

MND RESOURCES for PARENTS, CHILDREN & TEENAGERS 2019

Telling your children that a family member has been diagnosed with motor neurone disease is never easy. Each family is different and your MND Care Team Specialist or counsellor is available to discuss this issue with you. There are also published sources to help you. Please note that motor neurone disease is also known globally as Amyotrophic Lateral Sclerosis or Lou Gehrig's Disease.

Factsheet 29 Telling Children about MND (available on the website)

The following Resources are available for loan to patients, families and friends from the library.

Children under 5 years

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.

Children aged 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 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.

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/ALS 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 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.

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 from the (MND Association)

This guide is also available as a web app

<https://www.mndassociation.org/young-person-web-app/index.html>

Books for Mature Teenagers

Motor Neurone Disease. A Family Affair. 3rd edition

Dr David Oliver, Sheldon Press, 2010 ISBN:9781847091536

Motor Neurone Disease/The ‘at your fingertips’ guide.

Dr Stuart Neilson and Dr Frank Clifford Rose

Class Publishing, 2003 ISBN :9781859590478

General Sources for Parents

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.*

Websites

Facebook – Help Kids Connect

<https://www.facebook.com/groups/hlckidsconnect/> (closed group)

HLC Kids Connect is a safe place for the children of ALS patients to talk and support each other. Meet new friends, learn healthy ways to cope and feel less alone as you and your family are challenged by ALS.

MNDA – Motor Neurone Disease Association

A good range of booklets for children of different ages.

<http://www.mndassociation.org/life-with-mnd/publications-pabmnd/information-for-children-and-young-people/>

ALS Society of Canada

<http://www.als411.ca> ALS Society of Canada

Very good online resources for children, teenagers and parents

MND Australia

<http://www.mndaust.asn.au/Get-informed/Information-resources.aspx>

Provides a good range of booklets for children, teenagers and parents

Lou Gehrig's Disease (ALS) Nemours Foundation

<http://kidshealth.org/en/kids/als.html>

a useful site for children aged 9 and over.

WINSTON's WISH www.winstonswish.org.uk

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

Contact the Information Officer for further reading for health professionals supporting MND families and many other resources are available for everyone on bereavement issues, including items from our Media Collection.