

Tips for Caregivers for End Stage Dementia Care

Dementia is an illness that may last from a few years to many years. During the end stage, caring for a person with a dementia can be very difficult and, at times, intimidating. Caregivers who are properly trained and educated will make the care more manageable, meaningful, rewarding, and less intimidating. Below are basic tips for connection and communication with those who have dementia:

Some Questions To Ask Yourself When You Are Preparing To Connect With Your Loved One:

1. Can I help facilitate my loved one's ability to make a connection with another person in his/her world?
2. Can I center myself to be open to my loved one's very precious person, remembering that creative and quick thinking helps me a great deal when working with my loved one with a dementia?
3. Can I be aware and connect with my loved one at this moment and assess what would be best to do at this time?

Approaching and Connecting With Your Loved One

1. How you approach someone with a dementia is important to be able to connect with them for meaningful engagement. Always approach slowly and be observant. Introduce yourself and call them by name (know what name they prefer to be called. Some individuals prefer a nickname).
2. Be aware of their demeanor and body language. A person in the later stages of dementia may have left their normal states of awareness and cannot communicate verbally. Keep in mind, though, your loved one may still be aware of his/her surroundings and hear all or some of the things that are said. By staying aware of your loved one, the caregiver can still connect with, and assist, them. **(Volunteering/Palliative Dementia Care; Canadian Nursing Home Journal, March/April 2005)**
3. After you have approached and connected with your loved one, you can give them your attention with a gentle touch on the shoulder or arm. You might ask them if you can hold their hand. Some ways your loved one may show signs that they are responding in a positive way to your attention or touch are:
 - A. Relaxed posture, hands open
 - B. A gentle sigh
 - C. Movement towards you
 - D. Eyes Open
 - E. A Genuine smile **(From the Heart Through the Hands; The Power of Touch in Caregiving; Oxford University Press, New York, NY 2001).**

4. Always be open to your loved one, be there for them to connect, and work to have positive experiences.
5. Most importantly, **have no expectations for your loved one or for yourself. Remember, we must enter their world; they can no longer enter ours.**
6. Let go of all agendas so you can enter their world, whether it is in the present or as far back as 30 years ago.
7. Stop and think, “How can I best serve my loved one today?”
8. If you connect with your loved one first, and they come to see you as a “safe” person, you will be able to accomplish your goals with as little frustration as possible.
9. A person with end stage dementia may not appear to be aware of you, but they may respond to sensory stimulation. Their sense of touch and hearing are the remaining abilities they have in these final days. Behave as if the person can hear you.
10. Some people will enjoy certain types of music, having you read to them, or even pray with them. Having a resource kit or resource bag containing essential oils, hand lotions, simple books, colorful pictures, and/or music will be very helpful.
11. **Everyone wants to be accepted, understood and loved.** Connection is the important word. Dementia patients have the same need.

Important Things to Remember

- **Approach is important; be respectful, observant, slow, nurturing, and comforting.**
- **Your goal is to connect where they are in this stage of the disease.**
- **Be open to your loved one, be there for them to connect, and work to facilitate positive experiences.**
- **ALWAYS HAVE NO EXPECTATIONS!**

The journey of dementia and/or Alzheimer's can be very scary and intimidating. Feeling inadequate and doubting your abilities are normal feelings. Remember, you are not alone. The Hospice of East Texas is here to answer any questions or concerns you may have. You can contact our Dementia/Alzheimer's specialist at the number below:

**The Hospice of East Texas
Julie Rucker, Dementia Specialist
903-941-6303.**