

The books, videos and DVDs listed in this factsheet are all available to borrow from the MND Scotland Library at Firhill Road Glasgow. Membership of the library is free of charge to people with MND, their families and carers and health professionals.

The MND Scotland library is a partner within the NHS Scotland on-line catalogue "SHEL CAT", which allows anyone connected to the internet to search the catalogues of an individual library such as ours, or those of all the NHS Scotland Libraries. Shelcat is available on-line at www.shelcat.org, and a link to the MND Scotland library (www.shelcat.org/pmnd/) is located on the opening page. You can search the catalogue by typing a keyword such as "Wheelchair" into the search box, choosing whether you want to search all health libraries, your local ones or ours and then selecting "Go". Resources tagged with the word you have put into the search box will then be displayed along with their location.

Only members of one of the participating libraries can order books and resources on-line. Non-members can see which resources are available and can telephone MND Scotland's Information Officer (0141 945 1077) to arrange membership and a loan.

Lists included in this factsheet:

Materials available to borrow from MND Scotland

Recommended Books

General Introductions
recommended for Patients/
Families

General Resources

for Parents
Books for under 5s
5-12 years
Teenagers
Adult books suitable for mature
teenagers

General Reading (Professional Texts)

Clinical Journal
Clinical Guidelines

DVD and Video Resources

On-line Web Resources to Download

MND Related Websites

Patient Associations
Drug Information
Neurology sites
Clinical Trials/Research
Familial or Hereditary MND

Email Lists/Discussion forums

Patient experiences

Web Resources for Children

MND Scotland is the working name of the Scottish Motor Neurone Disease Association, the only charity funding research and providing care and information for those affected by MND in Scotland.

BOOKS

General Introductions recommended for Patients/Families

Motor Neuron Disease: The facts series

Kevin Talbot and Rachael Marsden
Oxford University Press 2008

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

Dr Stuart Neilson and Dr Frank Clifford Rose
Class Publishing 2006

Motor Neurone Disease. A Family Affair. 2nd edition

Dr David Oliver
Sheldon Press 2006

Amyotrophic Lateral Sclerosis. A Guide for Patients and Families.

Hiroshi Mitsumoto and Theodore L. Munsat
Demos Medical Publishing 2001
Strong USA bias

Amyotrophic Lateral Sclerosis.

R.G. Miller, D. Gelinas and P. O'Connor
Demos Medical Publishing 2005
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.

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

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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.

UNDER 5s

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

Linda Saran

E & M Publishing 1999

A 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 SUITABLE 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 Reading (Professional Texts)

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

Motor Neuron Disorders and Related Diseases

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

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

Second edition
Edited by David Oliver, Gian Domenico Borasio and Declan Walsh
Oxford University Press 2006

Respiratory Management of ALS.

Amyotrophic Lateral Sclerosis.
Lee Guion
Jones and Bartlett Publishers 2009

CLINICAL JOURNAL

Amyotrophic Lateral Sclerosis

Informa UK Ltd First published Dec 1999
MND library has print copies since Dec 1999 and a full electronic subscription to the current issue. Full text of all copies except the current issue are also available on the NHS Scotland e-library
www.elib.scot.nhs.uk

CLINICAL GUIDELINES

Clinical Characteristics and Management of ALS

Borasio GD, Miller RG
Seminars in Neurology 2001 Jun; 21(2): 155-66

Practice parameter: the care of the patient with amyotrophic lateral sclerosis (an evidence-based Review):

report of the Quality Standards Subcommittee of the American Academy of Neurology:ALS Practice Parameters Task Force Miller RG, Rosenberg JA, Gelinas DF, Mitsumoto H, Newman D, Sufit R, Borasio GD, Bradley WG, Bromberg MB, Brooks BR, Kasarskis EJ, Munsat TL, Oppenheimer EA [Guideline. Journal Article. Practice Guideline]
Neurology 52(7): 1311-23, 1999 Apr 22

Clinical based guidelines in MND for health and social care professionals.

Motor Neurone Disease Association 2005.
Includes guidelines on making and communicating the diagnosis, nutritional management, respiratory management and a summary of all three guidelines for people affected by MND.

www.mndassociation.org/for_professionals/developing_services/guidelines.html

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Good practice in the management of amyotrophic lateral sclerosis : Clinical guidelines.

An evidence-based review with good practice points. EALSC Working Group Andersen, P.M. et al
Amyotrophic Lateral Sclerosis 2007; 8: 195-213

Paradigm for Disease Management in Motor Neurone Disease

Royal College of Nursing Motor Neurone Disease Working Party 2001
Publication Code 001544
Available in pdf. format on the MND Shared Space.

A Pathway for the Management of Pain in Motor Neurone Disease

UK Motor Neurone Disease Networking Group 2003

Available in pdf. format on the MND Shared Space.

Motor Neurone Disease – A Problem Solving Approach

For general practitioners and health and social care professionals
MND Scotland 2004
Available in pdf. format on the MND Shared Space.

