



## MND Factsheet 29 Telling Children About MND

Although MND is not primarily a disease of the young, it sometimes happens that the family of the person with MND includes young children. It is easy to forget that they need to know how the disease will affect you as a much loved parent or grandparent.

It is important that your family members and health and social care professionals helping your family take time to work through the problems children living in the house may have in coming to terms with MND in their family.

The feelings of adults and children in upsetting situations are quite similar. Anger, helplessness, fear, hope, and despair are commonly experienced. Children, however, have fewer ways of expressing their emotions and dealing with them. Younger children tend not to express themselves in words and will act out their feelings. Older children can find it hard to talk about how they feel, and teenagers often do not have friends with whom they can talk about serious situations. For children of all ages, feelings can be expressed in emotional and behavioural changes.

### Talking to Children

Children may have questions that they may be afraid to ask because everyone is so upset, and they do not know how to find things out by themselves. Although many people feel that children should be protected from sickness, this does not

#### **ALS: It's all in the family...**

**...Talk as openly as possible around children**, as secrets make everyone uncomfortable.

**...Encourage children to talk about how they feel**, to cry if they want to, and to talk about the situation to anyone with whom they feel comfortable. Children may hide their feelings at times, but that does not mean that they do not care, or are not feeling anything.

**...Encourage children to help when they express the desire to do so.** Being useful will make them feel involved and valuable. They do not have to help with medical care: Doing more chores at home or just reading and spending time with their relative with ALS are all possibilities.

**...Make sure life goes on as normally as possible for children** (and don't be afraid to ask others to help you make this happen) like keeping them in activities they have always done, spending time with friends, going out as a family.

**...Allow children to be involved in planning family activities that will include the relative with ALS.** This helps them feel useful and better understand lifestyle changes that must be made.

necessarily help the child. The child will know that something is wrong and may get upset anyway.

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When dealing with children experiencing sickness and big changes in their families and lives, it is necessary to explain everything as fully as possible.

Because adults tend not to explain to children what is happening, children often blame themselves for the sadness in the house and feel very guilty. They may want to know what exactly it is that the sick person has, whether they can catch it too, what will happen to the sick person, and whether that person will die. These questions are asked from a position of naivety in the child and should be answered as positively as possible. For young children in particular these are new experiences that many of their peers may not have experienced and may make them feel particularly trusted if they are given truthful answers, explanations and instructions as to how to deal with the information.

For example, instead of telling the child that a person is very sick or dying, something like: *"Well, they are not doing very well right now, but the doctors say that there are still things we can do. We can....."* gives hope without being dishonest. If the child pushes the question about whether someone will die it is best to be honest and to generalise the answer, admit to them that we will all die at some point and admit that this is a possibility, *"but not just yet."*

Children should know that they can ask questions and that someone will try to answer them.

If their parents do not feel able to talk to them, then a relative, friend, or doctor should make sure that the child knows that someone is always available to talk, not only about the illness but also about

anything that is worrying the child. Most children have powers of deductive logic far beyond what their parents imagine.

With the advent of the internet 8 year olds have been known to use their father's credit card number to order laptops for everyone in the family over the internet. The sending companies were understandably reluctant to accept the returned goods since the order had been properly completed. If an 8 year old can do that, what else have they deduced about the world around them, even if they don't appreciate that a credit card has to be paid for? They might not have completed the full jig-saw, but sometimes the parts that are in place for them are enough for them to see part of the bigger picture.

### **Long-term ways to help children cope...**

**...Pay adequate attention to children of parents with MND.** This may mean asking a grandparent or other family member or close friend to help you with this.

**...Explain to children that a change in appearance does not mean the sick person's feelings toward them have changed.** Protect children from the emotional swings of the sick person, if mood changes are occurring.

**...Allow children respite, too.** Like caregivers, they need a break to enjoy themselves.

**...Continue to encourage children to express their feelings.**

Frequently, a major concern of children is what will happen if the sick person

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becomes very sick or dies. They may want to know if they will have to move, who will look after them, if they will have to give up their favourite things, change schools, and so on. They may be afraid to ask about these things, so they should be reassured and told about any planned changes before a crisis interrupts their normal routine.

Very young children may be upset by what is going on, but will probably not be able to understand an accurate

explanation. Try to explain the situation in terms they can understand. Giving them lots of hugs, love and attention helps until they are old enough to understand the situation in more detail.

Whatever transpires, do your best to keep the children involved and feel secure. Do not hesitate to turn to members of your healthcare team or the Scottish MND Association for advice or help when you need it.

### Resources

The following Resources are available for loan to patients, families and friends from the SMNDA Library at Firhill .Road, Glasgow.

#### **UNDER 5s**

In My Dreams I Do. An Adult's Lasting Gift to a Child

Linda Saran, E & M Publishing 1999

Picture book encouraging communication between adults and young children. Two sisters escape the world of their grandmother's physical limitations to the freedom of her dream realm, a place where anything is possible and bodies are limited only by the mind.

#### **5-12 YEARS**

GRANDPA. WHAT IS ALS?

Bonny Gold-Babins, ALS Society of Alberta 2000

The author was inspired to write this book to help children understand MND and participate in being active caregivers.

