



## Communicating When Someone Has Dementia

by Elizabeth Landrum, Ph.D.

Currently, one in every five families is dealing with dementia. Within ten years, it is estimated to become one in two families. As more people are living with and beside dementia, Lopez Island Hospice & Home Support is dedicated to assisting those members of our community. We continue to offer caregivers' support (individually and in a confidential group setting), provide volunteer assistance at home, and organize community education on relevant topics.

While we have focused earlier articles on losses and stresses experienced by caregivers, in this article we offer some practical tips in communicating with people living with dementia. Learning to care for those with dementia requires patience, flexibility and compassion. It is important to understand that the loss of memory, confidence, autonomy, and personal dignity can be devastating as they enter an unfamiliar, often frightening, new world.

Even with multiple changes in language, memory, and behavior, the essential self remains intact. Persons with dementia will continue to feel an emotional connection to people and their environment. It is important to focus on who they are, what they still have, and what feelings may hide behind communications or behavior. We never lose the importance and meaning of communication, even when changes in our brains make clear, direct verbal communication difficult or impossible.

While people are unique in personality, style, and needs, there are some specialized techniques that can be helpful in communicating with persons with dementia. To be effective, patience, understanding, acceptance, respect, and calmness are essential, though often not easy. "It's not what you say but how

you say it" holds doubly true when communicating with someone with dementia. Alzheimer's disease and related illnesses impair the ability to understand words and to speak, but people with dementia will still attend to body language, tone, and facial expressions. As ability to process verbal information declines, the importance of how others communicate increases.

While we will use Alzheimer's as the most frequently encountered type of dementia, many of these suggestions can be helpful in communicating with anyone who has lost cognitive and language abilities.

**In the early stages of Alzheimer's disease, an individual is still able to participate in meaningful conversations and engage in social activities. However, they may repeat stories, have difficulty finding the right words, or feel overwhelmed by excessive stimulation.**

**Here are some commonly prescribed tips for successful communication:**

- Don't make assumptions about the ability to communicate because of an Alzheimer's diagnosis. The disease affects each person differently.
- Don't exclude persons from conversations with others.
- Speak directly if you want to know how they are doing.
- Take time to listen to how they are feeling, what they are thinking, or may need. Your concern and interest will mean a lot.
- Ask questions about the distant, rather than immediate, past. Reminisce, saying, "I remember..." instead of "Do you remember...?"
- Give them time to respond without interrupting or finishing sentences (unless asked for assistance).

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- Talk with them about what they are comfortable doing and what they may need help with. Promote ongoing autonomy where possible.
- Give verbal and non-verbal comfort and reassurance.
- Remember that they are likely to be frightened or frustrated, though there are a variety of ways individuals react to these feelings.
- It's OK to laugh. Sometimes humor lightens the mood and makes communication easier. Many individuals are even able to laugh at themselves in certain environments.
- Your attitude and body language communicate more strongly than words, so try to set a positive mood for interactions, but don't try to hide your feelings, as they may be read anyway.
- You may need to prepare yourself for visits with some relaxing breathing and/or positive self-talk. You may need to talk with others about your own losses and frustrations in order to be your best in this ever-changing relationship.
- Remember their reality and yours are different and you cannot change theirs; you can only control your reactions to them and to the disease.

**The middle stage of Alzheimer's is typically the longest and can last for many years. As the disease progresses, the person will have greater difficulty communicating and will require more direct care.**

### *Tips for successful communication:*

- Engage in one-on-one conversation in a quiet space with minimal distractions.
- Maintain eye contact; it shows you care about what they are saying.
- Get at the same level (or below) so they can look at your face and feel more equal.
- Allow time for response so they can think about what they want to say.
- Be patient and supportive. Offering comfort and reassurance can encourage people to explain their thoughts.
- If they become upset or agitated, respond to their feelings first, then try changing the subject or environment.
- Avoid criticizing, correcting, or arguing. If the person says something you don't agree with or you know isn't true, let it be. Instead, listen and try to find the meaning.
- Don't overwhelm with lengthy requests that require complex thinking. Break down tasks with

clear step-by-step instructions, gently reminding of steps they may have forgotten.

- Speak slowly and clearly, using simple language, keeping the usual cadence of your speech.
- If they don't understand, repeat. If they still don't understand, wait a few minutes and rephrase.
- Confusion can lead to suspicions and/or anger. Try not to take it personally. This is when distraction or humor can help.
- Ask one question at a time. Multiple questions can be overwhelming.
- Ask questions that require a "yes" or "no" answer ("Would you like some coffee?" rather than "What would you like to drink?"). Give visual cues. To help demonstrate a task, point or touch the item you want them to use, and name it ("Here is your fork"). Or, begin the task yourself.
- Provide the solution rather than the question ("The bathroom is right here" instead of "Do you need to use the bathroom?").
- Turn negatives into positives ("Let's go here" instead of "Don't go in there.")
- Written notes can be helpful when a spoken word seems confusing.
- Encourage ways they can hold on to important parts of their identity.
- Always look for the feelings behind the words, not just the content. For example, if they are distressed, believing Tom hasn't called for weeks (though you know it was yesterday), try responding with "You really like talking with Tom, don't you? Let's try calling him later."
- Your own creativity and flexibility will be gifts to both of you.

