



## *Talking to Children and Teens*

Alzheimer's disease impacts family life. Take the time to talk with the children and teens in your family so that they understand what is happening to the person with Alzheimer's.

The degree to which children and teens are affected by the disease depends on who has it — a parent or grandparent, relative or friend. Other factors include how close the child or teen is to the person and where the person lives (in the same home, assisted living or nursing home, out-of-state, etc.)

### Helping Children and Teens Cope

"This is the only childhood they will ever have, a crucial time of development. Choose to see your illness not as an obstacle but as a powerful platform from which your messages are amplified, helping your children understand and believe you and feel your love in a powerful way....When the facts are couched in love and hopefulness, you can guide your children toward a life-enhancing perception of reality."

- Wendy Harpham, MD\*

Children as young as 18 months begin to understand the world around them. It's important to be honest with them and explain that your loved one has Alzheimer's. Experts say that telling children the truth about Alzheimer's is better than letting them imagine the worst.

Your own daily stresses and fears can affect how you act with your kids. You may be torn between wanting to give time to your kids, and knowing your loved one with Alzheimer's also needs your time. That's why it's good to let children know how you are feeling, as well as to find out how they are feeling. And never assume you know what your children are thinking. You don't know how they will react to information, either.

### Start Giving Information

For some families, talking about serious issues is very hard. But as hard as it may be, not talking about them can be worse. Here are some things you might want to say to children of any age about your loved one's Alzheimer's:

#### About Alzheimer's

"Nothing you did, thought, or said caused the Alzheimer's."

"You are not responsible for making her well. But there are ways you can help her feel better while the doctors try to make her improve."

"You can't catch Alzheimer's from another person."

"Just because someone has Alzheimer's doesn't mean other people in the family will get it - even later. And that includes you."

#### About Dealing with Alzheimer's

"It is okay to be upset, angry, scared, or sad about all this. You may feel all kinds of feelings. You'll probably feel happy sometimes, too. It's fine to feel all these things."

"No matter what happens, you will always be taken care of."

"People may act differently around you because they're worried about you or worried about all of us."

#### Be Open to All Forms of Communication

Talking about the impact of Alzheimer's may be hard for very young children. You might try asking them to draw a picture of the person with Alzheimer's. Or have them play dolls, with one doll being the patient. Other forms of art can help older children express themselves.

Keep in mind that young children may ask the same question over and over. This is normal, and you should calmly answer the question each time. Teens may ask difficult questions or questions for which you don't have answers. Be honest with them. Remember that thinking through these issues is part of your children's process of growing up.

#### Talking About Death\*

Be prepared for questions and concerns about death from your children. They may worry, even if your loved one's prognosis is good.

Teach them that Alzheimer's is an illness. If your loved one's prognosis is good, let them know that the type of Alzheimer's he or she has is one the doctors feel they can treat for awhile.

Ask them what they think about your loved one's Alzheimer's and what they worry about. Then listen patiently to their answers. Correct misinformation.

Tell them the truth, couched in love and hopefulness. Instead of trying to convince them of a good outcome that you can't guarantee, reassure them that your loved one is getting good care, and that you can live well with the uncertainty.

Teach your children that even if the unexpected happened due to Alzheimer's or anything else, they would be taken care of and be okay. Although they would feel sad for a while and they would miss your loved one, they would also feel that love forever and learn how to be happy again.

Remind them that your loved one is not dying now. Reassure them that you will tell them if this ever changes and dying becomes a possibility. Conclude by encouraging them to focus on today.

### Stay Involved in Activities

It can be hard to remain active in your children's lives during your loved one's treatment. But it may be more important than ever to do so. Below are some ways that other caregivers have stayed connected with their children.

### Ways to Stay Involved in Your Children's Lives

Focus on the most important activities.

If you can only do one thing with each of your children, what's most important? Make a list of all the options. If possible, get the children's input. You may be surprised by what they choose.

Send someone else.

Is there another adult in your child's life who can go to an event that you can't? Maybe this adult can videotape or take pictures of the event.

Carpool.

Take turns driving with other parents.

Be around before and after.

Try to be around to help prepare your children for an activity and to welcome them home.

Ask for a replay.

If you can't be there, sit down with your children to hear about what they did. Or have your children re-create some of the things that happened.

