

The books, videos and DVDs listed in this factsheet are all available to borrow from the MND Scotland Library at Eagle Street Glasgow. People with MND, their families and carers and health professionals are welcome to borrow from the library.

MND Scotland's library catalogue is available for browsing and searching on NHS Education for Scotland's website 'The Knowledge Network'. We are a partner library within their network and as such we can share resources with other partner libraries within the network.

However, you must have an NHS Scotland OpenAthens username to borrow the library resources, but browsing is open to anyone with internet access.

<http://www.knowledge.scot.nhs.uk/home/help-and-training/books-and-ebooks.aspx>

If you wish to borrow any of our resources, you may find it easier to contact MND Scotland's Information Officer by phone or email.

**BOOKS** General Introductions recommended for Patients/Families

**Motor Neuron Disease: The facts series**

Kevin Talbot and Rachael Marsden  
Oxford University Press 2010

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

Dr Stuart Neilson & Dr Frank Clifford  
Rose  
Class Publishing 2006

**Motor Neurone Disease. A Family Affair.** 3rd edition

Dr David Oliver  
Sheldon Press 2011

**Amyotrophic Lateral Sclerosis. A Guide for Patients and Families.**

3rd edition, edited by Hiroshi Mitsumoto  
Demos Medical Publishing 2009  
Strong USA bias

**Amyotrophic Lateral Sclerosis.**

R.G. Miller, D. Gelinas and P. O'Connor  
Demos Medical Publishing 2005 (Kindle edition is now available)  
Strong USA bias

**ALS – Lou Gehrig's Disease Diseases and People Series**

Mary Dodson Wade  
Enslow Publishers Inc. 2001

**GENERAL RESOURCES FOR PARENTS**

**Helping Children Cope with ALS. Parental Information Guide.**

The Forbes Norris MDA/ALS Research Center  
Small pamphlet

**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, suggested answers to questions children ask about death, and a comprehensive list of resources and organisations that can help.

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

**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.

**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.

**As Big As It Gets. Supporting a Child When Someone in their Family is Seriously Ill.**

Julie Stokes and Diana Crossley

Winstons Wish 2001 (See online link under "Websites" below.)

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.

**Children Under 5 years**

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

Linda Saran

E & M Publishing 1999

A picture book which aims to encourage 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** by Eloise Lovelace Authorhouse, 2011

This book helps to teach young ones that although they might witness the progressive changes brought on by ALS, the basic personality of, and love generated by, a grandparent remains powerful and alive.

**Children 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.

**When Someone Special has ALS – a booklet for children**

Amyotrophic Lateral Sclerosis Society of Canada 2014

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 ALS- a booklet for young people.**

Amyotrophic Lateral Sclerosis Society of Canada 2014  
(Based on MNDA booklet from 2004)

**ADULT BOOKS SUITABLE FOR MATURE TEENAGERS**

**Motor Neuron Disease. The facts series.**

Kevin Talbot and Rachael Marsden  
Oxford University Press 2010

**Motor Neurone Disease. A Family Affair.** 3rd edition

Dr David Oliver  
Sheldon Press 2011

**So what is MND anyway? A guide to MND for younger people (teenagers)**

MND Scotland 2016

**General Reading (Professional Texts)**

**Amyotrophic Lateral Sclerosis**

Laura Simionescu, MD  
BMJ Best Practice, August 2015

**Amyotrophic Lateral Sclerosis**

Edited by Hiroshi Mitsumoto, Serge Przedborski and Paul H. Gordon  
Taylor & Francis 2006

**Motor Neuron Disease**

Edited by Michael D. Weiss and Gregory T. Carter  
Physical Medicine and Rehabilitation Clinics of America, Col. 19, No. 3  
Saunders 2008

**Amyotrophic Lateral Sclerosis Completing the Continuum of ALS Care : A Consensus Document**

Hiroshi Mitsumoto and the ALS Peer Workgroup Members  
Promoting Excellence in End-of-Life Care, a national program of The Robert Wood Johnson Foundation January 2004  
Appendices on enclosed CD-Rom  
[www.promotingexcellence.org](http://www.promotingexcellence.org)

**Motor Neuron Disorders and Related Diseases**

Michael J. Aminoff, Francois Boller and Dick F. Swab  
Handbook of Clinical Neurology Volume 82, Elsevier 2007

**Difficult Conversations – A guide for professionals caring for people with MND.**

This booklet aims to help explore hopes, fears and end of life issues.  
Published by NCPC and MNDA, 2012

**Palliative Care in Amyotrophic Lateral Sclerosis. From diagnosis to bereavement.**

3rd edition  
Edited by David Oliver, Gian Domenico Borasio and Wendy Johnston  
Oxford University Press 2014

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## MND Factsheet 47 Recommended Reading

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### **Respiratory Management of ALS.**

Amyotrophic Lateral Sclerosis.

Lee Guion

Jones and Bartlett Publishers 2009

### CLINICAL JOURNAL

#### **Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration**

First published Dec 1999, MND library has print copies since Dec 1999 and a full electronic subscription to the current issue.

### **Resources on DVD**

**Conversations to remember.** An intimate portrayal of how people deal with end-of-life issues,

The Kosh

DVD 2007

### **Live Everyday**

The MND Association

2004 DVD

### **Nutritional lifeline: the feeding tube**

decision. ALS.

