

# Preparing Families to Make Informed Decisions about Long-Term Care

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One of the roles of the Long-Term Care Ombudsman Program is to provide helpful information, make referrals to appropriate resources, and guide families through the process of locating a nursing facility that provides the services and care that meets their loved one's needs. In addition, once an individual becomes a resident in a long-term care facility, long-term care ombudsmen provide assistance to families experiencing difficulty either in communicating or problem-solving with the staff of a long-term care facility on behalf of their relative with Alzheimer's disease.

Families most often express concerns about protection of individual dignity, sufficient staff time to attend to personal hygiene, incontinence care, and adequate assistance with activities of daily living. Occasionally families share concerns when they think a facility staff member has failed to take the time to adequately assess why a resident with Alzheimer's disease may be exhibiting certain behaviors, particularly if the behaviors reflect aggressiveness or resistance to "hands-on" care.

Family members contact long-term care ombudsmen frequently for assistance when their loved one has experienced some type of acute episode that has In this commentary, we focus This article focuses on important issues families must work through to prepare themselves and their loved one for a smooth transition into the long-term care setting.

## Where to Begin

For some families or spouses, there comes a time when they realize they can no longer adequately manage all of their relative's

medical needs and activities of daily living in the home setting. Usually this awareness is triggered by rapidly escalating behavioral problems or medical emergencies that are occurring much too frequently. In such a situation, it would not be unusual for the family physician to be the one who first suggests that it may be time to begin planning for transitioning their loved one with Alzheimer's disease into a long-term care facility. It is very common for family

members who are the primary caregivers to undertake this often daunting task during a time when they are emotionally and physically exhausted and don't know what steps to take to begin the process.

As the discussion is begun, family members need to obtain information about several important issues before they

actively seek admission for their loved one. In some instances, there will be little or no time for planning because the older relative may already be in the hospital and recommendations have been made by the physician for the hospital discharge planner to work with the family to find appropriate placement in a long-term care facility right away. In other situations, some advance planning can provide valuable information for a family or spouse beginning their search for a long-term care facility. Key planning issues include designation of a legal spokesperson for the older relative, consultation with the attending physician to obtain important information about the person's current medical status, and collection of information about the family member's assets and income that could be made available to pay for the costs of care in a long-term care facility. Persons with Alzheimer's disease or a related dementia should always be included in the discussions about their future care to the extent they are able to participate.

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## Selecting a Spokesperson

Establishing legal authority is an important issue for many reasons, including the federal Health Insurance Portability and Accountability Act of 1996, Public Law 104-191, known as HIPAA. HIPAA laws have enhanced healthcare information security protections that prohibit healthcare providers from sharing any personal or medical information with others without appropriate written authorization from the individual or their legal representative.

When persons have Alzheimer's disease or a related dementia, it is important for their family caregivers to determine if their family member has chosen someone, usually an adult child or spouse, as the legal representative to act on their behalf, when they are no longer able to express their preferences or make decisions. If there is no legal representative, then an attorney experienced in elder law issues can be consulted to determine whether necessary legal documents, such as a durable power of attorney or a healthcare power of attorney, can be drawn up to reflect the relative's wishes. In situations where a family member has already experienced substantial declines in mental status without having designated a legal representative, the remaining option is for the family to petition the local Clerk of Superior Court to appoint a family member as the person's legal guardian.

## Talking with the Physician

Physicians have an opportunity to empower the primary caregiver to assume a positive supportive role for the person with Alzheimer's disease, particularly as their relative gradually loses cognitive and verbal skills. In order to represent their loved one's wishes in care decisions, family members, or legal representatives need clear information about their relative's current medical condition, general medical history, currently prescribed medications, history of allergies, and the expected prognosis for each illness explained to them in laymen's terms. Accompanying their relative on a visit to their physician provides an opportunity for the family member and the physician to discuss recently observed changes in mental status, new safety issues in the home, or deteriorating health conditions. This thorough review of the loved one's current status will aid the physician in determining specific care needs and the care setting that can most appropriately provide the services needed. In some situations there may be an opportunity for the physician and family member to explore whether additional community resources, such as in-home services through the Community Alternatives Program for Disabled Adults (CAP-DA)<sup>1</sup> or respite services offered through the North Carolina Family Caregiver Program are options that may make it possible for their relative to continue living at home a little longer.

