



Care Partner Information

Tips for Providing Older Adult Care

Telling Others About Dementia

Many people feel worried and scared to tell others about a dementia diagnosis. They fear how they will be treated. But talking about a dementia diagnosis can be helpful — now and in the future.

Why tell others about your dementia diagnosis?

- In the early stages, it is helpful to have friends and family who know about the diagnosis. People who know can listen, give support, and tell the person that they are loved.
- If others know about dementia, they can help the person to make plans for when dementia gets worse. When dementia gets worse, friends and family who helped make care plans can speak up for the person to make sure they get the care they need and want.
- A lot of people don't know that dementia is a disease, just like diabetes is a disease. Sometimes, they will blame the person living with dementia for the changes caused by the disease. Talking openly about dementia can help them know about the changes and be more willing to help.

Who should be told about dementia?

Some people only talk with close family and friends about their diagnosis. Some may tell neighbors, coworkers or others they know. It is up to the person living with dementia to decide who to tell and when. The person may want to think about:

- Who they feel close to and trust.
- Who they feel will support them.

Call the Alzheimer's Association helpline at 1-800-272-3900 or visit www.alz.org.

This Care Partner Information page is part of a series on older adult caregiving tips. They are written to help family and community caregivers, direct care workers and community health representatives care for older adults. Available in English and Spanish at www.aging.arizona.edu

Decide What to Say

It can be hard to find the right words to talk about a dementia diagnosis. Sometimes it helps to practice what to say before telling others.

Ways to tell people about a dementia diagnosis
“I have a disease that makes it hard to think and remember.”
“I have dementia, but I’m still me. I can still love and feel. I can still do many of the things I’ve always done.”
“I have a disease that causes memory problems. Please be patient if I say the same thing again and again, or forget something you said.”

Tips for telling others about dementia

- Plan when and how to tell others. Decide if it is better to tell others one at a time, or as a group. Expect to have more than one talk over time.
- Find a quiet place to tell others. They may have strong feelings about the diagnosis.
- Explain that Alzheimer’s disease is a brain disease, not a mental illness. Share facts about dementia.
- Invite family or friends to dementia support groups.
- It is also important to tell children and teens about Alzheimer’s disease. Decide when and how it would be best to tell them.

How will others react?

Many people will offer love and support to help the person cope. Others may spend less time with the person. Often, this is because they do not know what to say or how to act. That can be hurtful. Giving facts about dementia may help.

Get more help

The Alzheimer’s Association has up-to-date information and facts about dementia that may help. They can provide more tips on how to tell others about a dementia diagnosis. The helpline and website are on the prior page.

- Who will respect their privacy.

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