



MND READING LIST FOR HEALTH AND SOCIAL CARE PROFESSIONALS 2010

This reading list is intended to be a quick introduction to the disease. Please note that the disease is also known globally as Amyotrophic Lateral Sclerosis or Lou Gehrig's Disease

FACTSHEETS

The charity funds a Care Team who visit patients in their own home bringing a patient information pack. A full range of our factsheets on living with the disease in Scotland is available to download from our website.

BOOKS – General Introductions recommended for Patients/Families

Motor Neurone Disease. A Family Affair. 2nd edition

Dr David Oliver

Sheldon Press 2006

best introduction

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

Dr Stuart Neilson and Dr Frank Clifford Rose

Class Publishing 2006

question and answers

Motor Neuron Disease – the facts

Kevin Talbot and Rachael Marsden

Oxford University Press 2008

good for "expert patients"

Amyotrophic Lateral Sclerosis.

A Guide for Patients and Families.

Hiroshi Mitsumoto and Theodore L. Munsat

Demos Medical Publishing 2001

strong USA bias

ALS – Lou Gehrig's Disease

Diseases and People Series

Mary Dodson Wade

Enslow Publishers Inc. 2001

good for teenagers

BOOKS – General Reading for Health Professionals

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

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

Motor Neuron Disorders and Related Diseases

Michael J. Aminoff, Francois Boller and Dick F. Swab (series editors)
Edited by Andrew A Eisen & Pamela J. Shaw (volume editors)
Handbook of Clinical Neurology Volume 82
Elsevier 2007

Respiratory Management of ALS.

Amyotrophic Lateral Sclerosis.

Lee Guion
Jones and Bartlett Publishers 2009

Amyotrophic Lateral Sclerosis

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

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
<http://www.promotingexcellence.org>

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
<http://www.elib.scot.nhs.uk>

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.

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

**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

Scottish Motor Neurone Disease Association 2006

[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/mnndoc.pdf**

Cochrane Reviews

Riluzole for amyotrophic lateral sclerosis (ALS)/motor neurone disease (MND)

Miller RG, Mitchell JD, Lyon M, Moore DH

Cochrane Database of Systematic Reviews 2002, Issue 2

Amino acids for amyotrophic lateral sclerosis/motor neuron disease.

Parton , Mitsumoto H, Leigh PN

Cochrane Database of Systematic Reviews 2003, Issue 4

Enteral tube feeding for amyotrophic lateral sclerosis/motor neuron disease.

Langmore SE, Kasarskis EJ, Manca ML, Olney RK

Cochrane Database of Systematic Reviews 2006, Issue 4

Treatment for spasticity in amyotrophic lateral sclerosis/motor neuron disease.

Ashworth NL, Satkunam LE, Deforge D.

Cochrane Database of Systematic Reviews 2006, Issue 1

**Recombinant human insulin-like growth factor I (rhIGF-I) for amyotrophic lateral
sclerosis/motor neuron disease.**

Mitchell, JD, Woke JHJ, Borasio GD

Cochrane Database of Systematic Reviews 2002, Issue 3

Ciliary neurotrophic factor (CNTF) for amyotrophic lateral sclerosis/motor neuron disease

Bongioanni P, Reali C, Sogos V.

Cochrane Database of Systematic Reviews 2004, Issue 3

Antioxidant treatment for amyotrophic lateral sclerosis/motor neuron disease

Orrell, RW, Lane RJM, Ross M

Cochrane Database of Systematic Reviews 2005, Issue 1

Diagnosis

ALS : pitfalls in the diagnosis.

Baek WS, Desai NP

Practical Neurology Apr 2007 7 (2) : 74-81

El Escorial revisited: revised criteria for the diagnosis of amyotrophic lateral sclerosis.

Brooks BR, Miller RG, Swash M, and Munsat, TL
Amyotrophic Lateral Sclerosis & Other Motor Neuron Disorders; Dec 2000, Vol 1 Issue 5, p293-299

Management of MND

Diagnosis and management of motor neurone disease.

McDermott, Christopher J and Shaw, Pamela J.
BMJ Vol 336, 22 March 2008, p658-662

Care of chronic conditions. Nursing role in the multidisciplinary management of motor neurone disease.

Skelton, J.
British Journal of Nursing 14 (1):20-4, 2005 Jan 13-26 (review article)

Managing motor neurone disease.

Morrison, Karen E.
Practitioner 249(1674): 612, 614, 617 passim, 2005 Sep (review article)

The Management of Motor Neurone Disease

Leigh, PN et al
J Neurol. Neurosurg. Psychiatry 2003; 74(Suppl IV):iv32-iv47

Palliative Care

Promoting excellence in end-of-life care in ALS.

