



MND Factsheet 29 Telling Children About MND

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Sometimes the family of someone with MND can include children or teenagers. Often these will be grandchildren but, since about one in ten people affected by MND are under the age of forty-five, they will sometimes be the children of the person affected by MND. Children are adept at noticing changes and will need help to understand how the disease might affect not only the person with MND, but the wider family too.

This help should not only come from you but should be asked from other family members and from any professionals involved with the 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 the kinds of relationships with friends where they can talk about serious situations. For children of all ages, feelings can often be expressed in emotional and behavioural changes.

Talking to Children

Even though they don't know what is happening, children can recognise when adults are avoiding talking in front of them, or to them, about certain topics. They can also recognise changed moods

and emotions within the household. If adults have not explained to children what is happening, the child can often assume that they are not being included in what is going on because they are

Helping Children Cope

Talk as openly as possible around children; 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: Helping out at home or just reading and spending time with their relative who has MND are all possibilities.

Make sure life goes on as normally as possible for children by maintaining routines such as school and activities they have always done, spending time with friends, going out as a family. Ask others to help with this too.

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

MND Scotland is the only charity funding research and providing care and information for those affected by MND in Scotland.

somehow to blame. This can lead them to feel guilty and to blame themselves for any sadness in the house.

Children may have questions that they are afraid to ask because everyone is upset, and they might not know how to find things out by themselves. Although many people feel that children should be protected from serious matters, such as illness, this does not necessarily help the child understand what is going on. The child will know that something is wrong and may become unsettled or upset anyway.

It is important to explain everything as fully as possible to children who are experiencing big changes in their family and their lives as a result of illness in the family.

When you talk to children 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 friends may not have experienced and it may make them feel particularly trusted if they are given truthful answers as well as 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

Long-term ways to help children cope...

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

...Explain to children that a change in appearance does not mean the sick person's feelings toward them have changed. If the person has mood swings protect children from these.

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

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

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 always 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 can work things out for themselves far beyond what their parents might imagine.

One eight year old used his father's credit card number over the internet to order laptop computers for everyone in the family. The sending companies were understandably reluctant to accept the returned goods since the order had been properly completed. If an eight year old

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can do that, what else have they worked out 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.

Frequently, a major concern for children is what will happen if the sick person becomes worse or even dies, especially if the person is a parent. Although they may not ask outright, most children will have similar concerns. They may want to know who will look after them, will they need to move house or change schools, will they move away from their favourite friends, and so on. Even when these questions aren't asked children should be reassured about these kinds of things and

promised that they will always be included in making any plans for the future. If changes like these are possible then they should be 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 MND Scotland for advice or help when you need it.

Resources

The following are available for loan to patients, families and friends from the MND Scotland Library at Eagle Street, Glasgow.

Books and Pamphlets

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.

Your Ema Loves you Eloise Lovelace, Authorhouse 2011

A child often feels confused and scared as he witnesses the physical or mental

decline of a grandparent. Although this book deals specifically with ALS, a progressive physical ailment, it could apply to any disease. It teaches the young one that, though he or she may witness these changes, the basic personality of, and love generated by, a grandparent remains powerful and alive.

5-12 YEARS

The Stars that Shine Jodi O'Donnell-Ames, OpenDoor Publications 2013
ISBN:9780988831919

The Stars That Shine is a lovely tribute to all children who live with a disabled or

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terminally ill parent. Enclosed are resources for ALS patients, their caregivers and children. Although this story is about ALS, the message resonates with all families who live with similar challenges.

When someone close has MND-
produced by the MND Association

This is an interactive workbook thoughtfully developed to inform children aged between 4 years and 10 years about Motor neurone Disease (MND) The workbook is not intended to be given as a handout and has been designed so that adults and children work through the book together, so that information about MND can be introduced to children as and when the time is appropriate.

Helping Children to Cope with Change, Stress and Anxiety - a photocopiable activities book

Deborah Plummer, Jessica Kingsley Publishers 2010. Children who have difficulty coping with change or who experience uncomfortably high levels of stress and anxiety often need help with understanding and managing their emotions. This creative book combines accessible theory with a wealth of games and activities designed to help children with these difficulties and build emotional awareness and resilience.

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.

LOU GEHRIG. THE LUCKIEST MAN

David A. Adler, Gulliver Books 1997
The story of Lou Gehrig, famous US

baseball player.

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

TEENAGERS

ALS – Lou Gehrig’s Disease from the Diseases and People Series
Mary Dodson Wade, Enslow Publishers Inc. 2001

Small easily read book which covers the subject well.

So what is MND anyway? – a guide for younger people (MND Scotland)

So What is MND, anyway ? A guide for young people affected by motor neurone disease (MNDA - motor neurone disease association) 2016

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. 2nd 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

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Question and answer format for more mature readers

On-Line Resources

The ALS Society of Canada, provides information at two levels aimed at either younger children or teenagers. The site has resources to help users gain knowledge about the disease and to explore how to cope with their situation.

Their section <https://www.als.ca/about-als/resources/for-youth/> is particularly useful for teenage or more mature pre-teenage children with downloadable pdf copies of publications.

- When Someone Special Has ALS
- When Your Parent Has ALS

ALS Canada also has an interactive website for children of all ages

<http://www.als411.ca/>

LOU GEHRIG'S DISEASE (ALS)

Nemours Foundation

<http://kidshealth.org/en/kids/als.html?WT.ac=ctg#catconditions> A useful site for children aged 9 and over.

GENERAL SOURCES – For Parents

WINSTON'S WISH

www.winstonswish.org.uk

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

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 Kingley 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.

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**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

VIDEO and DVD

**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.