

Reading List for Health Professionals 2011

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.

Books - MND General

Motor Neuron Disease : a practical manual

Kevin Talbot, Martin R. Turner, Rachael Marsden, and Rachel Botell.
Oxford University Press, 2010
ISBN : 9780199547364

Motor Neuron Disease

Edited by Michael D. Weiss and Gregory T. Carter
An issue of Physical Medicine and Rehabilitation Clinics of America, Vol. 19, No. 3
Saunders, 2008
ISBN: 9781416063377

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

Motor Neuron Disorders

Edited by Pamela J. Shaw & Michael J. Strong
Blue Books of Practical Neurology volume 28 (series)
Butterworth Heinemann, 2003
ISBN : 0750674423

Amyotrophic Lateral Sclerosis

Edited by Hiroshi Mitsumoto, Serge Przedborski and Paul H. Gordon
Taylor & Francis 2006
ISBN: 9780824729240

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/als/als_report/

Merritt's Neurology 12th edition

Edited by Rowland, LP and Pedley, TA.
Lippincott Williams and Wilkins 2010
Chapter 128 'Amyotrophic Lateral Sclerosis, Primary Muscular Atrophy and Primary Lateral Sclerosis'
By Rowland , LP Mitsumoto, H and Przedborski, S
(e-book available on NHS Scotland's The Knowledge Network)

Amyotrophic Lateral Sclerosis : a guide for patients and families, 3rd edition

edited by Hiroshi Mitsumoto.
Demos Publishing , New York 2009
ISBN:9781932603729

[Motor neurone disease – a family affair 3rd edition](#)

Dr David Oliver
Sheldon Press, 2011
ISBN : 9781847091536

[Motor neurone disease: the 'at your fingertips guide'](#)

Edited by Stuart Neilson and Frank Clifford Rose
Class Publishing, revised edition 2006
ISBN: 9781859590478

Books – Palliative Care/End of Life Care

[Palliative Care in Amyotrophic Lateral Sclerosis. From diagnosis to bereavement. 2nd edition](#)

Edited by David Oliver, Gian Domenico Borasio and Declan Walsh
Oxford University Press 2006
ISBN : 9780198570486

[Palliative Care in Neurological Disease – a team approach](#)

Edited by Judi Byrne, Penny McNamara, Jane Seymour and Pam McClinton
Radcliffe Publishing, 2009
ISBN : 9781846192937

[Palliative care nursing – quality care to the end of life 3rd edition](#) (strong US bias)

Edited by Marianne Matzo and Deborah Witt Sherman
Springer Publishing 2010
ISBN: 0826157947

[Treatment and care towards the end of life : good practice in decision making](#)

General Medical Council (Great Britain), 2010
ISBN: 9780901458469

[Psychosocial Issues in Palliative Care – 2nd edition](#)

Edited by Mari Lloyd-Williams
Oxford University Press, 2008
ISBN : 9780199216420

Books – Ventilation

[Respiratory Management of ALS : Amyotrophic lateral sclerosis.](#)

Guion, Lee
Jones and Bartlett, 2009
ISBN: 9780763755454

Books - Dementia

[Dementia and motor neuron disease.](#)

Michael J Strong
Informa UK Ltd, 2006.
ISBN: 9780415391665

Guidelines

[Practice parameter update: The care of the patient with amyotrophic lateral sclerosis: multidisciplinary care, symptom management, and cognitive/behavioral impairment \(an evidence-based review\): report of the Quality Standards Subcommittee of the American Academy of Neurology.](#)

Miller RG, Jackson CE, Kasarskis EJ, England JD, Forsshew D, Johnston W, Kalra S, Katz JS, Mitsumoto H, Rosenfeld J, Shoemith C, Strong MJ, Woolley SC; Neurology. 2009, vol 73(15):1227-33.

[Practice parameter update: The care of the patient with amyotrophic lateral sclerosis: drug, nutritional, and respiratory therapies \(an evidence-based review\): report of the Quality Standards Subcommittee of the American Academy of Neurology.](#)

Miller RG, Jackson CE, Kasarskis EJ, England JD, Forsshew D, Johnston W, Kalra S, Katz JS, Mitsumoto H, Rosenfeld J, Shoemith C, Strong MJ, Woolley SC; Quality Standards Subcommittee of the American Academy of Neurology. Neurology. 2009, vol 73(15):1218-26. Review. Erratum in: Neurology. 2009, vol 73(24):2134. Neurology. 2010, vol 74(9):781

[Motor Neurone Disease : the use of non-invasive ventilation in the management of motor neurone disease. \(NICE clinical guideline; 105\) Quick reference guide.](#)

National Institute for Health and Clinical Excellence, 2010.

