

PARENTS' GUIDE

HELPING CHILDREN AND TEENS UNDERSTAND ALZHEIMER'S DISEASE

HOW ALZHEIMER'S DISEASE AFFECTS KIDS AND TEENS

Alzheimer's can have a big impact on every member of the family, including children. Each child will react differently to someone who has the disease.

Young people might have questions about what's happening as the disease progresses. It's important to answer these questions openly and honestly, and share with them the changes the disease might bring.

Factors that may affect your child include:

- Their relationship to the person with dementia (a parent, grandparent, relative, friend).
- How close your child is to the person emotionally.
- Where the person lives (in the same home, long-term care facility, another state).

COMMON REACTIONS

When a family member is living with dementia, your child or teen might feel:

- Sad about how the person is changing.
- Curious about how people develop Alzheimer's.
- Confused about why the person acts differently or doesn't recognize him or her.
- Frustrated by the new things it's necessary to do, like repeating words or phrases.
- Guilty for resenting the time and resources the person requires of the family.
- Afraid of how the person may behave.
- Jealous of the additional time and attention given to the person.
- Worried that he or she — or other friends and family members — might also develop Alzheimer's.
- Embarrassed to have visitors if the person is home.
- Unsure how to behave around the person.

All of these feelings are normal. However, Alzheimer's disease impacts people, including children, in different ways. Some may respond with many of these reactions while others may have few problems or questions.

It might be difficult to recognize how your child is feeling. A child who is having a hard time understanding or accepting the disease might:

- Withdraw from or lose patience with the person with dementia.
- Express physical pain, such as an upset stomach or headache.
- Do poorly in school.
- Spend more time away from home.
- Stop inviting friends home to visit.
- Argue more, especially with those providing care for the person with Alzheimer's.

SPECIAL ISSUES FOR TEENS

Adolescence is challenging, and the disease may bring even more changes to your teen's life. For example, you may need to ask your child to pitch in more around the house or to assist with caregiving.

Teens may express a variety of thoughts, both good and bad, about how their lives have changed, such as:

- *When I help out with my uncle, I feel like my family really needs me.*
- *I feel good that I know how to do the little things that make a difference for my dad.*
- *I've never felt closer to my mom than I do now because we're facing this together.*
- *I don't like to talk with my friends about what's going on.*
- *Sometimes I feel embarrassed about how my grandpa is acting.*
- *I don't feel comfortable having friends over.*
- *My parents don't have as much time for me because my grandma takes all their attention.*
- *It's not fair to ask me to do so much. I'd rather be doing something fun.*

10 activities children and teens can do with a person with dementia:

1. Bake cookies.
2. Take a walk around the neighborhood.
3. Put a puzzle together.
4. Weed a garden or plant flowers.
5. Color or draw pictures, or look at photos.
6. Create a scrapbook or fill a memory box with mementos.
7. Read a favorite book or story.

8. Eat a picnic lunch outside.
9. Watch reruns of old TV shows together.
10. Listen to or sing favorite songs.

COMMON QUESTIONS

Encourage your child to ask questions. Answer honestly and using age-appropriate explanations. The Alzheimer's Association® can provide you with information to help answer these questions and suggestions for coping with changes that accompany the disease.

Possible answers to questions your child may ask:

Q: What is Alzheimer's disease?

A: Alzheimer's is not just memory loss; it's a disease that affects how the brain works and how a person thinks. Over time, it also changes the way a person's body works.

Q: Will my mom get Alzheimer's, too? Will I?

A: Many scientists believe that there's a greater chance of getting the disease if someone in your family has it, but not everyone who's related will get it. Most people who develop Alzheimer's are older.

Q: Why does my grandpa call me by my dad's name?

A: Changes inside your grandfather's brain may make it difficult for him to remember things like your name. This is not your fault or his. You may remind him of your dad at your age. It's best not to correct him, as that could upset or frustrate him.

Q: Will my grandma die from Alzheimer's?

A: We don't know for sure. Some people with Alzheimer's do die from the disease, while others may pass because of another serious health condition.

Q: Why does my aunt keep asking the same question?

A: People with Alzheimer's often remember events that happened years ago, but forget things that happened yesterday or even a few minutes ago. Your aunt may not remember that she already asked a question. It's important to be patient and respond, even if you've already done so.

Q: How can I help my grandpa?

A: Simply being there for your grandfather can show you care. Even when he reaches the point where communication is difficult, love and kindness can be felt in the moment.

Q: Will my uncle get better?

A: Your uncle will have both good and bad days. Even though there is no cure yet, scientists are working really hard to find one.

Q: Will I get Alzheimer's if I spend time with my aunt?

A: Alzheimer's is not contagious. You can't catch it from other people like you can the flu or chickenpox. It's a degenerative disease, which means it develops in the brain over time.

Q: What are some things we can do together?

A: Simple activities like listening to music, setting the table, reading a book and looking at photographs are great ways to spend time with the person with Alzheimer's.

Q: Will my grandma forget me?

A: As your grandmother's brain changes, she may forget many things, but she will still be able to feel your love.

HOW PARENTS CAN HELP

Keep lines of communication open

Good communication is the best way to help your child deal with the changes that are happening.

Answer questions honestly

Respond simply to questions in an age-appropriate way. Try not to sugarcoat the message. Children are excellent observers and often aware if an answer doesn't sound right.

Help your child learn more about Alzheimer's

Begin sharing information about the disease and its symptoms as soon as you can. Use words that are easy to understand and encourage your child to ask questions.

Reassure your child that just because a person in the family has Alzheimer's, it doesn't necessarily mean that he or she or other family members will get the disease,

too. Great progress has been made in scientific research and there are even treatments available now that will give some people with the disease more time to take part in daily life and spend with family. Let your child know that better treatments and even a cure could be discovered in their lifetime.

Let your child know their feelings are normal

Young people need a way to share their feelings about having a family member with Alzheimer's. Show comfort and support by letting them know that those feelings are normal.

Create opportunities for your child to express feelings

Make sure your child is getting enough support. Set aside a regular time to be together. Activities or outings can create great opportunities for a child to open up. If your child expresses feelings of helplessness, work together to find a way to get involved in the care process. For ideas, contact the Association's **24/7 Helpline** at **800.272.3900**.

Prepare your child for changes

Alzheimer's worsens over time. A person living with dementia may look healthy on the outside, but on the inside, the brain is not working properly.

Let your child know what changes to expect. Talk about what those changes will mean for him or her and your family. Also, make sure your child understands why you might have less time to spend together.

Assure your child it's not their fault

Alzheimer's can cause a person to direct confusion, fear or anger at the child. If this happens, be sure the child knows the person did not mean to act that way. People with dementia have good and bad days, and caregivers sometimes seem tired, frustrated and short-tempered. It's important for children to know that they're not responsible for how others are acting or feeling.

Inform your child's teacher and school counselor

Let them know the ways that Alzheimer's disease is affecting your child and the family. Teens may open up more to an adult outside of the family, so explore whether a teacher, counselor or another kind of mentor is available.

A RESOURCE FOR KIDS & TEENS

The Alzheimer's Association website features a Kids & Teens page (alz.org/kids) where you and your child can access information and support, as well as videos of others like them who are facing the disease in their families.

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