

Ten Real-Life Strategies for Dementia Caregiving

By Family Caregiver Alliance

As caregivers, we often use intuition to help us decide what to do. No one ever gave us lessons on how to relate to someone with memory loss. Unfortunately, dealing with Alzheimer's disease and other dementias is counterintuitive; i.e., often the right thing to do is exactly opposite that which seems like the right thing to do. Here is some practical advice:

1. Being Reasonable, Rational, and Logical Will Just Get You into Trouble.

When someone is acting in ways that don't make sense, we tend to carefully explain the situation, calling on his or her sense of appropriateness to get compliance. However, the person with dementia doesn't have a "boss" in his brain any longer, so he does not respond to our arguments, no matter how logical. Straightforward, simple sentences about what is going to happen are usually the best.

2. People with Dementia Do Not Need to Be Grounded in Reality.

When someone has memory loss, he often forgets important things, e.g., that his mother is deceased. When we remind him of this loss, we remind him about the pain of that loss also. When someone wants to go home, reassuring him that he is at home often leads to an argument. Redirecting and asking someone to tell you about the person he has asked about or about his home is a better way to calm a person with dementia.

3. You Cannot Be a Perfect Caregiver.

Just as there is no such thing as a perfect parent, there is no such thing as a perfect caregiver. You have the right to the full range of human emotions, and sometimes you are going to be impatient or frustrated. Learning to forgive your loved one as well as yourself is essential in the caregiving journey.

4. Therapeutic Lying Reduces Stress.

We tend to be meticulously honest with people. However, when someone has dementia, honesty can lead to distress both for us and the one we are caring for. Does it really matter that your loved one thinks she is the volunteer at the day care center? Is it okay to tell your loved one that the two of you are going out to lunch and then "coincidentally" stop by the doctor's office on the way home to pick something up as a way to get her to the doctor?

5. Making Agreements Doesn't Work.

If you ask your loved one to not do something ever again, or to remember to do something, it will soon be forgotten. For people in early stage dementia, leaving notes as reminders can sometimes help, but as the disease progresses, this will not work. Taking action, rearranging the environment, rather than talking and discussing, is usually a more successful approach. For example, getting a tea kettle with an automatic "off" switch is better than warning someone of the dangers of leaving the stove on.

6. Doctors Often Need to Be Educated By You.

Telling the doctor what you see at home is important. The doctor can't tell during an examination that your loved one has been up all night pacing. Sometimes doctors, too, need to deal with therapeutic lying; e.g., telling the patient that an antidepressant is for memory rather than depression.

7. You Can't Do It All. It's OK to Accept Help Before You Get Desperate.

When people offer to help, the answer should always be “YES.” Have a list of things people can do to help you, whether it is bringing a meal, picking up a prescription, helping trim the roses, or staying with your loved one while you run an errand. This will reinforce offers of help. It is harder to ask for help than to accept it when it is offered, so don’t wait until you “really need it” to get support.

8. It Is Easy to Both Overestimate and Underestimate What Your Loved One Can Do.

It is often easier to do something for our loved ones than to let them do it for themselves. However, if we do it for them, they will lose the ability to be independent in that skill. On the other hand, if we insist individuals do something for themselves and they get frustrated, we just make our loved one’s agitated and probably haven’t increased their abilities to perform tasks. Not only is it a constant juggle to find the balance, but be aware that the balance may shift from day to day.

9. Tell, Don’t Ask.

Asking “What would you like for dinner?” may have been a perfectly normal question at another time. But now we are asking our loved one to come up with an answer when he or she might not have the words for what they want, might not be hungry, and even if they answer, might not want the food when it is served after all. Saying “We are going to eat now” encourages the person to eat and doesn’t put them in the dilemma of having failed to respond.

10. It Is Perfectly Normal to Question the Diagnosis When Someone Has Moments of Lucidity.

One of the hardest things to do is to remember that we are responding to a disease, not the person who once was. Everyone with dementia has times when they make perfect sense and can respond appropriately. We often feel like that person has been faking it or that we have been exaggerating the problem when these moments occur. We are not imagining things—they are just having one of those moments, to be treasured when they occur.

This tip sheet was prepared by Family Caregiver Alliance and reviewed by Donna Schempp, LCSW. ©2011 Family Caregiver Alliance. All rights reserved.

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