Supporting Children of a Parent Living with ALS

ALS ASSOCIATION
Oregon and SW Washington Chapter
The ALS Association Oregon and SW Washington Chapter is the central source for care services and education for people with ALS, their families, caregivers and health care professionals in the State of Oregon and the six counties of SW Washington.

People diagnosed with ALS who have children or grandchildren can benefit from the information in this booklet. This information is insightful, accurate, and we believe useful for parents who will begin the process of ALS communication with their children or perhaps grandchildren.

We hope you find value, comfort and support in this booklet – *Supporting Children of a Parent Living with ALS*.

Our support of families is strengthened by our community based partnerships with organizations that provide compassionate care and support to children, teens and families experiencing the complexities of loss and grief. Their work helps our Chapter meet the needs of families living with ALS and their children.

We are grateful to The Dougy Center for Grieving Children and Families and their Pathways Program for children, teens, and families facing an advanced serious illness. *For more information about The Dougy Center, visit www.dougy.org.*

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SUPPORTING THE CHILDREN OF A PARENT WITH ALS

When a parent is diagnosed with ALS, it is natural for the entire family to experience a grief response. As you gain a greater understanding of how children experience change and loss, you can help your children through the normal and necessary process of adjusting and grieving.

While children are naturally strong and resilient, your intentional support is important in helping them establish a solid framework to make sense of difficult experiences now and throughout their lives.

This booklet has been created to explore the impact a parent’s serious illness can have on his or her children, including the unique grief responses that may occur. Many of the insights have been provided by families and children who have walked this journey. We encourage you to consider the tools and conversation examples as a way of increasing your confidence in sharing difficult information as you strive to best support your children.

GENERAL FACTORS

Children grieve as part of a family.

As roles and responsibilities adjust to accommodate new needs in your family, your children may grieve not only because their parent is ill, but also the many small and large changes that follow, such as:

- Changes in daily routine
- Decreased emotional availability of adult caregivers
- Increased individual responsibilities within the family
- Changes in the ability of the ill parent to interact as they have in the past

Children re-grieve.

Caregivers often express surprise when their children shift from “being fine” to having difficulties in school or relationships as a result of the illness. It may be helpful for you to know that children work through grief in cycles. As your children develop, they will use new skills to gain further understanding and an ability to express how their parent’s illness impacts their lives.
Children are repetitive in their grief.

Your children may ask the same questions repeatedly about the details of the illness; this is a normal way children attempt to better understand what is happening in their life. When you answer your child’s questions with consistent information, it enables a greater sense of stability and trust, a necessary foundation for them to be able to process their grief in healthy ways.

Young children are concrete thinkers.

You may find yourself wanting to use “softer language” to describe ALS to your children, but we’ve learned from other families that this can actually lead to more confusion. The best way to communicate with your children about ALS is through concrete, truthful language that utilizes correct medical terms. For example, “We’ve been told by the doctor that your father has a very serious illness called ALS or Lou Gehrig’s disease.

Children have “magical thinking.”

It is common for all children to think they have the power to make things happen in their lives, which can lead them to feeling responsible for their parent’s illness. It is important to convey to your children that thoughts and feelings are not powerful enough to cause sickness, emphasizing that the ALS is no one’s fault.

Children worry about their own well being.

It is developmentally normal for a child to be most concerned with his or her own security and well-being. Because you may become increasingly focused on the ill parent’s needs, your children may worry about how they will be taken care of. Many parents describe their children becoming more clingy, as well as the challenges involved in balancing time between caring for the ill parent and the children.

Children have regressive behaviors.

In the midst of this challenging time, your children may revert to behaviors they have previously outgrown (i.e., bedwetting, thumb sucking, etc). This is a common and normal expression of grief in children of all age groups. Your children may benefit from individual attention in a way they were comforted at an earlier age, for example, a favorite bedtime story, stuffed animal or blanky.
SUPPORTING YOUR CHILDREN AS THEY GROW AND CHANGE

As your children grow and develop, the way they experience, understand and interact with the world around them changes as well. As you have probably experienced already, this journey also requires you to grow in an understanding of their needs.

