

Our Mission

The mission of **CaringKind** is to create, deliver, and promote comprehensive and compassionate care and support services for individuals and families affected by Alzheimer's disease and related dementias, and to eliminate Alzheimer's disease through the advancement of research. We achieve our mission by providing programs and services for individuals with dementia, their family and professional caregivers; increasing public awareness; collaborating with research centers; and informing public policy through advocacy.

CaringKind Helpline 646-744-2900
www.caringkindnyc.org

caringkind *The Heart of
Alzheimer's Caregiving*

Easing the Transition: Moving Your Relative to a Nursing Home



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Staff

- Do you see staff members actively assisting residents?
- On average, how long have current workers been on staff?
- How are language needs met for medical care, social needs and in emergencies?

Food

- Does the food look and taste appetizing?
- Do most of the home's residents eat in the dining room?
- Does the menu reflect the ethnic backgrounds of residents?

Medical Services in Nursing Homes

- How often are physicians on premises?
- How are specialists arranged for if needed?
- What arrangements are made for emergency treatment if the resident's physician is not available?
- What hospitals are used if the resident becomes acutely ill?
- Does the home offer alternative medicine and complimentary therapies?

End of Life

- What are the home's policies about end-of-life treatment?
- Does the home offer a hospice program?

APPENDIX: Nursing Home Checklist

Location

- Is the facility convenient for the primary visitors?
- Is parking available? Is public transportation available?

Appearance

- Is the facility free of unpleasant odors?
- Do residents' rooms have personal belongings?
- Does the home offer private places to residents who have visitors?

Dementia Units

- If the home has a dementia unit, is it a separate area with skilled staff?
- Has the staff received special training to work with dementia patients?
- Will the person with dementia be able to take advantage of the activities offered in any other unit?
- Is the person with dementia's functional level higher or lower than that of most residents?
- How does the staff handle disruptive behaviors?
- If the person with dementia wakes often at night or wanders, how will this be addressed?
- What safety measures are in place to protect confused residents who may try to leave?

Activities

- Are the activities listed varied and do they include activities the person with dementia would enjoy?
- Where are activities held?
- Are outside volunteers involved in any program at the home?

Introduction

If a person with dementia's needs can no longer be met safely at home, or if he or she requires rehabilitative services after a hospitalization, it may be time to consider moving to a long term care facility.

For some people, the thought of seeking residential care for someone may be difficult to accept. Family members and caregivers often experience mixed emotions surrounding the decision to find a new home for the person for whom they have been caring. It is important to remember that moving someone to a long term care facility does not mean that you have failed in your caregiving efforts. Trust that you are making the best decisions possible for everyone involved including yourself. Although the transition to a long term care facility may be emotionally challenging, you can continue to have a rich relationship with the person with dementia in your life.



Long Term Care Placement Options

In New York City there are a variety of long term care placement options available. When researching a facility, consider the cognitive and physical condition of the person with dementia. It can be helpful to consult the person's physician, who can assess his/her overall condition. Typically, geriatricians are familiar with the assessment process required for placement.

One long term care option in NYC is an **Adult Home (AH)**. AHs provide room and board, housekeeping, personal care and basic case management services. Some AHs in NYC have an Assisted Living Program (ALP) license which allows a resident to stay in the home as his or her needs change. This means the AH is able to provide

residents with additional assistance with activities of daily living as needed. Typically, AHs are most appropriate for younger, psychiatric populations who have a higher level of cognitive functioning. Most AHs accept Medicaid with a small number being private pay. People with dementia often require greater assistance and supervision than can be provided in an AH setting.

Another placement option for people with dementia in NYC is an Assisted Living Facility (ALF). ALFs are residences for older adults that provide room and board, home health care services, activities and some social supports. The monthly cost of these facilities typically includes only room and board, so be sure to inquire about additional fees for extra services. ALFs do not accept Medicare or Medicaid as payment options. Some ALFs are better equipped than others to provide care for someone as his/her needs increase. You want to ensure that the facility's discharge policies are clearly stipulated in the admission agreement. For example, you would want to know if the facility can accommodate people who have chronic mobility problems or those who experience physical health or behavioral changes.



Nursing Homes are licensed 24 hour skilled nursing facilities that provide the highest level of medical care in a residential setting. Commonly, nursing homes are the only option available to a person with dementia who requires extensive supervision and medical services. In New York City, nursing homes provide 24-hour skilled nursing care, social services and recreational activities. Nursing homes also offer specialty care such as physical, speech and occupational therapies provided to those returning from a hospitalization.

communicating with the supervising nurse on the floor. If the concern goes unresolved, address the issue with the department head or senior staff member most responsible for the task, such as the Director of Nursing or the Director of Social Services.

Document. Put your concerns in letter form. It is important to be concrete and factual when describing a problem. Be specific and provide dates, times, places and staff members involved. The letter can be addressed to the Administrator, Director of Nursing, Social Worker or whomever is responsible for helping to resolve the problem.

