

living with alzheimer's

for younger-onset alzheimer's



tips

tip 1: genetics of alzheimer's

Scientists know genes are involved in Alzheimer's. There are two types of genes that can impact whether a person develops a disease—**risk genes** and **deterministic genes**. Alzheimer genes have been found in both categories.

- Most people with younger-onset Alzheimer's have sporadic Alzheimer's disease, whose genetic ties are not very clear, but may be impacted by **risk genes**.
- The **risk gene APOE-e4** increases the likelihood of developing Alzheimer's, but does not guarantee it. APOE-e4 may be a factor in 20-25% of cases and may cause symptoms to appear at a younger age.
- A few younger-onset families have a very rare form of Alzheimer's disease called familial Alzheimer's disease which has a strong genetic link impacted by **deterministic genes**. Deterministic genes directly cause a disease, guaranteeing that anyone who inherits them will develop the disorder.
- Scientists have discovered three deterministic genetic variations that directly cause Alzheimer's disease, called "autosomal dominant Alzheimer's disease (ADAD)" or "familial Alzheimer's disease," and many family members in multiple generations are affected.

If you are considering genetic testing for yourself or a family member, be sure to consult your physician, carefully consider all the issues below, and discuss them with a skilled genetic counselor:

- Because there are no preventive treatments available, the results have no practical impact on medical treatment decisions.
- How would genetic testing impact your employment, health insurance, long-term care insurance and future plans?
- Find a genetic counselor through the National Society of Genetic Counselors at www.nsgc.org.

tip 2: get support to cope after a diagnosis

Please check below the feelings you have experienced since the diagnosis:

- | | |
|-------------------------------------|--|
| <input type="checkbox"/> Anger | <input type="checkbox"/> Fear |
| <input type="checkbox"/> Denial | <input type="checkbox"/> Frustration |
| <input type="checkbox"/> Relief | <input type="checkbox"/> Isolation |
| <input type="checkbox"/> Depression | <input type="checkbox"/> Sense of Loss |
| <input type="checkbox"/> _____ | |

Please check below the techniques you have found helpful as you learn to live with the realities of a younger-onset Alzheimer's diagnosis:

- Find healthy ways to express your frustrations and emotions. This can include physical exercise and artistic expression.
- Join an Alzheimer's Association support group and gain support from others who understand.
- Connect with other individuals with YO AD and their family members on the online community at www.alz.org, available for 24/7 connection, information and support.
- Work with a care consultant or counselor. Call the 24/7 Helpline at 800-272-3900.
- Share your feelings with trusted family and friends.
- Talk to a member of the clergy or someone who can help with spiritual needs.
- Become an advocate and talk to your legislators about the issues affecting YO AD families.

tip 2 (continued)

What other healthy coping techniques have you used?

New ideas to try:

Notes:

tip 3: assist family and friends

A diagnosis of younger-onset Alzheimer's disease may be difficult for family and friends to understand. They may have impressions of the disease that do not match what the person with the diagnosis and care partner are experiencing. They may need your help to know how to interact and assist.

Please check the tips below that you are already using and finding helpful:

- Keep participating in the activities that you enjoy as you are able to do so.
- Adapt activities to fit your needs.
- Talk with your family members about everyone's feelings and how you can help and support each other.
- Work together to compile a file with information you may need later about caregiver services and their costs, including housekeeping and respite (caregiver relief) care.
- Discuss with a professional counselor any role changes in your relationships.
- Continue to find ways to connect with each other and other family members.
- Attend support groups for people with Alzheimer's and for caregivers.

In what other ways have you been able to help family and friends understand and deal with the diagnosis?

tip 4: help children deal with the disease

Please check below the emotions you have observed in your children or grandchildren since the diagnosis:

- | | |
|--|---|
| <input type="checkbox"/> Anger | <input type="checkbox"/> Fear |
| <input type="checkbox"/> Denial | <input type="checkbox"/> Frustration |
| <input type="checkbox"/> Anxiety | <input type="checkbox"/> Loneliness |
| <input type="checkbox"/> Grief | <input type="checkbox"/> Awkwardness |
| <input type="checkbox"/> Embarrassment | <input type="checkbox"/> Resentment and Guilt |

Please check below the techniques you have found helpful as you endeavor to support your children through this time:

- Talk openly about the changes you are experiencing because of the disease.
- Answer questions honestly. Be patient and use words that are easy to understand.
- Teach children about the disease so they know what is happening now and what to expect in the future.
- Notify school social workers and teachers about your situation. Provide information about the disease and how it affects children.
- Take time for fun and engaging activities that you can still do with the children in your life. Bake cookies, take walks, go fishing, or listen to music.
- Make a point to just listen. Look for signals of their emotional needs and find ways to support them. Consider meeting with a counselor who has experience helping children with seriously ill parents.

tip 4 (continued)

- Include children in family counseling sessions.
- Invite older children to attend support group meetings.
- Record your thoughts, feelings and wisdom in writing, audio or video. Your children can use this counsel when they grow older. Important life stages you might want to discuss include: graduation, dating, marriage, births, and end of life.
- Make time for one-on-one interaction with the child.
- Refer children to the ***Kids and Teens*** page on www.alz.org.

What other techniques have you used to help your children?

New ideas to try:

Notes:

tip 5: consider your work situation

If you are impacted by Alzheimer's and are still working, there are some important things to consider and steps to take.

Do a personal work assessment:

- Review your job description.
- What are the essential functions of your job?
 - _____
 - _____
 - _____
- What job tasks are still manageable for you to complete?
 - _____
 - _____
 - _____
- What job tasks are difficult to do now?
 - _____
 - _____
 - _____
- What types of accommodations would help you be successful?
 - _____
 - _____
 - _____

Explore your benefit plans *before* making any decisions:

- Short-term disability plan _____
- Long-term disability plan _____
- Long-term care coverage _____
- Conversion options for health and life insurance _____

tip 7: plan for when the care partner is working

After a YO AD diagnosis, many people find it financially necessary for a spouse or partner to begin or continue working. This can make dealing with the disease more challenging for both the person with the disease and the care partner.

For the person at home

Please check the strategies you have used:

- Schedule a friend or neighbor to drop by during the day.
- Ask a friend to join you for exercise, lunch, coffee, or to do a hobby.
- Use programs at community centers, the public library and faith organizations to help stay active and engaged.
- Explore future care options to use as needs change.

For the working care partner

Please check the strategies you have used:

- Plan personal time off to accommodate doctor appointments and other care responsibilities.
- Speak with your Human Resources Department in order to determine which resources are available to you.
- As care needs change, consider a flexible work schedule, working from home, working part time, caregiver leave, personal leave or family medical leave.
- Find out if your employer offers an Employee Assistance Program (EAP) through which you can access counseling, case management and other caregiver resources.

What other techniques have you used?
