

PATIENTS AND THEIR FAMILIES

Talking to children about ALS/MND

A week after my brother Ben was officially diagnosed with ALS, my daughter was born. I know from experience that ALS/MND can have a serious impact on patients and their families, especially on children. Regardless their age, all children need someone who is prepared to listen to them; someone who can answer their questions in an age-adjusted way.

Some children ask many questions, but others keep everything to themselves, ponder in silence and never express their thoughts. There is no good or bad way for children to cope with the situation. But it is very important that they can talk to someone about their feelings around the situation.

Dr. Paul J. Kachoris is a certified paediatrician and child psychologist, youth psychologist and adult psychologist with more than 40 years of clinical experience. He is also very close to our family, so he knows very well what impact ALS/MND had on me, my wife and children. When I asked him to give me some tips on how to deal with this as parents, he stressed how important the role of parents was when talking about ALS/MND. Children (un) consciously pick up signals about how their parents deal with ALS/MND. This determines the children's reaction for a big part. This reaction is all-important for the dynamics in your family.

Below I'll give some more advice and tips for parents and their loved ones to talk appropriately and comprehensibly to children about ALS/MND.

Do I have tell children about ALS/MND?

All experts agree: YES. If parents stay silent about it, children could get the idea that you or they should feel ashamed or be afraid of ALS/MND. It's important to be open to your children and to be aware of the fact that children are always learning new things. So, their questions change as they get older. Some children have to be reminded repeatedly that it is okay to ask questions. They bring up ALS/MND often.

Be honest:

It is vital to be open and honest. Children know when a parent or loved one is scared or not honest to them. Some children refuse to listen if you are not honest. Make it clear to them that ALS/MND is not easy to understand and that you want to help them do so. Explain them that it is not their fault and that it is not a punishment. You can never know who gets diagnosed with ALS/MND and it is not contagious. ALS/MND influences

everyone differently and you never know what the future brings. Make it clear to them that there will always be someone to take care of them.

Balance:

You know what the best way is for your child to learn, but most children react better to small bits of information rather than telling them everything at once. Listen carefully to your child. He or she will

let you know (either direct or indirect) when they have received enough information and come back for more when necessary. This counts for children of all ages.

Comfort:

Try to talk as calm and comforting as possible. It may be good to try out some ideas and angles for such a conversation first on a friend or family member in a role play. Discussion groups can get an appropriate place to practice as well.

When should you look for help?

If your child is behaving strangely, if he or she has a regressive behaviour, seems depressed, or if you think something is wrong, then it is a good idea to seek help. Whether it takes the form of play therapy for a younger child, individual or group therapy for an older child, or an appointment with a teacher or a health care provider, it is always alright to ask help and to inform other adults in your child's life about the situation. Sometimes it is easier for children to share their worries with a therapist or social worker. If you need assistance to look for help in your environment, please contact The ALS Liga. You can find brochures for children of all ages on our website.

Talking to toddlers:

Use words that your child understands and try to keep it brief. If this is the first time you talk to a toddler about the disease of his or her parent, you can say something like 'Daddy's muscles don't function as well as they used to do. The doctors are trying to help him, but maybe he is not strong enough to play with you right now.' Make them clear which activities they still can do together. For example: reading a book, listening to music, watch telly. They can also help you to discover new things to do together.

Before you answer a question right away, it's good to know where it is really about first. The question 'Is mommy okay?' Of a young child, whose mother is diagnosed with ALS and has just tripped or fallen, probably just means: 'Does mommy need help now?'

Children of that age often want to help. They can, for example, bring their own plate to the kitchen, help clear away their toys, or bring something to someone. Make it clear to them that their help is appreciated, because that motivates them to help more!

Book tip for parents from young children:

Your Ema Loves You by Eloise Lovelace. She is a retired special education teacher, and was diagnosed with ALS. The book tells the story of a grandmother with ALS: her body may change, but her personality and the love for her grandchildren remains very strong.

Talking to a child of school age

Tell the child how the disease is called. It may help to write it down. Make it clear to them that the child is not responsible for the disease, and that it is not contagious like a cold. For children of school age, it may be helpful to tell them how the symptoms of the disease are treated. Keeping the daily routine as normal and consistent as possible may also be helpful. Reassure them that there will always be someone to take care of them as well. Tell them how they can help and which new things you can do together, for example: drawing, brushing mommy's hair or read a story to daddy. Children of school age often have the need to spend time with every parent separately.

Book tips for children of school age: What to Do When You Worry Too Much: A Kid's Guide to Overcoming Anxiety by Dawn Huebner. This interactive self-help book offers amazing tips and tricks to help children learn to cope with the worries they can have when a parent or loved one has ALS/MND.

Lou Gehrig: The Luckiest Man by David A. Adler, for children aged 6 to 9 years old.

Talking to a teenager:

Give them as much information as possible. Be prepared for every possible reaction, going from anger to sadness. Every reaction is normal. Answer every question as complete and honest as possible. Tell them where they can find reliable information in case they want to know more. Also, make sure they can talk to someone outside your family; preferably someone they trust and someone who can keep the conversation to themselves.

Adult children also need open discussions. It is possible that they take on a more caring role to the parent who has ALS/MND, what makes them to need a different kind of support than a younger child. In the near future, there will be a newsletter in which we will go deeper into the caring role of older children.

Book tips for teenagers and adult children:

Until I Say Good-Bye: My Year of Living with Joy by Susan Spencer-Wendel

Tuesdays with Morrie: An Old Man, a Young Man, and Life's Greatest Lesson by Mitch Albom

Luckiest Man: The Life and Death of Lou Gehrig by Jonathan Eig

My Brief History by Stephen Hawking

A New Reality: My Life with ALS by Eloise Lovelace

The personal journey of a grandmother with ALS disease:

Eloise Lovelace is an ALS patient, who has always been very open towards her grandchildren about her life with the disease. When it comes to talking about ALS to children, she gives the following advice: Let them be part of your process. Explain them which impairments you have, in a language that is appropriate to their age. Also, introduce your help tools carefully to them. Allow them to play with your walking cane or walking frame, let them ride in your wheelchair, let them help you with your drip-feet and let them taste it, and show them how mucus suction works. Answer all their questions. The more they know about the disease, the more their minds are put at rest and they will be more relaxed.

Eloise also published a new book, entitled A New Reality: My Life with ALS. In the book, she writes: 'Such a situation occurred on a 9-year-old's birthday party. During my mucus suction, a few curious girls came to look at it. Soon, there were more of them. We explained in understandable terms what ALS is and how it has affected my breathing and mobility. After that, the girls were totally at ease in my presence.'

Recreational moments for children:

Children and young adults whose parent or grandparent has ALS or another disease, also have the need to meet contemporaries to enjoy the holidays, possibly during a summer camp.

During these recreational moments, they can participate in challenging team building exercises, discuss a nice book, or take a walk in the park. By exchanging experiences with other youngsters, they can give them an insight on their way of life and the difficulties they sometimes face. Making a photo book together also forges friendships for life and in that way they create unforgettable memories.

You can find more tips on our website.

If you have any suggestions or you feel the need to talk about this subject, please contact us.

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