Create new ways of connecting.

Come up with new ways to connect. Make a point of tucking them in at bedtime, eating together, or talking on the phone or by e-mail. Have a set time when your children do homework while you do something else in the same room. Or take a walk together. Even 5 minutes alone with each child without interruptions can make a world of difference.

Involve your children in "your" activities.

Could your children join you for any of your activities? Even going to the grocery store could be time spent together. Your children may feel special if they can attend adult events with you.

Stay involved with their schooling.

Check with their teachers to find out how your children are doing in school. Or ask a guidance counselor or coach for input.

### Understand Your Children's Actions and Feelings

Children react to a loved one's Alzheimer's in many different ways. They may:

Be confused, scared, angry, lonely, or overwhelmed

Be scared or unsure how to act when they see the treatment's effects on your loved one

Act clingy or miss the attention they used to get

Feel responsible or guilty

Get angry if they're asked to do more chores around the house

Get into trouble at school or neglect their homework

Have trouble eating, sleeping, keeping up with schoolwork, or relating to friends

Be angry that someone else is taking care of them now

These behaviors are normal. Still, your child may need extra support to deal with their troubles.

### Understanding Teens' Feelings

With teens, problems may be less obvious or more complicated than with younger children. Here are some things to keep in mind:

Teens are supposed to be moving toward independence from their families. This is natural for them. Alzheimer's makes this harder to do, leading some teens to act out or withdraw.

Teens may give off the message, "leave me alone." But they still need and want your attention and support.

Being a teen is always stressful. Some moods you see may have nothing to do with your loved one's illness.

Teens want to feel normal. Make sure that they have time for regular activities.

Keep the lines of communication open. Involve teens in decisions as much as possible. Make sure that they have someone to talk to about what is going on in their life. It may be hard for you to stay on top of your teen's activities and feelings right now. If so, ask another responsible adult to stay connected with your teen.

### How Children May React, and What to Do\*

If your children seem confused or scared:

Remind them that you love them.

Set aside special time that each child can spend with you or your loved one.

Try to stick to reassuring routines, such as reading bedtime stories or checking in with them after school.

Be together, even if you are each doing different things in the same room.

Prepare children for changes and side effects so they won't be surprised.

If your children seem lonely or miss the attention they used to get:

Help your children talk about their feelings and ask you questions. Let them know you're listening and validate their feelings.

Find new ways to give your children attention. You may want to leave notes where they will find them or schedule special phone conversations if you're spending a lot of time at the hospital or away from home.

Think of a special treat your children might enjoy.

Encourage them to talk with other kids or adults to ease their loneliness.

If your children have stopped doing their regular activities:

It isn't okay for your kids to respond to the changes at home by stopping normal activities or letting grades and friendships slide. Find out why your children have stopped any usual activities. They may be:

Feeling tired

Feeling unhappy

Having trouble getting along with friends

Unable to concentrate or succeed

Talk about the importance of adjusting to these changes at home. Ask your children how you can help them get back to their normal routines.

If your children feel guilty and think they somehow caused the Alzheimer's:

State clearly, and remind them, "You did not cause the Alzheimer's. You can't cause Alzheimer's by anything you do, think, or say."

Explain in simple ways how Alzheimer's develops.

Read a children's book together for children of loved ones with Alzheimer's.

Ask a doctor or nurse to explain the facts.

If your children feel angry or resentful that their own lives are affected:

(for example, having to be quiet, doing more chores, missing out on fun activities with friends)

Validate their feelings. Talk with them about what is causing the anger. Even though you may know the anger comes from fear or fatigue, it's important to listen to what they say and acknowledge their feelings.

Help your children understand that their anger may be a stand-in for something else. Maybe they're really angry at the Alzheimer's or at the family. Maybe they're scared or worried. Or maybe they're sad.

Do your best to try not to get angry back at them. Again, the anger is probably about something else.

If your children start to rebel or get into trouble:

Tell your children that you understand how they feel. You know that this situation is hard.

Find out if they are acting out of fear, anger, loneliness, or boredom. Whatever the feeling, remind them that it is okay to feel that way. But it is not okay to act out in this way. If necessary, ask a teacher, pediatrician, or counselor for advice and support.

