget that the home is a legally regulated environment with many rules and regulations. The staff has to take care of residents with many medical problems requiring complex care.

Some typical family concerns are dissatisfaction with their loved one’s personal care and appearance, laundry and lost clothing, meals, toileting, and attentiveness to resident’s needs. Family members also voice concern that their loved one is bored and there is a lack of meaningful activities.

## Walk In Their Shoes

Staff caregivers are given a list of tasks that need to be completed before their shift ends and can find it difficult to complete the required work because providing good care for someone with dementia is time consuming, requires creativity and is difficult work.

Be considerate of the time it takes to care for your loved one. However, it is the responsibility of the home to provide enough staff to take care of the needs of the elders in their care. If staffing always appears to be inadequate you will want to discuss it with the administrator, the Ombudsman, or report it to the state regulatory agency.

Residents With Cognitive And Physical Disabilities:

- May exhibit unpredictable behaviors and act in ways that are frustrating, stressful or offensive to staff.
- May be combative. *(Physical aggression often occurs while workers are providing personal care such as bathing. With a proper approach, this should not occur.)*
- May not be able to complete tasks such as eating or dressing without assistance.
- May resist or strike out or not respond to caregivers at all.
- May not respond in the same way to techniques used in the past to address their behaviors.

Additionally, staff may not be adequately trained; and they may feel helpless and sad when they see the residents they have become attached to deteriorate no matter what they do.

## Working Closely With Staff

Because your loved one needs both your support and that of the staff to get the best care in a home it is important for families to work closely with staff.

Good communication-the cornerstone for developing a working relationship with the staff-can help bridge this gap. Let staff know your concerns and let them know the person behind the dementia-the person you love-so they are better able to work with and support them. Get to know the staff and try to understand the work involved in a home and what the day is like for them. Just as you want the staff to treat your loved one as an individual, you should try to treat the staff as individuals too. Be respectful and friendly. Smile when you greet them. Listen to them, and consider their feelings. Let them know that you understand how difficult their job can be. Get to know them on more of a personal basis. Find out what days they'll be working with your loved one and what their likes and dislikes are. And, show sincere appreciation for the care they provide.

## Problem Solving With The Staff

When you problem solve with the staff you need to strike a balance between advocating for your loved one and supporting those who are responsible for their care.

"I wish I had known what I know now when I placed my mother in a home years ago. Back then I was very aggressive when something went wrong and I deeply regret this. I think that there are times when it is necessary to be assertive, but the way to insure the best care for your loved one is to gently approach the individual that you have the problem with and problem solve together."

## Act-Don't React

Don't let anger build. Try to address your concerns as they occur. People with dementia often have difficulty remembering what is done for them. All resident complaints and accusations should be addressed to avoid misunderstandings. Instead of reacting angrily if your loved one says, "No one fed me," ask the staff person responsible when your loved one ate and what they ate. Gather the facts. If it is an everyday care issue that you think can be solved internally, express your concern to those directly involved in the person's care. For instance, if you have a problem with housekeeping, talk with the person who was involved and work with them to find a solution.

## Problem Solving With the Staff Person

- Identify the issue and describe it briefly and accurately.
- Make the conversation factual, not emotional.
- Try to separate the facts of the situation from your hurt, anger or guilt.
- Confirm that he or she heard you and understood what you said.
- Avoid blame. Believe in 'best intentions' unless proven otherwise.(Workers may become defensive.)
- See problems as mutual concerns.
- Listen. Don't let it become a one-way conversation-your way. Find out his or her point of view, needs and concerns.
- Work with the employee to solve the issue. Try to arrive at a win/win result, where neither side feels they've completely failed.

- Make sure the worker has personal information about your loved one so they can get to know them better and better understand their habits, routines and needs. And, share any concerns you have about your loved one, as well as constructive suggestions, with them.

## Problem Solving for Prevention

- If the issue is solved to your satisfaction, express your appreciation and then ask the worker what the two of you can do to make sure it doesn't happen again.
- If the issue isn't solved to your satisfaction, contact a Department Manager or the Administrator.

Keep a written list of department managers so you know the names of people to ask for when you have an issue.

## Problem Solving with Department Managers

- Locate the manager of the department that the issue is related to, i.e., nursing, food, laundry, maintenance activities.
- Present the facts to the manager. You may need an appointment for non-urgent matters so the manager can give full attention to the issue.
- Let the manager know you are angry or hurt but are willing to help with a solution to the issue.
- Document the agreed upon solution with the manager with a follow up letter.
- Ask the manager to offer training to the employees on solving the issue.
- Offer to talk with employees educationally about what families need from staff.

