



Care Partner Information

Tips for Providing Older Adult Care

When it may be Time to Stop Treatment

Advice for Families

At some point, people with dementia will be unable to care for themselves. They may not take medicine. They may not feed themselves. They may not eat or drink at all. They may become inactive. Some people with dementia want to live as long as possible, even if they are bedbound and can't think. Others may wish to stop treatment when they cannot function on their own. Everyone has the right to decide what treatment is right for them.

Stopping Treatment May Include:

- Stopping medications for dementia
- Stopping medications for other health problems
- Deciding not to treat infections with antibiotics
- Not forcing food or water
- Not calling 911, and not going to the emergency room or hospital when sick

Even if those treatments are stopped, treatment to relieve pain and assure comfort should always continue.

Advance Planning

As people living with dementia become less able to make their own decisions, they must rely on others. It is very helpful if they have signed papers that name someone to make decisions for them. They should also discuss their end-of-life wishes with that person and with their families. That will make it easier for others to know if, and when, to stop treatment.

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

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Some people don't plan in advance and it often creates problems because families might not know what the person wants. In fact, different members of the family might think different things should happen. This can cause arguments between family members, which can make a difficult situation harder for everyone.

Deciding to stop treatment is always a hard decision. It helps if families discuss this option with the person's health care provider. Seeking advice from a clergy member, social worker, or someone from the Alzheimer's Association may help. When families don't agree on what to do, a family meeting with a someone outside of the family can help.

Advice for Paid Care Partners

Paid care partners often help provide care for people with dementia. They may become close to the patient and the family. They may have strong feelings about stopping treatment, and may or may not agree with the family's decision. This can be stressful. But, it is not the paid care partner's role to pressure the family, or to discuss their decision. It is important that they support the family, not give their opinions. A smile, sitting together quietly, or a hand on the back may provide the best support.

Here are some helpful things that care partners can say:

- "This is very difficult. I know you will make the best decisions possible."
- "It might help to discuss this with your doctor or nurse."
- "The Alzheimer's Association, a clergy member, or social worker might be able to help decide what to do."

It is very important that paid care partners don't give advice or opinions to the family or the patient.

Remember that these issues should be kept private. You can discuss concerns with your supervisor. You can write out your feelings. You can discuss your feelings with a friend or counselor without naming names or specifics. Taking care of others can be difficult. Don't forget to take care of yourself!

Useful Websites:

Alzheimer's Association – Information on end-of-life decisions:

https://www.alz.org/national/documents/brochure_endoflifedecisions.pdf

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Alzheimer's disease and Related Dementia ~ Care Partner Information

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