#### Tips for Talking With Children of Different Ages

##### Youngest Children (2-5 years old)

Plan to talk for a very short time. Children this age can focus only for brief periods.

Be clear and simple. It may help to draw a picture of what is happening.

Tell them about any changes in their routine for the day or in the near future.

Offer to answer any questions and to talk any time.

##### Young Children (6-9 years old)

Plan to talk for a short time. Children this age can focus only for brief periods. Plan more than one talk to cover what you need to say.

Remember that young children may have strong feelings. They may express them by focusing on something else during your talk. This is okay. It allows them to deal with information and feelings at their own pace.

Use examples. You could remind them of a time when they got sick and went to a doctor to get better.

Help them to understand the things that will be happening soon. Children this age can't think weeks or months into the future.

Let them know they will be taken care of and by whom.

Answer all their questions. Invite them to talk more later.

Pre-Teens (10-12 years old)

Plan for a slightly longer talk. Let your children set the pace of the talk.

Find out if your children already know the facts about Alzheimer's. Make sure that what they have heard applies to your loved one's situation. If not, give them the right information.

Be aware that your children may ignore or avoid topics when they are afraid.

Use simple, concrete information.

Talk not only about now, but also about the future. For example, tell them how the Alzheimer's may affect your family at holidays or upcoming events.

Tell your children you will do your best to answer their questions. Let them know you're there to talk whenever they want.

Teens (13-18 years old)

You may be able to have a longer talk. Let your teens set the pace.

Be prepared if your teens try to ignore or avoid topics. Teens may act this way because they're afraid or even embarrassed.

Teens often need time to themselves to deal with their feelings. They may want to be alone or with friends. Give them this time.

Teens should be told the facts about the Alzheimer's. This can help you correct any wrong information that they may have. Give your teens booklets to read later. They may want to do their own research. If so, make sure that what they learn is from a reliable source and applies to your loved one's situation.

Often teens ask many "what if" questions. They may want to know more about the future. Again, answer their questions as best you can. And let them know you'll be glad to talk again later.

Teens may also want to know how the Alzheimer's will affect them. Will it disrupt their social life? Will they have to do more chores? This is normal. Be honest with them.

Communicating with Your Partner with Alzheimer's

"I try to give my husband time to think things through. Not to be so quick to try and fix everything." - Pauline

Some relationships get stronger during Alzheimer's treatment. Others are weakened. Nearly all caregivers and their partners feel more stress than usual as a couple. They often feel stress about:

- Knowing how to best support each other
- Dealing with new feelings that come up
- Figuring out how to communicate
- Making decisions
- Changing roles
- Juggling lots of roles (such as childcare, housekeeping, work, and caregiving)
- Changing their social life
- Changing their daily routine
- Not feeling connected sexually

People express their emotions differently. Some like to talk things out or focus on others. Others like to express emotions by doing things, such as washing the dishes or fixing things around the house. They may be more likely to focus inward. These differences can cause tension because each person may expect the other to act the way they would in their place. To reduce stress, it may help to remind yourself that everyone reacts differently.

### Bringing Up Hard Topics with Your Loved One

Bringing up tough subjects is emotionally draining. You may think, for example, that your loved one needs to try a different treatment or doctor. Or she may be worrying about losing independence, being seen as weak, or about being a burden to you, but doesn't want to talk about it. Here are some tips on how to bring up hard topics:

- Practice what you'll say in advance.
- Know that your loved one may not want to hear what you have to say.
- Find a quiet time and ask if it's okay to talk.
- Be clear on what your aims are. (Let your loved one know why you are having this talk and what you hope will come from it.)
- Speak from your heart.
- Allow time for your loved one to talk. Listen and try not to interrupt.
- Don't feel the need to settle things after one talk.
- You don't have to always say, "It'll be okay."

Sometimes the best way to communicate with someone is to just listen. This is a way of showing that you are there for them. It may be one of the most valuable things you can do. And it's important to be supportive to whatever your loved one wants to say. People need to process their thoughts and fears in their own time and their own way. You could

also ask whether she is willing to think about the issue and talk another time. Your loved one may even prefer to talk with someone else about the topic.