## For Unresolved Issues

If the situation is not resolved, or if there is a repeated pattern of inadequate care, meet with the administrator. Then, if the resolution is unsatisfactory, follow the facility's grievance procedure or contact the Long Term Care Ombudsman Program.

# In Conclusion

When someone you love is living with dementia and needs care in a care community, you can improve the quality of their life by participating in their care.

- Take care of yourself so you can care for those you love.
- Select a home that provides a dementia supportive environment and programming and well trained staff.
- Involve yourself in the life of the home.
- Visit often and at different times of the day.
- Know the resident’s rights and your rights as a family member.
- Know the home’s grievance procedure.
- Learn the home’s policies and procedures.
- Educate the staff about your loved one.
- Develop realistic expectations about your loved one by learning about the progression of the disease.
- Take an active part in monitoring the care of your loved one.
- Participate in assessment and care planning.
- Nurture a positive working relationship with staff.
- Problem solve with the staff.
- Show appreciation to the staff.
- Get involved with the family council.
- Know the Ombudsman’s phone number.
- Contact the Alzheimer’s Association and utilize their professional services.
- Report abuse, neglect, and infringement of Resident Rights.

# Resources And Support

**Ascension Living** (Catholic-sponsored health care organization that operates senior living, assisted living, long-term care communities and PACE programs across the United States)

<https://ascensionliving.org>

1-314-729-3500

**Alzheimer’s Association**

[www.alz.org](http://www.alz.org)

1-800-272-3900

**Alzheimer’s Association, Greater Missouri Chapter**

[www.alz.org/greatermissouri](http://www.alz.org/greatermissouri)

24-Hour Helpline

1-800-272-3900

**Alzheimer’s Special Care Services Disclosure Form**

Missouri Department of Regulation and Licensure

Section for Long-Term Care Regulation

<https://health.mo.gov/seniors/nursinghomes/pdf/580-2637.pdf>

**Checklist for Home Placement**

<https://www.medicare.gov/NursingHomeCompare/checklist.pdf>

**Eldercare Locator**

1-800-677-1116

Monday-Friday, 9 a.m. to 8 p.m. ET

**National Center on Elder Abuse (NCEA)**

<https://ncea.acl.gov>

1-202- 898-2586 or 1-855-500-3537

**The National Consumer Voice for Quality Long-Term Care** (This website includes contact information for all state long-term care ombudsmen and information about home care)

[www.theconsumervoice.org](http://www.theconsumervoice.org)

1-202-332-2275

**National Long Term Care Ombudsman Resource Center (ORC)**

<http://ltcombudsman.org>

1-202-332-2275

**Medicare - Home Compare**

1-800-MEDICARE (1-800-633-4227)

[www.medicare.gov/nursinghomecompare](http://www.medicare.gov/nursinghomecompare)

**Pioneer Network**

[www.PioneerNetwork.net](http://www.PioneerNetwork.net)

**VOYCE** (operates the Long Term Care Ombudsman Program in Greater St. Louis and Northeast Missouri)

[www.voycestl.org](http://www.voycestl.org)

1-314-918-8222

1-866-918-8222



# Appendix

## What is the Alzheimer's Association?

The Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support and research. For more than three decades, it has been the premier source of information and support for millions of Americans with Alzheimer's disease; the largest private funder of Alzheimer research; and the strongest national voice representing the interests of those affected by the disease.

The Association's vision is to create a world without Alzheimer's disease while optimizing quality of life for individuals and their families. Their mission is to eliminate Alzheimer's disease through the advancement of research and to enhance care and support for individuals, their families, and caregivers. The national headquarters is located at 225 North Michigan Avenue, Chicago, Illinois, 60601, and chapters and service centers are located nationwide.

## How can the Alzheimer's Association help me?

The Association offers a broad range of programs and services for people with the disease, their families, and caregivers. These services include a toll-free 24/7 Helpline, support groups, educational seminars, advocacy programs, and a variety of print and on-line resources on the disease, care giving approaches, and current research. Call the 24/7 Helpline at 800-272-3900 or send an email to [info@alz.org](mailto:info@alz.org). Contact your local chapter for information about programs, support groups, and other services in your area.