If the evaluation process results in a recommendation by the physician that the person with Alzheimer's disease has medical needs that require placement in a nursing facility, then the family member should ask whether the physician will continue

to be the relative's attending physician after the move. If the community physician does not visit nursing facilities to treat patients, families need to know that they must find a new physician. Each long-term care facility can usually provide a list of physicians that a family may use to arrange coverage by a new attending physician for their relative's medical care while in the nursing facility.

## Paying for Nursing Care

As stated earlier, primary caregivers or spouses will also need to collect and review financial documents and health insurance policies so that they have a clear understanding of their relative's assets, income, and any third-party health insurance, such as long-term care insurance, that may be available as a resource to pay for care provided by a nursing facility. Most people are not aware that Medicare Part A provides only a short-term skilled nursing benefit following a minimum three-day hospital stay. Often Medicare Part A coverage ends within two-to-three weeks or as soon as individuals achieve their maximum rehabilitation potential. At that point, long-term care expenses must either be covered by a person's personal assets, long-term care insurance benefits, other third-party insurance, or by applying for public financial assistance.

The state Medicaid Program is the primary provider of public financial assistance for nursing home care. The State County Special Assistance Program for Disabled Adults provides financial assistance to pay for assisted living level of care (also known as adult care). Both public programs are administered locally through county departments of social services and have stringent eligibility requirements. Some assisted living facilities and a few skilled nursing facilities admit only individuals who can pay privately for care. If a family member knows that it will be necessary to apply for Medicaid assistance in the near future, then he/she will need to investigate facilities that accept a mix of payment sources. This is important because, in a private facility, once their loved one becomes eligible for public assistance, they may be asked to move to another nursing home, which can be extremely traumatic for someone with Alzheimer's disease or a related dementia.

## Looking for a Nursing Facility

When searching for a long-term care facility, geographic location is an important consideration for many families. A nursing facility close to work or home affords families opportunities to visit their loved one and ease in responding to situations as they arise. A second important consideration for families is selecting a facility that has a good performance record and can meet their family member's medical and safety needs. Once several potential facilities have been identified, family members should obtain as much information as possible about each facility under consideration. Families can then compare the strengths and weaknesses of each facility before making a final decision. Important resources for specific information include:

- Each nursing facility's most recent survey records and quality indicator scores are posted on the Medicare web site at [www.medicare.gov/NHCompare/home.asp](http://www.medicare.gov/NHCompare/home.asp),
- Public survey information is available through the North Carolina Division of Facility Services, Licensure and Certification Section,<sup>2</sup>
- Other information is available through the local Regional Long-Term Care Ombudsman's Office,<sup>3</sup>
- Personal visits to facilities under consideration are recommended, and
- Each county department of social services' collects public monitoring records, which are available for each licensed adult care home in that county.

## Asking Important Questions

The placement process often triggers intensely mixed emotions for family members and can be a difficult period of transition for everyone. Because this situation is unlike anything that a family, particularly adult children, has ever experienced, they may have difficulty identifying the questions that need to be asked when meeting with the admissions staff in the facilities under consideration. Some of the crucial questions that need descriptive answers are:

*What is the organization's philosophy regarding the treatment and care of individuals with dementia?*

*Does your facility have a Special Care Unit?*

*What factors determine whether someone should be placed in a Special Care Unit?*

*What services are provided?*

*How is the Special Care Unit staffed?*

*What is the background and training of the individuals who work in the Unit?*

*What steps are taken by the facility to ensure the autonomy of each resident?*

*What happens when the type of care needed or payment sources change?*

*What are the facility's visitation policies?*

*How does the facility ensure good communication with family members about service provision issues?*

*How are individual resident or family concerns and grievances handled internally by facility staff?*

*Is this information provided in writing?*

Additional resources for guidance about important questions that need to be asked or assistance in developing a checklist that can be used during facility visits are available on numerous web sites such as [www.aarp.org](http://www.aarp.org), [www.medicare.gov](http://www.medicare.gov), and [www.myziva.net](http://www.myziva.net).