Some people won't start a conversation themselves, but may respond if you begin first. Here are some ways caregivers do this:

"I know this is hard to talk about, but know that I'm ready to listen or to talk any time."  
"I feel that it would be helpful to talk about how things are going so far and how we're both coping with it. Would you be willing to talk with me about that sometime this week?"

Sometimes it helps to ask other caregivers how they talk to those close to them. For example, you may want to ask:

How do you keep another person's feelings in mind when you're coping with so many feelings of your own?

How do you talk about tough topics and still stay supportive?

If you continue to have trouble talking about the Alzheimer's and painful issues, you could ask for help from a mental health professional. One may be able to explore issues that you didn't feel you could yourself. But if your loved one doesn't want to go with you, you can always make an appointment to go by yourself. You may pick up some ideas for how to bring up these topics, and talk about other feelings that you are coping with right now.

### Ways to Improve Communication

"I've noticed that my husband tries to stay really positive with everyone else, even his parents. He'll say he's doing great. This is frustrating for me because at home, I see that he isn't doing great." - Betty

Some couples find it easier to talk about serious issues than other couples. Only you and your partner know how you feel about this. The sections below may help you think about ways to communicate that work for both of you.

### Be Open About Stress

Some things that cause stress for you and your partner can't be solved right now. Sometimes talking about these things can be helpful. You may want to say up front, "I know we can't solve this today. But I'd like to just talk about how it's going and how we're feeling."

Topics to explore may include how each of you:

Deals with change and the unknown

Feels about being a caregiver or being cared for

Handles changing roles in your relationship or home

Wants to connect with one another  
Sees what issues may be straining the relationship  
Feels, or would like to feel, cared for and appreciated  
Feels thankful for the other person  
Become a Team

"I feel like it's been such a blessing to be able to show my husband way beyond words how much I love him. And to see him fighting Alzheimer's because of his feelings for our children and me. It's a privilege to be so closely involved in something of such value and importance." - Rose Mary

You and your partner may need to be a team now more than ever. It may help to think things through together:

Which decisions should you make together?  
Which decisions should each of you make alone?  
What were some other tough times that you got through together? How is this situation the same or different?  
Which family tasks could you share?  
What kinds of tasks are easier for you? Which ones are harder?  
What does each of you need?  
How can others help?  
Find Ways to Say Thanks

Perhaps your partner used to do a lot to keep your family going. And now you're trying to get used to less help. It may also be hard to notice the small things your partner is doing to get through this hard time. There's just too much going on. But when you can, try to look for these things, and thank your partner for doing them. Showing a little gratitude can make both of you feel better.

### Make Dates

Many couples find that it helps to plan special occasions. Some days may end up being better than others for these dates, depending on how your partner feels. So you may need to be okay with last minute changes.

You don't have to be fancy. It's about spending time together. That can mean watching a video, going out to eat, or looking through old photos. It can be whatever you both like to do. You can also plan these dates to include other people, if you miss being around others.

Any problems your family may have had before the Alzheimer's diagnosis are likely to be more intense now. This is true whether you are caring for an adult child, a parent, or a spouse. Your caregiver role can often trigger feelings and role changes that affect your family in ways you never expected. And relatives you don't know very well or who live

far away may be present more often, too, which may complicate things. Some people have said that:

Seeing your parent as someone who needs your help can be hard to accept.

"My mother got Alzheimer's. Just like she nursed me back to health as a child, I wanted to do the same for her. Yet she's used to doing everything herself. She keeps saying, 'I'm still your mother.'"

"I have my own life, with young kids to take care of, and a job. It's hard trying to figure out how to help my dad."

Seeing an in-law or a friend's parent worry or try to help out can feel like "too much."

"I need to run my own home. I know his mother just wants to help, but she's too much in my business right now."

### Communication Troubles

Studies show that open and caring communication works best. Yet caregivers often run into:

Tension from different ways of communicating

Lack of sensitivity or understanding about appropriate ways to talk and share feelings

People who don't know what to say, won't communicate at all, or won't be honest

### Hold a Family Meeting

"You do want to stay positive and upbeat. But at the same time, I feel like you want to share your reality with other people in your family so that they can know how to support you and how not to be shocked if things get worse." – Ken

Sometimes other close family and friends may not agree on what should be done. It's very common for families to argue over treatment options. Or they argue that some caregivers help more than others. While everyone may be trying to do what they think is best for your loved one, family members may disagree about what this means. Everyone brings their own set of beliefs and values to the table, which makes decisions hard. It is often during these times that families ask their health care team to hold a family meeting.