Mitsumoto H et al
Amyotrophic Lateral Sclerosis 2005, 6: 145-154

Palliative Care Service Needs of Motor Neuron Disease Patients

Goodyear-Smith FA
Journal of Palliative Care 21(2): 117-25, 2005

Palliative Care in Amyotrophic Lateral Sclerosis

Borasio GD, Voltz R and Miller RG
Neurologic Clinics 19(4): 829-47 2001 Nov (Review)

Quality of Life/Psychosocial Issues/End-of-Life Care

A review of psychosocial aspects of motor neurone disease

McLeod Janet E. and Clarke David M
Journal of the Neurological Sciences 258(1-2) : 4-10, 2007 Jul 15

Dysphagia and Nutrition

Nutritional Care of Patients with Motor Neurone Disease

Rio A, Ampong M and Johnson J.
British Journal of Neuroscience Nursing Vol 1 No 1, April 2005 p38-43
(includes information on PEGs and RIGs)

Nutritional Management in MND/ALS patients : an evidence based review.

Heffernan C et al
Amyotrophic Lateral Sclerosis & Other Motor Neuron Disorders 5(2) : 72-83, 2004

Communication

Purposes of AAC device use for persons with ALS as reported by caregivers.

Fried-Oken, M et al
Aac : Augmentative & Alternative Communication 22(3) : 209-21 2006 Sep

Communication strategies of people with ALS and their partners.

Murphy, J.
Amyotrophic Lateral Sclerosis & Other Motor Neuron Disorders 5(2): 121-6, 2004

Carers

A Review: Carers, MND and Service Provision.

Mockford C, Jenkinson C, Fitzpatrick R
Amyotrophic Lateral Sclerosis 7(3): 132-41, 2006 Sep

Burden of Care in Amyotrophic Lateral Sclerosis

Hecht, M. Graesel, E and Tigges, S.
Palliative Medicine 2003 Jun 17(4) p327-33

Improving the quality of life for people with ALS: the challenge ahead.

Mitsumoto H, Del Bene M
Amyotrophic Lateral Sclerosis & Other Motor Neuron Disorders 1(5): 329-36, 2000 Dec

Ventilation

Effect of non-invasive ventilation on survival, quality of life, respiratory function and cognition : a review of the literature.

Piepers S, van den Berg JP, Kalmijn S, van der Pol WL, Wokke JH, Lindeman E, van den Berg LH.
Amyotrophic Lateral Sclerosis 2006; 7(4) : 195-200

Non-invasive ventilation

How beneficial is non-invasive ventilation in patients with amyotrophic lateral sclerosis?
Lechtzin, Noah
Nat Clin Pract Neurol 2(7): 356-7 2006 Jul

Management guidelines for motor neurone disease patients on non-invasive ventilation at home.

Eng, D.
Palliative Medicine 20(2) : 69-79, Mar 2006 (review article)

Management of respiration in MND/ALS patients : an evidence based review.

Heffernan, C et al
Amyotrophic Lateral Sclerosis & Other Motor Neuron Disorders 7 (1):5-15, 2006 Mar

Effects of non-invasive ventilation on survival and quality of life in patients with amyotrophic lateral sclerosis: a randomised controlled trial.

Stephen C Bourke et al
Lancet Neurology 5(2):140-7 Feb 2006

Research - General

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
http://www.alsa.org/files/pdf/Pathways_Hope_2007.pdf

OTHER SOURCES OF INFORMATION ON MOTOR NEURONE DISEASE

MND LIBRARY CATALOGUE – working in partnership with NHS Scotland Knowledge Services the MND library catalogue is available to search online at
<http://www.shelcat.org/pmnd>

To join the library and borrow resources download the library user registration form from the library page of our website at <http://www.mndscotland.org.uk/library.htm>

LITERATURE SEARCHES – if you require a literature search ask the librarian.

MND WEBSITES – We can help you find quality websites on MND. These are available as links from the website and in a separate publication.

MND RESEARCH UPDATE - keep up to date. The Information Officer produces a monthly update of the latest clinical journal articles on the disease. Contact Lynn Black if you would like to receive this by email or post. It is also available to download from our website.

EDUCATION SERVICE – is free and flexible and caters for all groups of health & social care professionals. We hold Family Information Evenings and regular study days and fund a Care Team who can also provide training. Contact the Education Officer by email Robert.Bestow@mndscotland.org.uk

***MND Community Space** – If you work in the NHS or in social work departments you can gain access to the *NHS Scotland e-library* (www.elib.scot.nhs.uk), a web portal of e-journals, databases and e-books to support you with access to evidence-based medicine. Register online for your Athens password. Once registered you can also gain access to the *MND Community Space*, a community of practice knowledge management tool. What does this mean? It means health & social care professionals can share local and personal knowledge of MND, work collaboratively, share dialogue and interpretation, keep up-to-date with developments and interact with members of multidisciplinary teams. Contact the Information Officer or Education Officer for further information.

MND LIBRARY & INFORMATION SERVICE

76 Firhill Road, Glasgow G20 7BA

Tel: 0141-945-1077 Fax: 0141-945-2578

Email: info@mndscotland.org.uk

Website: www.mndscotland.org.uk

Information Officer: Lynn Black

Search the online library catalogue at <http://www.shelcat.org/pmnd>

The Library and Information Service was established in 1998 and is available to people with motor neurone disease and their families/carers free of charge. Health & Social Care Professionals are welcome to make a donation. A visit to the Library will enable you to make the best use of the service but please phone to make an appointment. The Library and Information Service has wheelchair access and facilities for the disabled. Parking for disabled visitors is available at the rear of the building.