

## SUPPORT TO TEENAGERS FROM FAMILIES DEALING WITH ALS

Being a teenager is not always easy, even when everything is in balance. If a parent or a family member is confronted with the deadly disease ALS, life can become even more overwhelming.

The first thing parents and family members should do, is informing their teenagers about the disease. The more they know, the better they might understand the situation. Specialists say that most teenagers benefit from talking openly about such painful subjects, because they do not want to be treated as children.

Teenagers want to be involved and help in their own way, but that engagement will be determined by the relationship they have with their parents, their commitments in school and their social life. Teenagers are going through a phase in their life during which they want to discover themselves, pushing their parents away and in need of more privacy. For that reason, finding a balance

between spending time with a sick parent and spending time with friends is not easy.

For teenagers, it is important to be trusted in assisting their families in critical situations. However, it is equally important to them to have enough time for their friends, hobbies and extracurricular activities. They should regularly be able to take some distance from the difficult situation. For that reason it is good to find out if the teenager has that balance in his or her life.

Families confronted with ALS experience more stress and sadness and thus more mood swings in everyday life. In order to cope with that, it may be useful to gain some insights from outside by talking to a counsellor like the family doctor, a priest, a psychologist or an employee of a mental health center. Teenagers should be included in those talks as well. More information can be found on [www.ALS.be](http://www.ALS.be), under the section 'brochures for children'.

## PATIENTS & FAMILY

### Talking with children about ALS/MND (Motor Neuron Disease)

A week after my brother had been officially diagnosed with ALS, my daughter was born. I know from experience that ALS/MND has an enormous impact on families, and especially on children. Nevertheless their age, all children need someone to listen to them, someone to answer their questions in a way they can understand it.

There are children who ask a lot of questions, others keep to themselves and have silent thoughts. There is no right or wrong way for a child to cope with the situation. The most important thing is that they can talk about it whenever they need to.

Dr. Paul. J. Kachoris is a certified pediatrician and psychiatrist for children, adolescents and adults with over 40 years of clinical experience. Since he became a family friend, he was well aware of the impact ALS/MND had on my family. When I asked him for tips for parents, he stressed the importance of the role of the parents in talking about ALS/MND. A child can sense conscious and unconscious signals from the way a parent deals with ALS/MND. That determines to a large extent, the way the child reacts, which is determinative for the dynamics within the family.

In the following sections, we will provide additional advice and reading tips for parents and loved ones on how to talk to children about ALS/MND in a successful way.

### Should I tell children about ALS/MND?

All the experts agree: YES. If there is no room to talk about it, parents can subconsciously give the idea that ALS/MND is something to be ashamed or afraid of. It is important to be open about it with children and to be aware of the fact that children are constantly learning new things. Their questions will change as they get older. Some children need to be reminded that it is okay to ask questions more often. They will bring up ALS/MND regularly.

### Be honest:

It is also of great importance to be open and honest. Children will notice if a parent or loved one is not being honest, or if they are afraid. In that case, sometimes, some children will refuse to listen. You can make it clear that ALS/MND is difficult to understand and that you are there for them to help. Explain that it is not their fault, it is not a punishment. That you can never know who will be affected by ALS/MND and that it is not contagious. ALS/MND has a different impact on everyone so you will

never know what the future holds. Make them understand that there will always be somebody to take care of them.

### **Avoid an overload of information**

You know your child and what the best way is for them to learn, however most children will react best to smaller amounts of information at a time. Listen carefully to the child. He or she will let you know, directly or indirectly when he or she has heard enough and come back later for more information. That applies to children of all ages.

### **Comfort**

Talk as much as possible in a calm and comforting way. It may be good to try out ideas and approaches for such a talk in a role play with a friend or family member. Support groups may also be an appropriate place to practice.

### **When do I start looking for help?**

If a child acts strangely or shows signs of regressive behavior or depression, or if you have the feeling something is wrong, it might be a good idea to start looking for help. That may happen in various ways: play therapy for a younger child, individual or group therapy for an older child, contacting a teacher or caregiver. It is always okay to ask for help and inform other adults who have a role in your child's life about the situation. Sometimes it is easier for a child to share his or her concerns with a therapist or social worker. If you need assistance with searching for help in your area, you can contact the ALS Liga or visit our website for children's brochures for all ages.

