



MND LIBRARY & INFORMATION SERVICE

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MND RESOURCES for PARENTS, CHILDREN & TEENAGERS 2009

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 the MND 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 – Telling Children about MND. Download from our website.

WEBSITES

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

Very good online resources for children, teenagers and parents

“What is ALS?” for KIDS

<http://www.march-of-faces.org/KIDS/moe1.html>

explains ALS/MND for children aged 6-12 years

Lou Gehrig's Disease (ALS) Nemours Foundation

<http://www.kidshealth.org/kid/feeling/adults/als.html>

a useful site for children aged 9 and over.

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

UNDER 5's

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/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.

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.

When Someone Special has Motor Neurone Disease

MND Association 1996

Simple booklet as above 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.

MND Association 2004

Small pamphlet

ADULT BOOKS FOR MATURE TEENAGERS

Motor Neuron Disease. The facts series.

Kevin Talbot and Rachael Marsden

Oxford University Press 2008

Motor Neurone Disease. A Family Affair. 2nd edition

Dr David Oliver
Sheldon Press 2006

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

Dr Stuart Neilson and Dr Frank Clifford Rose
Class Publishing 2003

GENERAL SOURCES FOR PARENTS

Helping Children Cope with ALS. Parental Information Guide.

The Forbes Norris MDA/ALS Research Center
Small pamphlet

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.

***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.