Because of the challenges your family is already facing, this may feel somewhat daunting. You may find it difficult to distinguish whether your children’s behavior is due to normal developmental changes or as a result of the impact of ALS in your family. Both are probably true!

Below is a simple outline of behaviors to anticipate at the different stages of your child’s development, considering the challenges your children experience with a parent living with ALS. We have also included suggestions intended to assist you as you support your children. Note that the many of the characteristics described are often interchangeable between age groups, depending on each child’s unique development.

AGES 2 - 4

Characteristics:

- Because language is not yet mastered, feelings are often seen in behavior.
- Grief responses are intense but brief.
- Are highly aware of parent’s reactions.
- Often regress in behavior and skills.

Ways to support:

- Provide comfort and reassurance that they will be cared for. If there will be changes in who will provide care, share specific names and any other details.
- Continue to meet basic needs, such as healthy meals and snacks, consistent bedtimes, and other activities related to maintaining a regular schedule.
- Provide honest information.
AGES 4 - 7

Characteristics:

- May act as though nothing has happened, grieving in spurts.
- Are often concerned about how and why their loved one became sick, and ask repetitive questions about this.
- Exhibit regression in behavior and skills.

Ways to support:

- Provide clear, honest information regarding ALS.
- Provide consistent answers to questions.

AGES 7 - 11

Characteristics:

- Have morbid curiosity.
- Wish to “fit in;” are more socially aware and concerned with how others are responding.
- May desire privacy, and not want information shared, i.e., with friends and teachers.

Ways to support:

- Encourage and validate healthy expression of feelings.
- Engage in physical activities as an outlet for grief expression.
- Be available, but also allow alone time.
- Consult with them about what information they want shared.

AGES 12 - 18

Characteristics:

- Have a more complex understanding of death and loss.
- Experience an emotional struggle between independence and dependence.
- More likely to talk with someone outside the family.
- May demonstrate grief through physical or behavioral expressions.

Ways to support:

- Encourage and validate healthy expression of feelings.
- Listen, listen, and listen with openness.
- Recognize and affirm the need for time alone and with peers.
TALKING TO YOUR CHILDREN ABOUT THEIR PARENT’S ILLNESS

You may find it challenging to share difficult information with your children about the ALS Diagnosis

It is normal to:

- want to protect your children.
- worry about how they will be affected by your emotions.
- be concerned about the effect of the illness on them.
- be unsure of their ability to understand what’s happening.
- receive mixed advice from others.

However, without good information your children may:

- intuit that something has changed.
- interpret body language, stress & tone of voice.
- become concerned or anxious.
- overhear confusing conversations.
- imagine a situation to be different than it actually is.

HELPFUL SUGGESTIONS:

Anticipate the best time and setting to initiate the conversation with your children. Be aware of any initial fears that may need to be addressed, such as relocation and changes in routine.

Allow some choice and control about when and where your children would like to hear the information, such as at dinner, bedtime or in the car.

Example: “Would you like for us to talk about it now, or would you prefer a different time?”

Inform your children that there is information about their parent’s health that you would like to talk about. This honors your children’s importance in the family.

Example: “The doctor told us some information about your dad’s health that feels important for us to share with you.”
Tell the truth using simple, correct medical language.

**Example:** “You know dad has been in the hospital all week. We’ve learned from the doctor that he has an illness called ALS or Lou Gehrig’s disease. There will be lots of appointments and changes in your dad.”

If the information feels too difficult to share at this time, an example of being truthful would be, “It’s too difficult for me to give you all of the information right now.”

Expressing your own emotions can give your children the confidence to share their feelings.

**Example:** “The reason that I am crying is because this new makes me sad. It’s okay for you to have feelings too.”

Invite your children to ask questions. Provide honest, simple answers.