Talk with your loved one to see if she wants a family meeting. Ask if she would like to be involved. At the meeting, all members share as much information as they can. You can ask a social worker or counselor to be there, if needed. If you need to, you can bring a list of issues to discuss. Meetings can be used to:

Have the health care team explain the goals for treatment.

Let the family state their wishes for care.

Give everyone an open forum in which to express their feelings.

Clarify caregiving tasks.

During these meetings, family members may want to talk about how they feel. Or you may want to decide what kind of help they can offer. Each person may have certain skills to offer.

At the end of the meeting, ask the health care team to summarize and plan the next steps.

Choose the Right Time

Sometimes when one person feels like talking about important things, the other person doesn't. Try choosing a time when you and the person you want to talk to won't be doing other things. Find a quiet place, turn off the TV, and don't answer the phone.

Keep People Updated

Often, you will be the main person updating family, friends, and coworkers about how the patient is doing. Ask your loved one what he wants to share, with whom, and when. If this is a task that someone else can do, select a "point person." This person can make phone calls or send e-mail or letters to update others. It's important to let others who care know whether your loved one likes getting cards, calls, or visits.

How to Communicate When Support Is Not Helpful

"My sister-in-law came by and commented on how much television the kids were watching. She made some remark about how she knew I was stressed, but could I find something better for them to do? It's like she was trying to make me feel like a bad mother or something." - Carrie

If people offer help that you don't need or want, thank them for their concern. Let them know you'll contact them if you need anything. You can tell them that it always helps to send cards and letters. Or they can pray or send good thoughts.

Some people may offer unwanted parenting advice. This may come from feeling helpless to do anything, yet wanting to show their concern. Since they can't offer advice on medical care, it helps them to express their opinion on child care. While it may come from a good place, it may still seem judgmental to you.

It's your decision on how to deal with unwanted advice about your kids. You don't have to respond at all if you don't want to. If you think their concerns are valid, then talk to a counselor or teacher about what steps to take. Otherwise, thank them. And reassure them that you are taking the necessary steps to get your children through this tough time.

Feelings and reactions

Children and teens may feel:

Sad about changes in a loved one's personality and behavior

Confused or afraid about why the person behaves differently

Worried that the disease is contagious and that they will get it

Worried that their parents might develop the disease

Angry and frustrated by the need to repeat activities or questions

Guilty for getting angry or being short-tempered with the person

Jealous and resentful because of the increased amount of time and attention that is given to the person with Alzheimer's

Embarrassed to have friends or other visitors to the house

Children and teens may exhibit their emotions in ways you may not easily recognize. They may:

Verbalize vague physical complaints, such as a stomachache or headache

Perform poorly in school

Spend more time away from home

Stop inviting friends to the house

Ways to help children and teens cope

Offer comfort and support

Provide opportunities for them to express their feelings - give them permission to express themselves without repercussion. Don't be judgmental. Remember, they see the world and what is going on around them through a young, inexperienced 'eye'. Just LISTEN - that is what they need most, and honesty from you.

Let them know their feelings are normal and they can talk to you about them at any time.

Educate them about the disease and encourage them to ask questions

Respond honestly to questions

Activities that can help and be done as a family;

Go for a walk

Do household chores together, such as folding laundry, raking leaves or washing dishes

Listen to music, dance or sing

Look at old photographs

Read a favorite book or newspaper

Create a scrapbook or photo album about the person

Make a family tree

Watch a movie

Keep a journal together

Let them help with the Care Giving – make them feel important about the job they do.

Behavior watch:

Watch for signs of Depression in your child. This can be precipitated by lack of attention. Most children want structure in their lives. They really don't like 'changes'. Be sure you maintain a structure – including discipline – so they feel safe and secure. Children worry a lot – they create 'monsters' real quick. Communication is the key to keeping your child feeling safe and secure. Letting them know what is going on, and why things are happening the way they are. They cope much better with honesty than they do with the way they fill in the blanks for themselves.