**The late stage of Alzheimer's may last from several weeks to several years. As the disease advances, the person may rely on nonverbal communication such as facial expressions, repeated behaviors, or vocal sounds.**

### *Tips for successful communication:*

- Always treat people with dignity and respect. Avoid talking down to them, or speaking as if they aren't there.
- Approach from the front and identify yourself. Use their name.
- Encourage nonverbal communication. If you don't understand what is being said, ask them to point or gesture. Continue to make eye contact.

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- Use touch, sights, sounds, smells and tastes as forms of communication.
- People may lose language and yet retain rhythms of speech, so communicating in rhythm or even song can be a way to connect. They can only use what they have left, but you can be flexible and creative.
- The emotions being expressed are more important than what is being said. Continue to look for the feelings behind words, gestures, or sounds. Read body language for signals, and check for what you suspect may be their needs. They could be in pain, thirsty or hungry, frightened, over-stimulated, or frustrated. Even difficult behaviors may be their best way of communicating a feeling or need.
- It's OK if you don't know what to do or say - your presence and kindness are most important.

*For further information, you might find helpful tips on the internet. Many people have benefitted from YouTube videos by Teepa Snow, especially her "Making Visits Count" series. Other helpful resources are listed on our website at [www.lihhs.org](http://www.lihhs.org)*



## When Breath Becomes Air

Book Review by Rosie Sumner

"At the age of thirty-six, on the verge of completing a decade's worth of training as a neurosurgeon, Paul Kalanithi was diagnosed with stage IV lung cancer. One day he was a doctor making a living treating the dying, and the next he was a patient struggling to live. Just like that, the future he and his wife had imagined evaporated. *When Breath Becomes Air*, which features a foreword by Dr. Abraham Verghese and an epilogue by Kalanithi's wife, Lucy, chronicles Kalanithi's transformation from a naïve medical student 'possessed, ' as he wrote, 'by the question of what, given that all organisms die, makes a virtuous and meaningful life' into a young neurosurgeon at Stanford, guiding patients toward a deeper understanding of death and illness, and finally into a patient and a new father to a baby girl, confronting his own mortality. "

The above description is from the catalog of the Lopez Library, where resides both the print and audio version of this book. It is also available in our lending library.

(con't)

I started reading Kalanithi's work with some trepidation, already aware that the author and hero of the tale doesn't make it. It is a deceptively short book. Every time I came to it, I picked it up with a reverence for the gift this man left us. I read it slowly and carefully. Perhaps earlier in his career, Kalanithi imagined living a long life as a productive doctor and medical researcher. He ended up struggling to finish the book before he died. Because of his full way of living and giving, I believe strongly that anyone who reads what this brilliant young man chose to say to us before he died will feel deeply enriched. And he has left a strong legacy for his daughter. She will know him, who he was, what he stood for, how full of integrity he was. In lucky moments, she will recognize in herself the strong compassion her father had for the people he interacted with: patients, friends, family, those healers who cared for him in his last two years of life. Most importantly, she will be strong in knowing how very much he wanted and loved her.

Besides being a work of interest to anyone who wishes to learn more about the medical world from the perspective of a doctor, this book is poetry, philosophy and expressions of honest love, carefully chosen and offered as a man's last great work. Most of all, it is one man's journey of letting go of life, while living it each day, something all of us are doing in our own ways, something all of us have in common as we swing through the cycle of life and death.

I feel such gratitude for this man, his great effort, his shining example of grace in dying, acceptance and awareness, but most of all his love, imperfect and radiantly extraordinary, as all loves are. And I grieve for his loss, for the family and friends and patients and readers who have experienced all they had of him, and no more.



## Did you know...

- Our lending library is available to everyone.
- Our medical equipment (walkers, crutches, shower benches, canes) is available free of charge.
- In 2015, our volunteers made over 1,700 client visits.
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Summer 2016 Information and Resources

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### Jingle Bell Tickets on Sale in October

Bring out your sparklies and your holiday sweaters, your festive ties and those Christmas pins...it's just about time to party!

Mark November 26th on your calendar for the 8th Annual Lopez Island Hospice & Home Support Jingle Bell Dinner. The Jingle Bell Dinner is our major fundraiser of the year, and gives you an opportunity to support our Lopez Island neighbors and have fun at the same time.

Join us for a Lopez Island tradition – The Jingle Bell Dinner. Tickets go on sale in October. Last year we sold out, so get your tickets early.

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*Lopez Island Hospice & Home Support is looking for new board members. If you believe in our programs and services and have some time to share, please contact the office at 468-4446, or admin@lihhs.org.*



### Watch for Living Long on Lopez Events

Lopez Island Hospice & Home Support is dedicated to assisting Lopez residents who want to remain at home as long as possible. In an effort to assure that you are informed about available resources, we are sponsoring a series of informational programs under the heading of "Living Long on Lopez." The next panel discussion, "Finding Help at Home," will include representatives from various organizations available to provide assistance. It is scheduled for October 22. Watch for announcements for this and other programs, including one on dementia care, coming soon. Visit our website, [www.lihhs.org](http://www.lihhs.org), or call the office at 468-4446 for more information.