

**When I tell you that I have Alzheimer's disease or another type of dementia:  
Some tips of what to and not do and say.**

It is a very personal decision whether to share a diagnosis of Alzheimer's disease or another type of dementia with family & friends. Some people with Alzheimer's disease don't feel they need to tell others that they have this disease. Those who do decide to share their diagnosis, may call it a memory problem, say they have dementia or a specific type of dementia.

**Why is it important for me to I tell you I have dementia?** I want you to understand:

- "I am living with a disease that is difficult for me."
- "I may not be able to say what I want to say or remember to do things sometimes."
- "I don't look different so it may be hard for you to understand why some things are more difficult for me to do now."
- "I want to be honest with you."
- "I don't want to hide anymore, or worry that you are noticing things (like I'm forgetting, getting confused, etc.)"
- "I want to educate (create awareness, end stigma) my friends and family. I can still **do** things. I still have value."
- "The more I talk about my diagnosis and disease, the more I identify with who I am."
- "I want you to know that some days are better than others." *"There will be days my friends..."*
- "Keep in mind that **I AM STILL ME.**"

**IT MAY NOT JUST BE ALZHEIMER'S:** Since there are many types of dementia other than Alzheimer's disease, I might just call it dementia or memory loss. If I do mention my illness by name, you can start learning more about these conditions on the following websites:

- Mild Cognitive Impairment ([nia.nih.gov/alzheimers/topics/mild-cognitive-impairment](http://nia.nih.gov/alzheimers/topics/mild-cognitive-impairment)), Alzheimer's disease ([alz.org](http://alz.org)),
- Lewy Body Dementia ([lbda.org](http://lbda.org))
- Frontotemporal Dementia ([theaftd.org](http://theaftd.org))

Information about other types of dementia is also available online.

**HOW YOU RESPOND CAN HELP US**

Many of us confide in family and friends whom we know care about us. We tell people with whom we have a strong relationship and trust.

We know that it can be hard for you to hear that I have Alzheimer's disease or another memory disorder. You may not know what to say when I tell you my diagnosis.

## **Please try NOT to respond to me by saying:**

***“You don’t look like you have Alzheimer’s disease.”*** I am not making this up! At this point, I may not look different, so it may be hard to accept what I am telling you.

***“Oh, I forget all the time too.”*** This is not the same thing. Alzheimer’s is a disease and is more than occasional forgetfulness. Please don’t doubt what I am telling you.

***“You already told me that.”***

**Nothing.** I know it is hard to know what to say, but please acknowledge what I have told you.

## **Other responses that are NOT helpful:**

- Don't shy away. I'm not contagious.
- Don't talk to me or treat me like I'm dying or diseased.
- Don't hover over me, like I might break.
- Don't talk to me super slowly, like I'm stupid, like I'm deaf.

## **Here are some tips of how to respond that DO make me feel better:**

**Listen.** Acknowledge what I told you. You may not need to talk about it, but I do. I want you to hear *“I have Alzheimer’s disease.”* It is important to me that you know and understand that I have a disease that affects me.

**Ask questions.** Alzheimer’s disease affects each person differently. Knowing how it is affecting me right now will make both of us more comfortable with each other.

“Can you tell me more?” or “I would like to hear how things are going for you if you want to tell me more.”

### **Offer your support.**

- *“I am sorry to hear this.”*
- *“How can I help?”*
- *“Can you tell me ways that I can best support you?”*

***“Thank you for telling me.”***

It makes me feel better just to know you care and to hear your compassionate words. I’d love to hear from you after you have given yourself some time to think about what I have told you. Keep in touch.

Developed and written by members of the Early Stage Support Groups in Santa Rosa, California, and shared with members of Early Stage Support Groups in Northern California who contributed to this piece.

**To learn more about Alzheimer's disease and other types of dementia, contact the Alzheimer's Association, [alz.org](http://alz.org) or 1-800 – 272-3900**

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