Association of British Neurologists Guidelines for the Management of Motor Neurone Disease 23/06/99

www.theabn.org/downloads/mnddoc.pdf

Pathways to Hope. The State of Research into Amyotrophic Lateral Sclerosis.

Lucie Bruijn. Updated January 2006 by Roberta Friedman and Bill Oldendorf
The ALS Association
www.alsa.org/files/pdf/Pathways_Hope_2007.pdf

DVD and Video Resources

The Secret's Out. An introduction to Motability, the leading car scheme for disabled people.

Motability
DVD 2007

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

The Kosh
DVD 2007

Nutritional lifeline: the feeding tube decision. ALS.

DVD 2007

Fading away. A film by Helle Toft Jensen.

Muskelsvindfonden
1997 DVD

Mobility, activities of daily living, and home adaptations

ALS Association
2004 Video

Hospice. Patient and carer voices.

Rosetta Life
2004 Video

The Theory of Flight

Fiction starring Helena Bonham Carter
1999 Video

PEG video for health professionals : 1) Flocare Peg : 2) Jejunostomy.

Nutricia Clinical Care
2004 Video

Poison that waits

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British Broadcasting Corporation.

Video

The pride of the Yankees. (The story of Lou Gehrig, USA baseball player who died from MND/ALS.

Samuel Goldwyn Productions

1987 Video

Stories for Eleanor.

A video of J.S. Pegg's fight with motor neurone disease. Channel 4

Video

The best kept secret : a video about motor neurone disease.

The MND Association

Video

Talking to people with severe communication difficulties : an introductory training video.

Murphy, Joan Scott, Janet AAC research team, University of Stirling

2001 Video

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.

PATIENT ASSOCIATIONS

MND Scotland

www.mndscotland.org.uk

Motor Neurone Disease Association (Rest of UK plus the Isle of Man and Channel Isles)

www.mndassociation.org

International Alliance of ALS/MND Associations

www.alsmndalliance.org/

Details of member organisations and websites at

www.alsmndalliance.org/directory

The ALS Association (USA)

www.alsa.org

Muscular Dystrophy Association – ALS Division

www.als-mda.org

In January 2007 they 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/)

DRUG INFORMATION

SanofiAventis

www.rilutek.com/Patients/Default.aspx

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

Lithium

www.pnas.org/content/105/6/2052.full.pdf

Although flawed, this trial gave sufficiently

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interesting results that it is being repeated in Europe, The USA and Canada.

NEUROLOGY SITES

CARE & RESEARCH CENTRES
King's Motor Neurone Disease (MND)
Care & Research Centre, London
www.iop.kcl.ac.uk/departments/?locator=341&context=research

World Federation of Neurology ALS
Page
www.wfnals.org/index.html

MEDLINEplus
www.nlm.nih.gov/medlineplus/amyotrophiclateralsclerosis.html
see also interactive tutorial at
www.nlm.nih.gov/medlineplus/tutorials/amyotrophiclateralsclerosis/htm/index.htm

CLINICAL TRIALS/RESEARCH

Clinical Trials Summary from the
National Institute for Health (USA)
www.clinicaltrials.gov
search for "amyotrophic lateral sclerosis"

Muscular Dystrophy Association –
ALS Division (USA)
www.als-mda.org/research

The ALS Association (USA)
www.alsa.org/research/news.cfm

ALSTDI – ALS Therapy Development
Institute (USA)
www.als.net

The Robert Packard Center for ALS
Research at John Hopkins University,
Baltimore (USA)
www.alscenter.org/research/projects.cfm

Pathways to Hope. The State of
Research into Amyotrophic Lateral
Sclerosis.
Lucie Bruijn. Updated January 2006 by
Roberta Friedman and Bill Oldendorf
The ALS Association
www.alsa.org/files/pdf/Pathways_Hope_2007.pdf

FAMILIAL or HEREDITARY MND

Genetics Home Reference: ALS
(National Library of Medicine) (USA)
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

EMAIL LISTS/DISCUSSION GROUPS

build-uk.net This site is for people affected by MND e.g. who live with MND, care for someone with the condition, have a family member or friend with MND or work in health or social care services

www.build-uk.net/index.htm
Patients like me describes itself as the only online treatment and outcome sharing community where patients and

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their doctors can see what's working for others.

www.patientslikeme.com

PATIENT EXPERIENCES (video format on the web)

Health Talk Online (formerly DIPEX)

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

Patientslikeme

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.

Speaking From Experience

www.realtimehealth.com/conditions/motorneurodisease

RESOURCES FOR CHILDREN

Winston's Wish

www.winstonswish.org.uk

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

ALS411- All for Kids

Information booklets for parents, children and teens. Also cartoons and teenagers' stories.

www.als.ca/als411

Nemours Foundation

Section on Lou Gehrig's Disease (ALS)

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

"What is ALS?" for kids

www.march-of-faces.org/KIDS/moe1.html