[NHS Greater Glasgow and Clyde palliative care guidelines. 3rd version](#)

NHS Lothian, 2010

[NHS Greater Glasgow and Clyde palliative care pocket guidelines.](#)

NHS Lothian, 2010

[Palliative care in amyotrophic lateral sclerosis: a review of current international guidelines and initiatives.](#)

J Neurol Neurosurg Psychiatry. 2011 Apr;82(4):413-8.

Bede P, Oliver D, Stodart J, van den Berg L, Simmons Z, O Brannagáin D, Borasio GD, Hardiman O.

[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; volume 8: pages 195-213

[Saliva control in Motor Neurone Disease: guidance for healthcare professionals in primary care](#)

Department of Neurology, Glasgow Southern General Hospital, 2009

Available from MND Scotland.

Journals

[Amyotrophic Lateral Sclerosis](#)

Informa UK Ltd - First published Dec 1999

MND library has hardcopy since Dec 1999 and full electronic access to the current issue. Full text of all issues except the past year are also available on the [NHS Scotland Knowledge Network](#)

Reviews on MND

General

[Amyotrophic Lateral Sclerosis \(review\)](#)

Wijesekera, LC and Leigh, N

Orphanet J Rare Dis, 2009, vol 4:3 doi: 10.1186/1750-1172-4-3 ([free article](#))

[Amyotrophic Lateral Sclerosis \(review\)](#)

Kiernan, MC etal

Lancet, 2011, vol 377, iss 9769, pp 942-955

Available on www.mndcare.net.au with publisher's permission ([article pdf](#))

[Amyotrophic lateral sclerosis: current practice and future treatments. \(review\)](#)

Bedlack RS.

Current Opinion in Neurology. 2010 vol 23(5):524-9.

[Recent advances in motor neuron disease. \(review\)](#)

Van Damme P, Robberecht W.

Current Opinion in Neurology. 2009 vol 22(5):486-92.

Diagnosis

[ALS : pitfalls in the diagnosis.](#)

Baek WS, Desai NP

Practical Neurology 2007, vol 7 (2) : 74-81

[Electrodiagnostic criteria for the diagnosis ofALS.\(Awaji Algorithm\)](#)

De Carvalho M, Dengler R, Eisen A, England JD, Kaji R, Kimura J, et al.

Clin Neurophys. 2008, vol 119:497-503.

[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 2000, Vol 1 Issue 5, p293-299

Treatment

[Riluzole for amyotrophic lateral sclerosis \(ALS\)/motor neurone disease \(MND\)](#)

Miller RG, Mitchell JD, Lyon M, Moore DH

Cochrane Database of Systematic Reviews 2002, updated 2007 Jan 24;(1):CD001447.

Management of MND

[Diagnosis and management of motor neurone disease.](#)

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

[Managing motor neurone disease. \(review\)](#)

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

[Clinical recognition and management of Amyotrophic Lateral Sclerosis: The Nurse's Role](#)

Clarke, K and Levine, T
Journal of Neuroscience Nursing, 2011, vol 43, (4) :205-214

[The management of amyotrophic lateral sclerosis.](#)

Phukan J, Hardiman O.
J.Neurology. 2009 , vol 256(2):176-86

[The Management of Motor Neurone Disease](#)

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

[Motor neurone disease: a practical update on diagnosis and management.](#)

Wood-Allum C, Shaw PJ.
Clin Med. 2010, vol 10(3):252-8.

[Medication in the last days of life for motor neuron disease/amyotrophic lateral sclerosis.](#)

Oliver DJ, Campbell C, O'brien T, Sloan R, Sykes N, Tallon C, Taylor-Horan J, Udoma M.
Amyotroph Lateral Scler. 2010, vol 11(6):562-4.

Cognitive Impairment and Dementia in MND

[Dementia and cognitive impairment in amyotrophic lateral sclerosis: a review.](#)

Giordana MT, Ferrero P, Grifoni S, Pellerino A, Naldi A, Montuschi A.
Neurol Sci. 2011 vol 32(1):9-16

[Cognitive impairment in amyotrophic lateral sclerosis.](#)

Phukan J, Pender NP, Hardiman O.
Lancet Neurol. 2007 vol 6(11):994-1003.

