

A Guide for Families Having the Conversation about Long Term Care

Nearly half of all Americans will need long term care at some point in their lives. In fact, one in five over the age of 50 is at a high risk of needing long term care within the next 12 months. Therefore, planning is crucial if you are to designate a facility that will be able to provide your loved one, relative or friend with the highest quality of care and quality of life in a safe and secure environment. It helps to diminish the feeling of loss or guilt that some experience, either when entering or placing a loved one or relative in an assisted living residence or a nursing facility. In addition, it aids in making the transition less stressful for the new residents, families and loved ones. Having a conversation about a person's long term care wishes in advance will be helpful when the time comes to make more concrete decisions about the daily care of loved ones or friends who can no longer care for themselves.

Yet, the decision to reside in a long term care setting can be a difficult one to make. The best scenario is one where all parties realistically evaluate both the current situation and how it may change in the short or long term future. Ideally, being proactive will help everyone arrive at a mutual decision that is the best solution. The first step in the planning process is having the conversation about a person's long term care wishes.

This guide provides numerous tips on how to make this sometimes challenging conversation – and decision – easier.

Talk Sooner Rather Than Later

Have the conversation about long term care before the need arises.

By planning ahead, you can find the quality of care and quality of life that you desire in a long term care facility for yourself, loved one or other person. Planning ahead will also make the transition easier because many important decisions will already have been made or at least discussed.

When considering long term care, a key advantage to planning ahead is that you will be better prepared financially. While many people pay for long term care with their own funds, purchasing long term care insurance is an excellent way to prepare for these expenses. In some cases, employers will provide long term care insurance in their benefits package. Medicare, a government program for citizens 65 and older, may cover the first 20 days of skilled care in a nursing facility and may partially pay for the next 80 days for a total benefit not to exceed 100 days, as long as the person qualifies. Another way long term care is financed is with Medicaid. Medicaid is a government welfare program for those individuals without the ability to pay for health care themselves. Financial concerns can be the most challenging part when considering long term care. The level of care needed, the setting where the care is provided and the geographic location determines cost. To ease the process, your financial records should be well organized. For more information on financial considerations, you can consult AHCA's pamphlet "Understanding Long Term Care Insurance."

Prepare Yourself

Take the initiative by doing your homework and offering options.

Before beginning the conversation with your loved one, it is important to know the basics of long term care. Being knowledgeable about the types of care available in your community will help you through the conversation. With this information, you will be able to lessen the fears of your loved one by providing educated answers to questions he or she might have.

Many people experience feelings of guilt when they consider long term care for their loved one. This is normal and, despite your feelings, you have to realize that you are looking out for his or her best interests. There may come a time when your loved one is going to need more care or supervision than you have the knowledge or time to provide. Long term care gives professional caregivers the opportunity to provide the quality of care and quality of life your loved one needs and deserves in a safe, secure environment.

Prepare Your Loved One

Ask permission of your loved one to have the discussion.

Having a conversation about the need for long term care is in the best interest of the entire family. Because the need for long term care is a challenging topic to discuss, some people might need more time to think and reflect on it than others. Asking permission assures your loved one that you will respect his or her wishes and honor them. Some ways of asking permission are:

- ◆ *“There is something very important to me that I would like to speak with you about. I’d like to talk about your wishes and desires for the time when your health requires more care than you or I can provide at home.”*
- ◆ *“I would like to speak with you about the options and benefits of long term care. I don’t want to alarm you, but it will make me feel better if I know your wishes when it comes to your health in the future.”*

Choose the Right Time and Environment

Look for opportunities in connection with significant life events. Drafting of wills, advanced health care directives or legal papers also provide time to have the conversation.

In addition, family gatherings may be opportune times to get loved ones to focus on their needs and wants concerning long term care.

Choose a place to have this conversation where you know your loved one is comfortable. It should be a quiet place, free from distractions. Usually, a private setting is best. This is also a good setting to have this conversation with a loved one who is mentally impaired or has dementia.

Stay Positive

Understand that it is normal to encounter resistance the first time you bring up long term care. Don’t be discouraged, just plan to try again at another time.

