



# Frequently

## ASKED QUESTIONS

Written by Rachael Wonderlin, MS from Dementia By Day

### **What is dementia and what does that mean for my loved one's care?**

Dementia is not a specific disease, but an umbrella term that describes a list of symptoms that are severe enough to interfere with daily life. Dementia symptoms include impairments in memory, thinking, movement, judgment, ability to toilet and feed oneself, loss of understanding of time, and more. There are over 100 different causes of dementia.

### **What causes of dementia are there?**

#### **What is the difference between Alzheimer's and dementia?**

The most common causes of dementia are Alzheimer's disease, Lewy Bodies diseases (this includes Parkinson's disease dementia and Dementia with Lewy Bodies), Vascular dementia, and Frontotemporal Lobar dementia. Alzheimer's disease is just one cause of dementia. If we think of cancer as an umbrella term, we can remember that there are many different types of cancer. If we think of dementia as an umbrella term, we can remember that there are many different causes of dementia—Alzheimer's is just one of them.

### **Why is positive communication important in dementia care?**

Positive communication can completely change the way that you interact with a loved one who has dementia. It can make all the difference in maintaining a happy, positive relationship throughout the course of the disease.

### **Is it okay to lie to my loved one living with dementia?**

The best thing to do is take the word "lying" and remove it from your vocabulary. Instead, focus on a new phrase: Embracing Their Reality. This means that we always agree and go along with the story that our loved ones tell us. Even if we know that story is not true—for example, if a person living with dementia believes that she is 20 years old—we go along with her reality. Although this can feel like lying, it is important to remember that a person with dementia does not always live in the same reality that we do, so what is true for them must also become true for us. Arguing and trying to "correct" someone living with dementia does not work.

### **My loved one says things that aren't true. What can I do?**

The most important thing that you can do when talking to your loved one is to avoid arguing with them. Although you may feel that you are "helping" by explaining something to your loved one, he or she will not understand, and it will probably make this person more upset.

For example, your mother with dementia may say, "I want to go see dad." Although her father may have died years ago, please do not inform her that her father is dead. Instead, you could say, "Great, let's go later." We want to live in the truth of their reality, even if that reality looks different from ours.



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### **What is the purpose of offering baby dolls and stuffed animals to older adults with dementia?**

Many people living with dementia believe that realistic-looking baby dolls and stuffed animals are real. Because of this, many people with dementia gain a lot of positive feelings and energy from spending time with a doll or stuffed animal. We always treat the baby doll or stuffed animal as real, unless the person living with dementia does not believe that it is real. We go along with their reality and do not try to force them to accept or not accept the dolls.

### **When is the best time to visit my loved one in dementia care?**

The best time to visit your loved one is in the early afternoon, usually before 2:00 PM. Many people with dementia become more tired as the day wears on, a process called "sundowning." Unlike other people, however, those with dementia may not be able to express verbally how tired they are. Instead, residents may get anxious, aggressive, upset, and irritable. You may find that your loved one is happier and more talkative when you visit earlier in the day.

### **I feel uncomfortable when I visit. What can I do?**

It may be challenging to visit your loved one living with dementia. He or she may be irritable or easily upset, but that does not mean that he or she does not want to see you. Residents always look forward to visits from their families, but it is important to note what time of day works best for you and the person you are visiting.

There are plenty of ways to interact with your loved one while you are here. Bring a favorite item from home, cook a homemade dish to share, or tell them about your own day.

### **I never know how to leave when my visit is over. What's the best way to say goodbye?**

While some people living with dementia do understand that you live elsewhere, others do not. Although it is very challenging to say goodbye to your loved one after your visit, please do not tell them that you are "going home." He or she may not understand what you mean, and will probably wish to go with you. This could turn into a serious argument.

Please do not explain to your loved one that he or she "lives here now." This will most likely cause him or her to become very upset and confused.

Instead, suggest an activity that he or she can get involved in, and then, once he or she is involved, walk away. You could also talk about something else you need to do that day, so you must leave to complete that task. Let your loved one know that you will see them again soon, but you need to "run out to the store" or "get something to eat."



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### **What if my loved one doesn't speak? Is it still worth visiting?**

It may be that your loved one can no longer communicate verbally. This can sometimes happen with dementia, but do not be afraid to visit. Have patience with your loved one and try to ask "yes or no" questions. Tell him or her about your day, the vacation you went on, or maybe a beloved pet you are both familiar with. Just because this person cannot speak does not mean that he or she does not understand what you are saying.

### **My loved one doesn't seem to recognize me when I visit. Should I stop coming to visit?**

No, please do not stop visiting them. It's not uncommon for a person living with dementia to encounter some Timeline Confusion. Since time is not always linear for a person living with dementia, they may think that you, as a grown adult, are someone else. They may be looking for a younger version of you because they themselves believe they are younger. Don't correct them and say, "No, I'm your daughter!" instead, go along with it unless they are making you uncomfortable. If you are uncomfortable, find a kind excuse to exit the room.

### **I keep replacing my loved one's items because they keep going missing. What can I do?**

Please let a staff member know if something goes missing so that they can start looking! The best thing that you can do is to label all of your loved one's items with a black permanent marker. The other thing that you can do is understand that some items will go missing. Many people with dementia pick up items, move them around, and then forget where they left the items.

### **I want more information. Where can I go for that?**

My blog, Dementia By Day, is a wealth of posts and resources for care partners. It can be found at [DementiaByDay.com](http://DementiaByDay.com). My book, "When Someone You Know is Living in a Dementia Care Community," is also available online or in Barnes & Noble. Johns Hopkins University Press has number of fantastic titles for you to check out, as well, including "The 36-Hour Day," by Dr. Peter Rabins and Dr. Anne Kenny's book, "Making Tough Decisions About End-of-Life Care in Dementia."

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