A BOOKLET FOR YOUNG PEOPLE

Amyotrophic Lateral Sclerosis Society of Canada 1998

Very simple booklet with explanation of the disease, chapter on feelings and further reading sources.

LOU GEHRIG. THE LUCKIEST MAN

David A. Adler, Gulliver Books 1997

The story of Lou Gehrig, famous US baseball player.

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WHEN SOMEONE SPECIAL HAS MOTOR NEURONE DISEASE, MND Association, A simple booklet, but with no further reading sources.

### TEENAGERS

ALS – LOU GEHRIG'S DISEASE

Diseases and People Series

Mary Dodson Wade, Enslow Publishers Inc. 2001

Small easily read book which covers the subject well.

WHEN YOUR PARENT HAS MOTOR NEURONE DISEASE. A booklet for young people.

Motor Neurone Disease Association

MOTOR NEURONE DISEASE. A FAMILY AFFAIR. 2<sup>nd</sup> Edition

Dr David Oliver, Sheldon Press 2006

Suitable for more mature readers

Motor Neurone Disease/The 'at your fingertips' guide.

Dr Stuart Neilson and Dr Frank Clifford Rose, Class Publishing 2006

Question and answer format for more mature readers

### WEBSITES

"WHAT IS ALS?" FOR KIDS

[www.march-of-faces.org/KIDS/moe1.html](http://www.march-of-faces.org/KIDS/moe1.html)

Explains MND for children aged 6-12 yrs

LOU GEHRIG'S DISEASE (ALS) Nemours Foundation

[www.kidshealth.org/kid/feeling/adults/als.html](http://www.kidshealth.org/kid/feeling/adults/als.html)

A useful site for children aged 9 and over.

### GENERAL SOURCES – For Parents

#### Websites

ALS411, created by the ALS Society of Canada, provides children with resources to gain knowledge about the disease and to explore how to cope with their situation. New and improved separate web sites for children and teens, launched in November 2008, can be accessed from the domain,

[www.als411.ca](http://www.als411.ca).

Their section [www.als411.ca/eng/teens/resources.html](http://www.als411.ca/eng/teens/resources.html) is particularly useful for teenage or more mature pre-teenage children with downloadable pdf copies of publications.

[www.als411.ca/eng/teens/When Someone Special Has ALS.pdf](http://www.als411.ca/eng/teens/When_Someone_Special_Has_ALS.pdf)

[www.als411.ca/eng/teens/When Your Parent Has ALS.pdf](http://www.als411.ca/eng/teens/When_Your_Parent_Has_ALS.pdf)

[www.als411.ca/eng/teens/Parental Information Guide.pdf](http://www.als411.ca/eng/teens/Parental_Information_Guide.pdf)

WINSTON'S WISH

[www.winstonswish.org.uk](http://www.winstonswish.org.uk)

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A charity supporting bereaved children and young people with resources for families and professionals.

### **Books and Pamphlets**

HELPING CHILDREN COPE WITH ALS (Simple booklet)  
Parental Information Guide, The Forbes Norris MDA/ALS Center

AS BIG AS IT GETS. Supporting a Child When Someone in their Family is Seriously Ill.  
Julie Stokes and Diana Crossley

WINSTONS WISH 2001 \*

This booklet aims to help families cope with the serious illness of a parent or child. It provides a range of ideas for parents or carers so that they may feel more able to explain to their children or teenagers what is happening. The booklet also includes some suggestions about what parents might say to them and how to offer support. The message throughout is that although life can be very different and difficult when someone is faced with a life-threatening illness, families can learn to cope with the uncertainties and stresses of their lives.

HOW TO HELP CHILDREN THROUGH A PARENT'S SERIOUS ILLNESS

Kathleen McCue and Ron Bonn, St. Martin's Griffin 1994

The aim of this book is to help you help your children, from the moment a parent is diagnosed with a serious or life-threatening illness.

HELPING CHILDREN TO MANAGE LOSS. Positive Strategies for Renewal and Growth.

Brenda Mallon, Jessica Kingsley Publishers 1998

As well as covering the short and long term implications that arise when loss occurs, it provides positive approaches that enable children not only to cope but to grow through their experiences.

TALKING ABOUT DEATH. A Dialogue Between Parent and Child

Earl A. Grollman, Beacon Press 1990

A compassionate guide for adults and children to read together, featuring a read-along story, answers to questions children ask about death, and a comprehensive list of resources and organizations that can help.

THEN, NOW AND ALWAYS. Supporting children through grief: A guide for practitioners.

Julie A Stokes, Winston's Wish 2004

Useful resource for parents even though aimed at practitioners

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### VIDEOS

A DEATH IN THE LIVES OF... 30 minutes

Childhood Bereavement Network 2002. Shows a group of young people, aged 13-16, from a range of backgrounds talking about the kind of support they needed to help them cope with bereavement.

GRIEF IN THE FAMILY 14 minutes

Narrated by Michael Rosen 2002

Animated video looks at the ways children and young people respond to grief, and what the adults around them can do to help. It gives parents and carers an insight into the process of grieving, its physical and emotional effects, and the special needs of children and young people.