Dysarthria and Communication

[Dysarthria in amyotrophic lateral sclerosis \(review\)](#)

Tomik B, Guilloff RJ.
Amyotroph Lateral Scler. 2010;11(1-2):4-15.

[Communication Support for People with ALS.](#)

Beukelman D, Fager S, Nordness A.
Neurol Res Int. 2011 Epub 2011 Apr 14.

The role of augmentative communication devices in the medical management of ALS.

Brownlee A, Palovcak M.
NeuroRehabilitation. 2007, vol 22(6):445-50.

Dysphagia and Nutrition

The management of drooling in motor neurone disease. (review article)

Dand P, Sakel M.
Int J Palliat Nurs. 2010, vol 16(11):560-4.

Nutritional state, energy intakes and energy expenditure of amyotrophic lateral sclerosis (ALS) patients. (review article)

Genton L, Viatte V, Janssens JP, Héritier AC, Pichard C.
Clin Nutr, 2011 epub July 26

Nutritional care of patients with Motor Neurone Disease

Rio A, Ampong M and Johnson J.
Br J. Neurosci Nurs. 2005 vol 1(1); 38-43
(includes information on PEGs and RIGs)

Palliative Care

Palliative care in amyotrophic lateral sclerosis: a review of current international guidelines and initiatives.

Bede P, Oliver D, Stodart J, van den Berg L, Simmons Z, O Brannagáin D, Borasio GD, Hardiman O.
J Neurol Neurosurg Psychiatry. 2011 vol 82(4):413-8.

Palliative care in multiple sclerosis and motor neurone disease.

Barnes J, Campbell C.
Br J Hosp Med (Lond). 2010, vol 71(1):21-5.

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

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

Palliative Care Service Needs of Motor Neuron Disease Patients

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

The central importance of spirituality in palliative care. (review article)

Amoah, CF
Int J Palliat Nurs, 2011, vol 17(7) :353-358

Quality of Life and Psychosocial Issues

A review of psychosocial aspects of motor neurone disease.

McLeod JE, Clarke DM.
J Neurol Sci. 2007, vol 15;258(1-2):4-10.

[Coping with amyotrophic lateral sclerosis: an integrative view.](#)

Matuz T, Birbaumer N, Hautzinger M, Kübler A.
J Neurol Neurosurg Psychiatry. 2010 vol 81(8):893-8.

Ventilation

[Early treatment with noninvasive positive pressure ventilation prolongs survival in Amyotrophic Lateral Sclerosis patients with nocturnal respiratory insufficiency.](#)

Carratù P, Spicuzza L, Cassano A, Maniscalco M, Gadaleta F, Lacedonia D, Scoditti C, Boniello E, Di Maria G, Resta O.
Orphanet J Rare Dis. 2009, vol 10;4:10.

[Mechanical ventilation for amyotrophic lateral sclerosis/motor neuron disease.](#)

Radunovic A, Annane D, Jewitt K, Mustfa N.
Cochrane Database of Systematic Reviews 2009, Issue 4. Art. No.: CD004427.
DOI: 10.1002/14651858.CD004427.pub2.

[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, vol 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, vol 2(7): 356-7 2006 Jul

[Management guidelines for motor neurone disease patients on non-invasive ventilation at home. \(review \)](#)

Eng, D.

Palliative Medicine 2006, vol 20(2) : 69-79

[Management of respiration in MND/ALS patients : an evidence based review.](#)

Heffernan, C et al

Amyotrophic Lateral Sclerosis & Other Motor Neuron Disorders 2006, vol 7 (1):5-15

[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 2006, vol 5(2):140-7

Carers

[From symptom onset to a diagnosis of amyotrophic lateral sclerosis/motor neuron disease \(ALS/MND\): experiences of people with ALS/MND and family carers - a qualitative study.](#)

O'Brien MR, Whitehead B, Jack BA, Mitchell JD.

Amyotroph Lateral Scler. 2011 vol 12(2):97-104.

[Burden, depression, and anxiety in caregivers of people with amyotrophic lateral sclerosis.](#)

Pagnini F, Rossi G, Lunetta C, Banfi P, Castelnuovo G, Corbo M, Molinari E.

Psychol Health Med. 2010 vol 15(6):685-93.

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 NHS Scotland Knowledge Network (www.knowledge.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

The Library and Information Service 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.