DVD 2007

### **Fading away. A film by Helle Toft Jensen.**

Muskelsvindfonden, 1997 DVD

## **MND Related Websites**

There are hundreds of websites available on motor neurone disease. Be wary of the information available as anyone can put a site on the web and some can be positively misleading with claims of miracle cures. The list below will guide you to sites with quality information.

Remember, if you are searching the internet, that motor neurone disease is

also known as Amyotrophic Lateral Sclerosis (ALS) or Lou Gehrig's disease.

There is a huge amount of information on all different aspects of MND on YouTube about MND.

### **MND Scotland**

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

### **Care-MND – Scotland**

<https://www.care-mnd.org.uk/>

### **Motor Neurone Disease Association**

(Rest of UK plus the Isle of Man and Channel Isles)

[www.mndassociation.org](http://www.mndassociation.org)

### **International Alliance of ALS/MND Associations**

[www.alsmndalliance.org/](http://www.alsmndalliance.org/) Details of member organisations and websites at

[www.alsmndalliance.org/directory](http://www.alsmndalliance.org/directory)

### **The ALS Association (USA)**

[www.alsa.org](http://www.alsa.org)

### **Muscular Dystrophy Association – ALS Division**

[www.als-mda.org](http://www.als-mda.org)

In 2007 MDA-ALS collaborated with the former ALS Therapy Development Foundation, a not-for-profit biotechnology company dedicated to developing novel therapies. Now called ALSTDI (ALS Therapy Development Institute

[www.als.net/](http://www.als.net/))

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### DRUG INFORMATION

Rilutek is made by SanofiAventis and is the only drug to slow the progress of MND.

SanofiAventis

[www.rilutek.com/Patients/Default.aspx](http://www.rilutek.com/Patients/Default.aspx)

Teglutik is a new formulation of Rilutek which was launched in 2016. It is an oral suspension of Rilutek which makes it easier to take for those with swallowing difficulties. It is supplied by Martindale Pharmaceuticals Ltd.

### RESEARCH/ CLINICAL TRIALS

#### ALS Untangled

This is a free resource where scientists and medical experts have reviewed the evidence for off-label and alternative treatments for MND such as 'Coconut Oil' and the 'Deanna Protocol'.

<http://www.alsuntangled.com/>

#### Clinical Trials Summary from the National Institute for Health (USA)

[www.clinicaltrials.gov](http://www.clinicaltrials.gov)

search for "amyotrophic lateral sclerosis"

#### Muscular Dystrophy Association – ALS Division (USA)

[www.als-mda.org/research](http://www.als-mda.org/research)

#### The ALS Association (USA)

[www.alsa.org/research/news.cfm](http://www.alsa.org/research/news.cfm)

#### ALSTDI – ALS Therapy Development Institute (USA)

[www.als.net](http://www.als.net)

#### The Robert Packard Center for ALS

Research at John Hopkins University, Baltimore (USA)

[www.alscenter.org/research/projects.cfm](http://www.alscenter.org/research/projects.cfm)

### CARE & RESEARCH CENTRES

#### Euan MacDonald Centre (Edinburgh)

<http://www.euanmacdonaldcentre.com/about-the-centre/>

#### King's Motor Neurone Disease (MND)

Care & Research Centre, London

<http://www.kcl.ac.uk/ioppn/depts/bcn/Our-research/Neurodegeneration/al-chalabi-sporadic-als/Index.aspx>

#### Oxford MND Centre

<https://www.ndcn.ox.ac.uk/research/oxford-motor-neuron-disease-centre>

#### SiTran – University of Sheffield

<http://sitran.org/research/motor-neuron-disease/>

#### World Federation of Neurology ALS

Page

[www.wfnals.org/index.html](http://www.wfnals.org/index.html)

### FAMILIAL or HEREDITARY MND

#### Genetics Home Reference: ALS

(National Library of Medicine) (USA)

[www.nlm.nih.gov/medlineplus/tutorials/amyotrophiclateralsclerosis/htm/index.htm](http://www.nlm.nih.gov/medlineplus/tutorials/amyotrophiclateralsclerosis/htm/index.htm)

#### Understanding ALS: Genetic Testing

for ALS (ALS Association) (USA)

[www.alsa.org/als/gentest.cfm](http://www.alsa.org/als/gentest.cfm)

### PATIENT EXPERIENCES

#### Health Talk Online

[www.healthtalkonline.org](http://www.healthtalkonline.org)

An award-winning charity website, lets you share in other people's experiences of health and illness. You can watch or listen to videos of the interviews, read

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about people's experiences and find reliable information about conditions, treatment choices and support.

### **Speaking From Experience**

<http://portal.realtimehealth.com.au/conditions/motorneuronedisease>.

A website where you can watch first-hand stories of those who have been diagnosed with MND.

### **Patientslikeme**

[www.patientslikeme.com](http://www.patientslikeme.com)

Describes itself as the only online treatment and outcome sharing community where patients and their doctors can see what treatments are working for others.

## **RESOURCES FOR CHILDREN**

### **Winston's Wish**

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

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

Nemours Foundation

Section on Lou Gehrig's Disease (ALS)

<http://kidshealth.org/kid/grownup/conditions/als.html>

### **ALS411- All for Kids**

Information booklets for parents, children and teens. Also cartoons and teenagers' stories produced by ALS Canada

<https://www.als.ca/about-als/resources/for-youth/>