If you don’t know the answer, it is okay to say, “That’s a really good question, but I don’t know the answer either. Would you like for me to try to find out some more information about that for you?”

Reassure your children that their needs will continue to be met by the people in their lives who love them. Your children may need specific details, including names of those who will help care for them, and should definitely be told if there will be significant changes in their routine.

**Example:** “Grandma will be staying with us and helping while dad is receiving treatment. She will drive you to school and soccer practice.”

Causation and contagion. Explain to your children that no one caused ALS, and that they cannot catch the illness.

When the parent’s needs are increased, provide information to your children about any equipment and treatment that will be provided in the home. Try keeping your children’s routines as normal as possible is helpful. Acknowledge the impact and talk openly about any changes which will occur in their routine. If possible, involve your children in simple care giving tasks, such as sharing a comfort item or glass of water.

If your children are school age, it is important to consult with each child in your family about his or her wishes before sharing any private information with school staff or other families. It is not unusual for a child to desire that no one at school be told about the illness.
Look for these books at your public library. Most are also for sale at online retailers such as www.amazon.com

**AGES 3-6**

*Lifetimes: The Beautiful Way to Explain Death to Children*
*by Bryan Mellonie and Robert Ingpen*
Explains life and death in a sensitive and natural way.

*Sad Isn’t Bad: A Good-Grief Guidebook for Kids Dealing with Loss*
*by Mechaelene Mundy*
Promotes honest and healthy grief and growth by providing a comforting, realistic look at loss and life-affirming ideas for coping.

*When Bad Things Happen: A Guide to Help Kids Cope*
*by Ted O’Neal*
Helps adults talk to children about the child’s feelings, fears and skills for coping and healing in times of change and challenges.

**AGES 6-12**

*Aarvy Aardvark Finds Hope*
*by Donna O’Toole*
A read aloud story about loving and losing, friendship and hope.

*Ocho Loved Flowers*
*by Anne Fontaine*
The story of a young girl who learns how to say goodbye to her beloved cat while treasuring memories. A helpful, sensitive way to support a child when the death of a loved one is anticipated.

*The Invisible String*
*By Patrice Karst*
A story that shares that there is an invisible string, or bond, between kids and their loved ones, even when the loved one isn’t physically present.

*The Memory String*
*by Eve Bunting*
Invites readers to remember family history while welcoming new memories.
AGES 6-12, CONTINUED

Tough Boris
by Kathryn Brown
Through the story of a rough and greedy pirate, Tough Boris explains that having feelings is normal and that it is okay to be sad sometimes.

AGES 13-18

Common Threads of Teenage Grief
by Janet Tyson and Teens Who Know
Available at www.centering.org
Promotes an understanding of grief and healing for teens, their families and friends. Written by a middle school counselor and nine teens.

Facing Change: Falling Apart & Coming Together Again in the Teen Years
by Donna O’Toole
Information to help teens cope, understand and grow through their losses.

Healing Your Grieving Heart For Teens: 100 Practical Ideas
by Alan D. Wolfelt, Ph.D.
Written to help teens understand and deal with their unique grief.

Help for the Hard Times: Getting through Loss
by Earl Hipp
A guide that helps teens understand how they experience grief and loss and gives them tools for coping with their grief in healthy ways.

FOR PARENTS

The Journey Through Grief and Loss: Helping Yourself and Your Child When Grief is Shared
by Robert Zucker, M.A., L.C.S.W.
Offers parents and other concerned adults important insights into managing their own grief while supporting grieving children.
OUR MISSION

The ALS Association leads the fight to treat and cure ALS through global research and nationwide advocacy while also empowering people with Lou Gehrig’s Disease and their families to live fuller lives by providing them with compassionate care and support.

For more information about ALS and additional resources available in your community, please visit us at www.alsa-or.org, call us at 800-681-9851 ext 100 or email us at careservices@alsa-or.org.