Follow Up. Make a list of the actions the facility plans to implement to correct the problem. Include a timetable for the changes and follow up with the facility to ensure the changes have been executed.

Know Your Rights. If you have completed the complaint process at the facility and the quality of care for the person with dementia has not changed, you may wish to contact an outside agency:

The New York State Ombudsman Program
212-962-2720

The New York State Department of Health
Central Complaint Intake Program
888-201-4563

Office of the New York State Attorney General
Medicare & Medicaid Fraud Control Unit
800-771-8000

Remember to set realistic expectations. Nobody will care for the person with dementia in the same way you would. The transition to a long term care facility can be challenging for both you and the person with dementia. However, over time, a positive relationship usually develops. Know you can always call CaringKind's Helpline at 646-744-2900 for information and support throughout this process.

Be Involved in Care Planning

Each long term care resident is required to have a comprehensive care plan (CCP). The person with dementia and the person most involved with his/her care have the right to request and actively participate in a CCP meeting. It is beneficial if you have questions prepared prior to the meeting. This is an opportunity for you to become acquainted with the person's care providers and share personal information about the person that is relevant to his/her care and preferences.



Importance of Communication

The quality of care a nursing home resident receives is likely to improve if you stay involved, are visible to the staff, and advocate on his/her behalf when problems occur. Openly communicating will not only inform the staff, but may improve the person with dementia's quality of life. Remember, the needs of the person will increase as the disease progresses. Active communication with the staff can ensure the best care plan for someone.

If a Problem Occurs:

Address the Issue. It is important to prioritize concerns and speak to a staff member at the facility if you notice something is missing in the person with dementia's care. It is best to start by

The Placement Process

It is best if you begin looking for a long term care facility before the person with dementia actually needs it as the process often takes longer than expected.



In order to be eligible for nursing home care, the person with dementia must require 24-hour skilled nursing or custodial care. A person requiring custodial care requires assistance with daily activities such as eating, dressing, bathing, ambulating, and medication management. Individuals applying from hospitals generally have higher admission priority because they typically have higher skilled nursing needs. Skilled care is provided by licensed professionals such as a registered nurse (RN), licensed practical and vocational nurses, physical and occupational therapists and speech-language pathologists and audiologists. Examples of skilled care include intravenous injections, physical therapy and medication administration.

Assessment tools for residential care focus mainly on someone's physical and skilled nursing needs. Many people with dementia have high custodial needs that are not captured in the current assessment and as a result, tend to score low on these measurements. This can make it challenging to gain admittance to a nursing home.

Nursing homes use an assessment tool called the Patient Review Instrument (PRI), which is completed by a doctor or RN to evaluate someone for admission. A family member should be present during the evaluation to report on the person's functioning and the level of care required. When choosing a nursing home, be sure to submit a completed PRI before asking to be added to the wait list.

Once on a waiting list, communicate with the admissions staff periodically so they will be familiar with you when it is time to place your relative. It is common for someone to spend months on a waiting list if he/she is moving from his or her home into a nursing home. Individuals coming from hospitals for rehabilitative services and those with high skilled nursing needs are considered priority admissions.



Choosing a Home

There are many things to consider when deciding on a new home for the person with dementia. It is important to look beyond the physical characteristics of a facility and to place emphasis on the

quality of care provided to residents. Quality of care means doing the right thing, at the right time, in the right way for the right person, and having the best possible results. If possible, look for a home that you feel will be responsive to your requests, and will try to accommodate the person's daily routine.

When you are looking for a new home, you may notice facilities referring to a care perspective called “person-centered care” or “culture change.” These terms refer to a movement which aims to make long term care facilities more home-like and to encourage resident choice and respect resident routine. Long term care facilities which emphasize person-centered care will likely be more open to individual input from residents, family members, and friends when responding to daily care needs.

Choose a Place Convenient to You and Other Visitors. It will be important for you to visit frequently. The more visitors the person with dementia has, the more likely it is that issues with care will be noticed and appropriately addressed.

long term care facility staff where these items are located.

Visiting the person with dementia is important, even if he/she does not recognize you or does not seem to want you there. Once the person has moved, try to visit often during the first few weeks to help the person feel secure. Be aware of your relative's responses and reactions before, during, and after your visits. Individuals with dementia may not be able to verbalize their needs to you or the staff caring for them. Behaviors and other nonverbal clues may assist in identifying their needs. Allow time for the person to adjust to the new surroundings. If he/she expresses a desire to leave with you, this may be his/her way of showing anxiety or unhappiness. Give the person reassurance and affection.

It is a good idea for you to familiarize yourself with all the staff involved in the care of the person with dementia. Note that the direct care providers, Certified Nursing Assistants (CNAs), are responsible for the day-to-day care of the person and are often the most knowledgeable about the subtle changes in the person's status.