## After the Move

After moving a loved one into a nursing facility, it is not uncommon for family caregivers to experience an array of mixed feelings such as guilt and relief. They may experience lingering

concerns that facility staff will not be able to care for their loved one like they did at home. Sometimes a family member or spouse may worry that their loved one will be frightened because he/she cannot understand where he/she is and will not recognize the staff as caregivers. Other family members may be uncomfortable initially with the idea that their loved one is confined behind locked doors or wearing a monitoring device.

Daily routines in a long-term care setting are very different from those one is accustomed to in a private home. Such a change in setting can be very disconcerting, especially for the person with Alzheimer's disease. The most significant changes in the daily routine generally will revolve around the new resident's wake/sleep cycles, eating habits and bathing routines. It is important for both family members and facility staff to allow the newly admitted resident some time to adjust from having been the center of attention in the home, to now being one of several people depending on staff for care and personal attention. Another important adjustment that may surface is the issue of sharing personal living accommodations with a stranger in a space much smaller than their bedroom at home. In terms of new residents becoming more comfortable in their new surroundings, it is essential that families make an effort to provide staff with personal information about their family member. They can also informally share information with the direct care staff, such as the best way to approach the person, the name their relative responds to, situations that are frightening to them, favorite foods, foods they will not eat, allergies, activities that interest their relative, and a host of other intrinsic characteristics that make their loved one "unique."

This transitional phase is also an ideal time for families to explain to the facility staff, including the resident's new attending physician, how they can be contacted and what types of information or notifications they wish to receive regarding changes in their loved one's health status or problems encountered during daily care. The legal representative for the resident should provide neatly printed or typed instructions including all telephone numbers to be placed in the front of their relative's medical chart along with a copy of their durable power of attorney, healthcare power of attorney or guardianship documents. This information should also be placed on file with the facility social worker and passed on verbally to nursing staff on duty during visits with the resident.

It is important that residents and family members quickly learn to whom questions or issues of concern should be addressed. Once they have identified the appropriate staff members, the next step would be to determine the best way of conveying information. The most effective method is to speak directly with staff about a specific issue or concern and then follow up the conversation in writing. Communication should always be courteous and respectful and focused on specific issues in order to achieve a satisfactory outcome. Many times, situations that initially need minimal attention or intervention turn into matters of seemingly great magnitude as a result of poor communication. It is crucial for residents and family members to know about the facility's internal grievance procedures and the process by which concerns that have been

expressed are addressed by facility management. All long-term care facilities have a responsibility to ensure staff familiarity with the facility's policies and procedures for communicating with a resident, resident's family or legal representative, especially in the event of acute changes in condition, accidents, or injuries. When all parties use this frame of reference, then the lines of communication will remain open. Well established communication systems within the facility can help alleviate misunderstandings and reduce a family's anxiety about their loved one's care.

If/when these channels do not produce the desired results, then other avenues of assistance should be sought out to address the issues, such as contacting an objective third-party, like a local long-term care ombudsman. The Long-Term Care Ombudsman Program's mission is to protect residents' rights,

welfare, safety, and improve the quality of care and life for residents in long-term care facilities. When complaints are received by or on behalf of residents, long-term care ombudsmen offer an informal grievance resolution process as a tool to resolve issues in a manner that is mutually acceptable to the involved parties.

The North Carolina Division of Aging and Adult Services has several resources available to families on its web site at <http://www.dhhs.state.nc.us/aging/ombud/ombtools.htm>.

One document "Nursing Home Concerns" details which staff member(s) to direct questions or concerns to based on the nature of the issue(s). A second document "Puzzle Solved" gives suggestions on steps to take to ensure messages are conveyed effectively. **NCMJ**

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## REFERENCES

- Berger SG, Fraser V, et al. For the National Citizens Coalition for Nursing Home Reform. *Nursing Homes Getting Good Care There*. Impact Publishers, Inc., Atascadero, CA, 2002.
- 1 The State County Special Assistance Program for Disabled Adults is administered locally through county departments of social services. In many counties there is a waiting list for these services.
  - 2 North Carolina Division of Facility Services, Licensure and Certification Section may be contacted at (919) 733-7461 for additional survey compliance history about any licensed nursing home in North Carolina.
  - 3 <http://www.dhhs.state.nc.us/aging/ombud/ombstaff.htm>