### **Talking with toddlers**

Use words your child understands and try to keep the explanation brief. If this is the first time that you talk to a child of this age about his or her father with ALS/MND, you can say something like "Daddy's muscles do not work as well as they used to. The doctors are trying to help him but he may not be strong enough to play football with you right now". Make sure to also mention activities they can do together, for instance reading a book, listening to music or watching sports. That way you can help them discover new things you can do together.

Before answering a question directly, it might be good to get a clear idea of what the child means exactly. If a mother with ALS stumbled and fell and her child asks

"Is mommy alright?", he or she probably is asking "Does mommy need help now?". Children around this age often want to help. They can, for instance, bring their own plate to the kitchen after eating, clean up their toys or bring something to someone. Make them understand that their help is appreciated, and maybe they want to help even more!

### **Reading tips for parents with toddlers:**

"Your Ema loves you" – Eloise Lovelace. This story is written by a retired teacher of special education, who was diagnosed with ALS. It is the story of a grandmother with ALS: her body may change, but her personality and love for her grandchildren remains strong and alive.

### **Talking with children of school-going age**

Do not hesitate to tell the child the name of the disease. It may help to write it down. Make clear that the child is not responsible for the disease and that it is not contagious, like a cold. For children of this age it may be good to tell how the symptoms of the disease are being helped. It may also help to plan the daily routine as close to normal and consistent as possible, and to make sure that there is always somebody there to help them. Tell them how they can help and think of new things to do together such as drawing, combing mommy's hair or reading to daddy. Children of this age very often have the need to spend some time with each parent separately.

### **Reading tips for children of school-going age:**

"What to Do When you Worry Too Much: A Kid's Guide to Overcoming Anxiety"- Dawn Huebner. This interactive self-help book offers great tools for children in learning to cope with the concerns and sorrows they have when a parent or a loved one has ALS/MND;

"Lou Gehrig: The Luckiest Man" – David A. Adler, for children of 6 to 9 years old.

### **Talking to teenagers**

Try to give as much information as possible. Be prepared for every possible reaction going from anger to sadness. Every reaction is normal. Answer each question as completely and honestly as possible. Tell them where to find reliable information if they need to. Make sure they can talk to someone outside of the family, preferably someone they trust and who will keep those conversations private.

Adult children need open dialogue as well. It is possible that they will take on a caring role towards the parent with ALS/MND, for which they require a different kind of

support than a younger child. In a few weeks, a newsletter will be available in which we will elaborate on the caring role of older children.

### **Reading tips for teenagers and adult children:**

“Until I say Good-Bye: My Year of Living with Joy” – Susan Spencer – Wendel;

“Tuesdays with Morrie: An Old Man, a Young Man, and Life’s Greatest Lesson” – Mitch Albom;

“My Brief History” – Stephen Hawking;

“A New Reality: My Life with ALS” – Eloise Lovelace

### **The personal journey of a grandmother with ALS**

Eloise Lovelace is a pALS who has always been very open towards her grandchildren about her life with the disease. She gives the following advice on talking with children about ALS: “Involve children in the pathological process. Explain them the limitations you encounter, in a language corresponding to their age. Carefully introduce them to your aiding tools: give them the chance to play with your cane or walker, let them ride in your wheelchair, or let them help with your feeding tube and let them taste the food, show them how mucus extraction is done. Answer all the questions they might possibly have. The more familiar they are with the disease, the more reassured and at ease they will be.

Eloise has also published a new book entitled “A New Reality: My Life with ALS” in which she writes: “Such a situation occurred on a birthday party of a nine-year-old. During my mucus extraction a few curious girls came to look at it. Very quickly, more of them came looking. We explained in a simple language what ALS is, how it had affected my breathing and mobility. After that, the girls were completely at ease in my presence.

### **Recreational moments for children**

Children and young adults whose parent or grandparent has been affected by ALS or another disease, have the need to meet peers so they can enjoy a holiday, possibly a summer camp.

During those recreational moments they can participate in challenging team building exercises, or the discussion of a good book or making walks in the park. By exchanging experiences with other teenagers they can give them an insight into their way of life and the difficulties they sometimes encounter. Creating a photo album together may also create friendships for life and that way they build up memories for later.

Please contact us if you have suggestions or ideas or if you simply need someone to talk with about this topic.

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