After Placement

Many friends and family members have grown accustomed to being the primary caregiver for the person with dementia. When the person moves to a facility, remember that you are going through a transition as well. It is always important to take care of yourself. Many caregivers experience a sense of loss or even symptoms of anxiety and/or depression during the decision process and after placement. Make sure to discuss any symptoms you may be having with your personal physician so that you can remain an active participant in your family member's care. Call our CaringKind Helpline at 646-744-2900 to learn more about options, including counseling or support groups.



having the admission take place during the staff shift change or meal times. You know the person with dementia better than anyone else and it's helpful to approach the situation in a way that will create a positive experience for the person.

If you think the person with dementia will understand, explain what is happening and why. Every individual is unique and will respond to change in different ways. Be creative when explaining the move. It may be helpful to brainstorm with other people involved in the person's life or to call CaringKind's Helpline at 646-744-2900 to discuss options with staff. Since that person may accept more from a professional, consider having a doctor or social worker tell him/her about the move.

It is important to take familiar items such as pictures, blankets, plants, or even furniture, if allowed, to the new residence. If possible, the person with dementia should choose items he/she may want to take. You may want to keep items of great monetary or sentimental value at home as it is easy for items to be misplaced. It can also be helpful to provide supportive tools to help remind the person that you have not forgotten about him/her. For instance, you can put a log next to the person's bed that states when you were there and when you will come again. You also may want to create a scrapbook that includes photos of people who are important in the person's life as well as details about that person's life and personal preferences, such as his/her favorite foods, hobbies, likes and dislikes. It is helpful to inform

Visit Several Homes. Make appointments for tours with several homes. While taking a tour, be sure you are shown a long term care floor. Facility staff may show visitors the sub-acute or rehabilitative floors which may be better staffed and furnished. Ask questions during your tour and refer to the Checklist in the Appendix of this Guide. Consider visiting during the daytime as well as during off-peak hours.

Review the Environment. See if the facility is clean, odor free and in good repair. Explore the types of activities made available to residents and consider if they would be appropriate and enjoyable for your family member.

Meet the Care Needs of the Person with Dementia, Not Your Personal Preferences. People with dementia have very different care needs. Some may have high skilled nursing needs while others may require complete custodial care. For instance, if someone requires significant medical care, you may want to look for a facility that is affiliated with a hospital and is accustomed to caring for people with high medical needs. In this instance, it is more important to find a facility that can properly care for the person with dementia, rather than a facility that has many activities or a pleasant outside space.

If someone does *not* have high skilled nursing needs, you may want to look for different qualities in a facility. For instance, look at the level of socialization between residents, ask about the level of dementia care training for staff, and see how the facility responds to the person with dementia as his/her needs change.

The Department of Health does not currently have any regulations determining the definition of a "dementia unit." Although you may find that facilities advertise dementia units, without regulations this phrase is not necessarily helpful. It may be more important to find a facility providing quality care to other residents with similar needs to the person with dementia.

Ensure Language and Cultural Needs Can Be Met. If the person with dementia has specific language, religious or dietary needs, it is important to inquire whether the facility can accommodate those needs *prior to placement*.

Ask About End of Life Care. Be sure to take into consideration the person with dementia's feelings about end of life care. Inquire about palliative care and hospice availability as well as the facility's religious or morally-based policies that may limit resident options.

Regulatory Information

Skilled Nursing Facilities (SNF) are certified to make sure they meet certain federal health and safety requirements. Information regarding individual facilities can be found online at the New York State Department of Health website, <http://www.health.state.ny.us/>. The site lists all the nursing homes in the state, the quality measurements gathered by the Center for Medicare and Medicaid Services (CMS), and the most recent survey data. The CMS data is presented in a 5-star rating system. Although the information made available through the CMS star rating system can be useful, it is important to note that some of the data presented is self-reported by nursing homes. The Department of Health survey, which can also be found on the Department of Health website, may be a more objective measure of nursing home care. This survey presents data gathered by on-site surveyors, ensuring there is no self-reporting involved in the results. In addition to being available on the Department of Health's website, surveys are required to be posted in each facility.

Before you make a final decision, consider visiting the facility unannounced. To get a better idea of how the facility runs on a daily basis, try visiting at a different time of day, on a weekend, multiple times, or with a friend.



Financial Considerations

In New York State, all nursing homes are required to accept both Medicare and Medicaid. In a nursing home, Medicare will cover the cost of short term rehabilitation but it does not pay for long term care. Long term care is very costly and the majority of nursing home residents are enrolled in the Institutional Medicaid program. Nursing homes will assist incoming residents with the Medicaid application process. As part of the process, nursing home staff can ask caregivers for a significant amount of documentation, including up to five years of the applicant's financial history.

Moving to a Long Term Care Facility

Once you have selected a facility, and as soon as the long term care facility agrees to admit the person with dementia and financial arrangements have been made, the next step is the actual move. If the person is being moved from a hospital, there may be little to no time to plan the transition. Try to remain calm during the process. It will likely be a difficult day for everyone involved, and remember that the person who is moving will be looking to you for comfort.

During the transition, you may encounter obstacles as the person is giving up his/her home, familiar possessions and independence. Try to arrange the move during the person's "best" time of day. Avoid