

# Early Stage Caregiving for Young-Onset Alzheimer's

## Getting a diagnosis of Young-Onset Alzheimer's

Early diagnosis is important; unfortunately, the diagnosis is difficult to determine for younger patients.

A diagnosis of Young Onset Alzheimer's is generally made when other causes have been ruled out by medical tests, and this process may take some time.

## Working with doctors

- Be sure to find a doctor you feel comfortable with, because it will likely be a long-term relationship. It's best to work with a physician or facility that specializes in Alzheimer's and other forms of dementia. The National Institutes of Health may be able to make a recommendation. Visit nih.gov **LINK TO: <http://www.nih.gov>**
- A family member should accompany the patient to doctor's appointments; if the main caregiver is someone else, it's helpful for them to attend also.
- Consider writing down what you have observed about the person, and faxing it to the doctor before the appointment. This may help avoid embarrassment or denial on the patient's part if those behaviors are discussed during the appointment.
- Alzheimer's does not require ongoing doctor's appointments; expect perhaps only two visits per year. Get involved in support groups or online tools to help with everyday challenges.

## What caregivers can expect in the Early stage of Young-Onset Alzheimer's

Early in the disease, people are generally able to accomplish tasks independently. They will usually complete their daily routines without help. Their ability to communicate will still be intact, but they may take a bit longer to respond.

People may deny their condition; sometimes they may be trying to mask problems they're gradually becoming aware of. Don't argue with them, or try to convince them that they are

ill. Provide emotional support by showing concern, giving reassurance, and praising them for what they do accomplish.

People at this level may be able to help others who are further along, and more severely limited, by Alzheimer's. Some caregivers have gotten people at Early Stage to attend adult day programs by convincing them they are volunteering to help with other participants.

## **A downward spiral begins**

Caregiving for people with Young-Onset (also known as Early-Onset) Alzheimer's includes watching the person closely for the following indicators:

- The first sign of problems may be with short-term memory; they may not be able to recall what happened, or what you told them, a short time ago.
- They'll also begin to have difficulties when faced with complicated tasks, handling a lot of information at once, problem solving, and planning ahead.
- Their judgment may become cloudy, as they start to have trouble with abstract thought, and grasping the big picture.
- They may not be able to tolerate change, and can become confused, withdrawn or even agitated in unfamiliar circumstances.

## **Caregiving ideas and strategies**

- **Encourage independent activity.** Simplify tasks and schedules for the person to make it easier for them to plan ahead.
- **Keep routines.** There's comfort in having routines, and they give structure to the day.
- **Monitor activity.** People at this stage might rush ahead in tasks and make mistakes, or they might get bogged down in a detail. Watch how they handle situations and tasks, especially in unfamiliar settings, and plan ahead to reduce potential frustration.
- **Provide directions when needed.** This can be done subtly and in the background. People at the Early stage of Young Onset Alzheimer's will generally listen to, and be able to follow, directions. They may also be aided by written instructions like notes and lists.

- **Supervise medication.** Not following directions for prescribed medicines can have serious consequences. Start now to oversee this activity, and keep a list of medicines and their schedules handy.

- **Talk about driving.** The process of getting the person to give up driving should begin as soon as the Alzheimer's diagnosis is received. A person at this level will still be able to drive, however their ability to plan a route, or react effectively in a crisis, is already compromised. You and other family members can offer to take them where they want to go, so they don't feel isolated.

- **Watch the person's feelings.** Be alert for signs of anxiety or depression. About one of every three persons with Young Onset becomes depressed, often in the early stages of the disease. Anxiety is also common. Both conditions should be looked at by a doctor. Both can be treated effectively.

- **Encourage discussion.** Many people at this level become aware that something is wrong. Talk about what's happening, and about how both of you are feeling about it. For help with these difficult conversations, try the Alzheimer's Association, family members, a member of the clergy, or a professional nurse, counselor or psychologist.

- **Find time for fun.** Plan time to enjoy outings and activities, including with groups. Let the patient make some of the choices, if possible. Take pictures to remember the events. Even a walk or a trip to a gift shop can be simple entertainment.

## Plan for the future

People at this early stage of the disease can still take part in making plans and decisions for when the disease has progressed. Begin involving the person in conversations about:

- **Legal and healthcare issues.** Talk about what the person wants as they become more ill. Who will they want to make health care or financial decisions for them? Learn more about these issues in "[Getting Your Affairs In Order.](#)" ***LINK TO THAT PAGE***

- **Living arrangements.** Where the person lives may affect the type and amount of care that's available. If it makes sense to move to a different place, this is a good time to talk about it. Moving early in the disease might help the person establish routines in the new environment. But also think ahead to later stages of the disease, when an assisted living

facility or nursing home may become the best option. Discussing these topics now, while the person is still able to reason about them, may make the choices easier for you later on.

- **Consider the caregiver.** As the disease progresses, caring for the person will become more strenuous, time consuming, and even overwhelming. You will need backup help, as well as some time off for yourself. For now, adult day programs or in-home help can give you a break. Do not be afraid to ask other family members to help with chores and errands.

- **Learn more.** The book *Hard Choices for Loving People* by Hank Dunn offers insights, ideas, and guidance for caregivers regarding the decisions that must be made. It's available at Amazon.com and other book sellers.