Getting your loved one to focus on and speak about this topic can be a very challenging process. A common response is, “I don’t need any special help.” Your loved one may not want to show signs of weakness or loss of control, which many people associate with long term care. Don’t be discouraged. Let him or her know you are concerned and that by discussing this topic, you are looking out for his or her best interests. Although you don’t want to pressure your loved one, be persistent and return to the topic over time.

Be a Good Listener

By listening, you can learn the wants and needs of your loved one.

It is important for you to understand what is best for your loved one when it comes to long term care, so spend most of the conversation listening. Your goal is to answer questions he or she might have and be able to provide insight on the topic. Here are some helpful tips:

- ◆ *Listen to his or her needs; what he or she is sharing is important.*
- ◆ *Show respect.*
- ◆ *Acknowledge your loved one’s right to make choices.*

Include Others in Decision-Making

There are other people who will be able to offer guidance on what kind of services your loved one will need and how to tap into community resources.

During the discussion, it is helpful to designate what is most important when it comes to your loved one's care. That can include input from many different sources, including your loved one, family members, his or her physician, spiritual advisor, close friends or neighbors. They may have an understanding of what type of care is necessary and some will be able to help determine what facilities can best meet your loved one's needs. Some other good resources are:

- ◆ *State affiliates of the American Health Care Association (AHCA)**
- ◆ *Centers for Medicare and Medicaid Services (CMS) web site***
- ◆ *AARP****
- ◆ *Physicians*
- ◆ *Ministers, priests, rabbis or other spiritual advisors*
- ◆ *Social workers or local social service agencies*
- ◆ *Geriatric case managers*
- ◆ *Local medical societies*
- ◆ *Area Agencies on Aging*
- ◆ *Long term care ombudsmen/State Offices on Aging*

*A list of state affiliates of AHCA is available on the Internet at www.ahca.org/who/pubstate.htm.

**CMS is the federal agency that administers the Medicare and Medicaid programs. More information is available at www.cms.gov.

***AARP is the nation's leading organization for people age 50 and older. Information can be found at www.aarp.org.

Signals To Look For

The following are signs that it is time to discuss long term care:

Isolation/Depression

- ◆ Is your loved one isolated from social contact?
- ◆ Are his or her sleeping habits, eating habits or activity levels changing?

Daily Activities/Eating Habits

- ◆ Is your loved one having a difficult time walking, dressing or eating?

Bruises/Falls

- ◆ Has there been an increased susceptibility to falling and bruising?

Cognitive Ability

- ◆ Is your loved one's mental reasoning ability at a level where his or her personal safety and the safety of others is at risk?

Increasing Medical Needs

- ◆ Does your loved one need medical care that you or he or she cannot provide?
- ◆ Does your loved one's medication need to be increased?
- ◆ Does he or she need more and more help taking medications?
- ◆ Does he or she use medical equipment like an oxygen tank or need daily or weekly treatments like dialysis?

- ◆ Is your loved one in need of rehabilitative care?

Caregiver Burnout

- ◆ Is a family caregiver exhausted due to the amount of care your loved one needs?

Medication Errors/Missed Doctor's Appointments

- ◆ Is your loved one mixing up medications, taking them incorrectly or not taking them at all?
- ◆ Is your loved one keeping his or her doctor's appointments?

Household Management

- ◆ Can your loved one still manage the components of running a household, such as keeping a checkbook or paying bills?
- ◆ Is there a dramatic change in how the house is kept?

Planning for Yourself

Everyone needs to explore their options and share their preferences.

All parties will realize that the process of entering long term care will be much easier if these topics are discussed early and openly. By dealing with this issue up front, there is less pressure on everyone to discuss this topic. Remember, it's never too early to consider your own needs and plan for your future.

Conclusion

Long term care facilities strive to be like a community where the residents can feel comfortable, find familiar faces and build relationships just like they would in their homes. Many people have a mistaken impression of these services, so it is important that you gain as much knowledge about them as possible. To make it easier for everyone, it's best to plan ahead and have the conversation about long term care. By doing so, you can ensure that your loved one will be provided with the highest quality of care and quality of life.

FOR MORE INFORMATION CONTACT:

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