



Susan Gardner/Gardner Communications. Photo courtesy of Generations Together.

Helping Children and Teens Understand Alzheimer's Disease

10-year-old Susie's mother has early-onset Alzheimer's disease. Her mom loses patience with her easily, and has frequent outbursts. Susie is very confused about the changes in her mom's behavior.

Nathan, 5, is jealous that his mom is giving so much attention to his grandma. She recently moved in with them and Nathan now has to share a room with his sister. His grandma doesn't play with him like she used to; sometimes she doesn't even seem to know who he is.

15-year-old Melanie's father has early-onset Alzheimer's disease. Her mother died when she was seven. Melanie is her father's primary caregiver. She has missed several days of school, has withdrawn from after-school activities and has stopped spending time with her friends.

Alzheimer's disease is a family disease — it changes the lives of everyone it touches. Being an adult who has a parent with Alzheimer's is hard, but being a child in a family experiencing Alzheimer's is perhaps more difficult. Relationships are redefined, the individual with the disease becomes more dependent on family members, and the person they once knew is lost to the effects of the disease. A long grieving process ensues. And younger family members are often going through many other physical and developmental changes at the same time.

When children or teens learn that a family member, friend or neighbor has Alzheimer's, they may experience a range of emotions.

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How Parents Can Help

- Explain in age-appropriate terms what is happening to the person with dementia.
- Give children opportunities to express their feelings and let them know their feelings are normal.
- Answer their questions honestly.
- Help them identify activities they can do with the individual with dementia.
- Be aware of signs of anxiety or stress, such as changes in behavior, poor performance in school, or withdrawal from family and friends.
- Inform teachers and school counselors of the impact Alzheimer's disease is having on your family.

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They may feel:

- sad about changes in the person's personality and behavior.
- confused about why the person behaves differently.
- afraid of disturbing behaviors.
- worried that they or their parents might develop Alzheimer's.
- angry and frustrated by the need to repeat activities or questions.
- lonely, jealous or resentful of time and attention given to the person with the disease.

Children and teens may exhibit these emotions in ways you may not easily recognize. It is important to watch for changes in behavior that will help you to understand what they are feeling. If children and teens are having a difficult time understanding Alzheimer's disease, they may withdraw from or lose patience with the person with the disease. The emotional impact of coping with changes in family life may cause children to perform poorly in school. In some cases, stress may manifest as vague physical complaints such as stomachache or headache. Feelings of embarrassment may cause children to stop inviting friends over to the house or to start spending more time away from home.

One of the most important things you can do for your children is to learn as



Mark Luinburg/Alzheimer's Association
Photo courtesy of ONEgeneration Day Care

much as you can about the disease. Be prepared to address questions such as:

- What is Alzheimer's disease?
- Is Grandma crazy?
- Is Grandma going to die?
- Will I get it?
- Is it my fault?
- Why can't she remember my name?
- Why does she keep asking the same thing?
- How can I help?

Children As Care Partners

The impact of Alzheimer's disease on children and teens depends largely on their relationship with the person who has the disease. Most children are amazingly resilient, and the desire to relate to their loved one with Alzheimer's usually remains strong.

Because teens are at an age where they can be left at home alone and can be responsible for household chores, many teens are left to handle some caregiver responsibilities when their parents need to work or be away from home. Parents need to be aware that placing this responsibility on a teen can be overwhelming.

In spite of the challenges, adolescents who have taken on caregiving responsibilities have also reported some positive outcomes, such as feeling needed or valued, understanding the needs of people with illnesses and having a closer relationship with the parent who is the primary care partner.

How Parents Can Help

It's important to maintain open lines of communication with children and teens. Comfort and support them by offering them the opportunity to

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express their feelings and let them know that what they are feeling is normal. Begin the education process early and encourage them to ask questions. If your child is reluctant to talk with you, it may be necessary to seek the services of a counselor.

You may want to help your child or teen identify activities that they can do with the person with Alzheimer's (see list below). Activities provide an opportunity to interact and spend time together. Doing everyday chores and tasks or other fun activities can provide a positive experience for everyone involved. It may also help to find opportunities for your child to interact with other children affected by Alzheimer's. Call the Alzheimer's Association for help locating an e-mail pen pal who may be experiencing many of the same feelings.

Above all, you can help your child by making sure you are receiving support that you need. It is hard to remain in control of challenging situations when you are tired, depressed and overwhelmed. Take advantage of caregiver support groups, call the Alzheimer's Association's Helpline, ask your friends for help, and get professional advice if you feel you need it. It is important for children to have at least one person with whom they can feel secure.

For more information on how you can help children and teens cope with Alzheimer's disease, contact the chapter office nearest you at 800.337.3827 and request age-appropriate information that will help you talk with your child about Alzheimer's. Books and other resources can provide an opportunity to start a conversation about the disease. •

Excerpted from Advances Vol. 23 No. 3, Fall 2003, the Alzheimer's Association and Helping Children Understand Alzheimer's, MayoClinic.com.

Activities Children and Teens Can Do With a Person With Dementia

- Create a scrapbook together
- Collect items for a Memory Box - include items important to the person with dementia
- Write a poem together
- Interview the person about his life with a tape recorder or video camera
- Look at family photographs
- Read out loud chapters from Harry Potter books or other favorite stories
- Play favorite songs and sing
- Look at pictures in a book
- Take a walk together around the yard

Resources

Books for Children and Teens

Available through Chapter Lending Library

"The Voice of the Climbing Rose: A Tribute to Caregivers"
Perry, 2003

"When Meme Came to Live at My House"
Langdon, 1998

"Singing with Mama Lou"
Altman, 2002

"Daddy, I Remember: Hope and Healing for Families of Alzheimer's"
McWilliams, 2004

Video

Available through Chapter Lending Library

"Just for the Summer"
SVE & Churchill Media
1990

Brochures and Fact Sheets

"Helping Children and Teens Understand Alzheimer's Disease; A Guide for Parents"
Alzheimer's Association, 1997

"Just for Children: Helping You Understand Alzheimer's Disease"
Alzheimer's Association, 1997

"Just for Teens: Helping You Understand Alzheimer's Disease"
Alzheimer's Association, 1997

To locate a lending library in or near your community or to request a brochure or fact sheet, call the chapter office nearest you at 800.337.3827.