

The Long-Term Care Conversation:

A GUIDE TO KNOWING WHERE TO BEGIN

“My husband has had Alzheimer’s for the past five years and much of that time I took care of him myself. Eventually, it became clear that it wasn’t safe to have him at home. One night he wandered out of the house, leaving all the doors open, and walked 10 miles before the police picked him up in the middle of a road. I awoke to find the police in my bedroom; the open doors made them worried that something had happened to ME. Another time he almost drank a bottle of cleaning fluid. Finally, it became too much. I had to place my husband in an assisted living facility.”

The above excerpt is from a telephone call to NFCA. The family caregiver was seeking advice about how to respond to people who questioned her decision to seek alternative housing for her husband. Experts would agree that she clearly made the right decision for her husband’s continued well-being, as well as her own. How do you know when it’s time to begin a conversation about long term care options? How do you evaluate what’s best for your loved one’s health and safety? What happens when your own health necessitates that Mom move out of your home and into alternative housing? There may come a time in every caregiving situation when, either for your loved one’s safety or your own health, you need to consider the possibility of alternative housing, including assisted living, a group home, or possibly a nursing home. When that time comes, it would be helpful to know what your options are in terms of finding safe and affordable housing for your loved one. These decisions are never easy, but they can be less stressful if you have had time to do proper research and to confer with family members and friends whose assistance and opinions you value. With this in mind, NFCA offers the following advice from SNAPforSeniors.com, a comprehensive national database for senior housing.

Long-Term Care Conversation Checklist

Having a conversation about long term care with an aging loved one, or someone with a chronic or disabling condition of any age, can be difficult for any family caregiver. Initiating that conversation can be stressful and uncomfortable. Here are a few hints and checklists that may help you begin the conversation about housing options with your loved one.

1. Determine if it’s time to think about long-term care assistance.

Reasons to seek long-term care vary from person to person. In addition to potentially offering a safer and more comfortable environment for your loved one, long-term care may be necessary for your mental and physical health. To ensure your loved one is able to contribute to decisions about his/her future, and to do so without a feeling of confrontation, introduce alternate housing options as early as possible, even before necessary. Evaluate your loved one’s lifestyle and health-related challenges. Be prepared to continue the conversation over time by sharing your observations and concerns, including any of the following physical and mental symptoms:

Physical Symptoms

Are they able to move around easily given the physical layout of the home? For example, are stairs, carpet, bath/shower or door handles obstacles for mobility? Is the heating and lighting adequate for any sensory impairment, including hearing, sight and circulation problems?

Are they experiencing balance issues, especially when changing positions? Are you concerned about them falling?

If they fell, are you confident they would be able to call for help? Is there a reliable source to respond to a call at all times?

Is your loved one repeatedly complaining of physical aches and pains?

Are they experiencing frequent incontinence? Can they attend to the problem when this happens or is help needed?

Do they have difficulty dressing, bathing or with personal hygiene such as hair and foot care?

Is your loved one experiencing frequent, significant sleep disturbances?

Are they capable of cooking or preparing healthy meals?

Has operating gadgets or appliances such as the can opener, stove or telephone become difficult?

Have household chores become a burden? Are vacuuming, sweeping, taking out the garbage, and cleaning the dishes or bathroom being done in timely ways?

Are finances such as bill payment, deposits, and investments being handled in a timely manner?

Is your loved one still driving? If so, are you concerned about his/her and others' well-being? Is public transportation a safe and viable option?

Are prescribed medications obtained and taken as indicated consistently?

Mental Symptoms

Is your loved one demonstrating personality changes, including but not limited to:

- Frequent irritability?
- Insensitivity to others?
- Disoriented to place and time?
- Aggressive behaviors?
- Repetitive behaviors?
- Communicating with inappropriate language?

Is your loved one socially withdrawn and not able or not wanting to get together with friends or family? Are there signs of depression?

Does he/she express negative comments about himself/herself?

Is your loved one demonstrating an inability to make decisions or making poor decisions?

Is your loved one able to understand communication or instructions from others?

2. Schedule a family meeting.

A family meeting can move the topic of long-term care to a more focused discussion that can lead to a plan. Here is a checklist for planning your family meeting:

Determine which family members should be involved directly or indirectly in decision making. This may include extended family members, close friends, or paid caregivers. Always include the

person if he/she is capable of taking part in any decision making.

Consider including an independent third party to play the role of mediator. This could be a minister or other member of the clergy, a social worker, or a case manager.

If necessary, find a neutral place to hold the meeting.

Prepare an agenda to help you stay focused. It may include:

- A medical update
- Sharing of feelings about the illness and caregiving
- Daily caregiving needs
- Financial concerns
- Who will make decisions
- What support role each person will play
- What support you need as the primary caregiver
- Next steps moving forward

3. Continue to involve family.

The move to a long-term care facility is an immense transition for any family, so it's important to involve everyone relevant to the care recipient:

Reach out to immediate family members to secure their input and support. For example, share online information about long-term care facilities to secure greater involvement and participation.

Is there an unequal financial or time burden on one family member? If so, acknowledge the distribution of resources and discuss a strategy for achieving a balance that appeals to everyone.

4. Continue to engage your parent or loved one.

Have ongoing conversations at times when your loved one is feeling best and there are few distractions.

Introduce the idea of an overnight visit to a long-term care facility or an extended afternoon visit to get a feel for the various available options.

5. Begin researching long-term care options in your area.

Find out as much as you can about the facilities in your area. Go to reputable Web sites, talk with your loved one's physicians, and ask friends and family members for referrals.

Contact the facility to ask questions and schedule a site visit.

Ask the facility you visit for a copy of its last annual licensing survey report.

Contact your local senior ombudsman to get perspective from a trusted local resource.

Check references from existing or prior residents or families.

From: National Family Caregiver Association *Take Care*.v.18#1 Spring 2009