## What is Alzheimer's disease?

Alzheimer's is the most common form of dementia, a group of disorders in which progressive destruction of brain cells leads to increasingly severe decline in memory, thinking, and reasoning. Millions of Americans suffer from Alzheimer's disease. Symptoms typically begin with difficulty remembering new information, then progress to greater and greater disruption in memory, reasoning, judgment, and personality. Affected individuals gradually lose the ability to perform customary daily activities and self-care, becoming bedridden in the final stages of the disease. The ability to communicate may become significantly compromised.

It is important to understand that although a person's ability to think clearly is affected, that person's ability to feel and tap into long term memory is usually intact, all the way to the end of life.

## What is an Ombudsman?

An ombudsman is an individual who assists residents in residential care communities and their families by:

- Communicating regularly with residents;
- Listening to resident and family concerns;
- Establishing a relationship of trust with residents;
- Keeping all information confidential;
- Encouraging residents to speak for themselves;
- Seeking to resolve problems within the community; and
- Helping to educate and protect residents and families regarding resident rights.

## Who can use the Ombudsman service?

- Residents of any residential care community;
- Friends and relatives of persons who live in residential care communities;
- Residential care community staff members and administrators with resident-related concerns;
- Individuals and families who are considering a move into a Residential care community as an option;
- The community-at-large; and
- Other groups concerned about the welfare of residents in residential care communities.

## When should you use the Ombudsman?

- To report a problem or concern;
- To seek information about residential care communities;
- Residential care communities' services or standards;
- Medicaid coverage;
- Resident rights; or
- Transfer/ Move out procedures.

## Long Term Care Ombudsman Program Goals

- Resolve resident complaints by involving concerned parties;
- Inform residents of their rights as established by law;
- Provide information on resident needs and concerns to their families and to the community;
- Advocate on behalf of residents for changes in laws, regulations and policies to improve long-term care services.

To find an ombudsman near you contact The National Long Term Care Ombudsman Resource Center (ORC) at [www.ltombudsman.org](http://www.ltombudsman.org) or 1-202- 332-2275; to find an ombudsman in Greater St. Louis and Northeast Missouri contact VOYCE [www.voycestl.org](http://www.voycestl.org) 314-918-8222 or 1-866-918-8222

## Resident Rights

As a resident in a residential care community you have the right to a dignified existence and to exercise your rights as a resident without fear of interference, coercion or reprisal. You have the right to:

### Participate in Your Care

- Choose your own doctor.
- Be informed of your care and treatment and any changes.
- Be invited to your care plan meeting.
- Refuse treatment.

### Choices

- Make choices about your life that are important to you.

### **Accommodation of Your Needs**

- Receive services based on your individual needs and preferences.
- Be notified prior to a room change.

### **Be Free from Abuse and Restraint**

- No chemical or physical restraints without a doctor's order.
- Only for a set period of time.
- Must treat a medical symptom.
- Be free from verbal, sexual, physical, and mental abuse.
- Must be protected from mistreatment, neglect or abuse.

### **Manage Your Financial Affairs**

- Must give written permission to hold your personal money.
- No one can spend your money without your permission.
- Receive a financial report quarterly and upon request

### **Be Fully Informed**

- About your rights and rules related to your stay.
- See your records on request.
- Facility survey report available at all times.

### **Privacy**

- For your treatment, telephone calls, visits, mail, resident meetings and all records.

### **Access to Visitors**

- Receive or deny visitors.
- Family may visit 24 hours a day, however, it is best if the family visit at "reasonable hours" so that neither residents or staff are unduly disturbed.

### **Remain in the Care Community**

- Asked to leave only for your own health, safety and welfare or that of others or for non-payment.
- Must be given a written, 30-day notice and you may appeal.
- When hospitalized, you must be given the home's written bed-hold policy.
- Must let you return to the first available bed if you choose not to pay bed-hold.

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## **Our Mission**

Rooted in the loving ministry of Jesus as healer, we commit ourselves to serving all persons with special attention to those who are poor and vulnerable. Our Catholic health ministry is dedicated to spiritually centered, holistic care which sustains and improves the health of individuals and communities. We are advocates for a compassionate and just society through our actions and our words.

## **Our Values**

- Service of the Poor - generosity of spirit, especially for persons most in need
  - Reverence - respect and compassion for the dignity and diversity of life
    - Integrity - inspiring trust through personal leadership
      - Wisdom - Integrating excellence and stewardship
        - Creativity - courageous innovation
- Dedication - affirming the hope and joy of our ministry