Facilitating a Coordinated Multidisciplinary approach to MND through ‘one stop shop’ online resources

Carol Birks

MND Australia
Living better for longer

- early diagnosis
- optimal symptom management
- timely referrals
- Multi/interdisciplinary team approach
- timely interventions
Symptom management

- respiratory
- swallowing
- communication
- movement and joints
- cognition
- emotional lability
- fatigue
- insomnia
Wellbeing and support needs

- planning - financial, legal, advance care
- information
- daily living and mobility
- equipment
- personal and home care
- psychosocial and spiritual needs - depression, anxiety, loss, bereavement, intimacy, isolation, social support
- carer wellbeing and support
- children and families
Health professionals and community care workers

Significantly involved in each person’s care

4-12 health professionals involved in the care of each person with MND (MND NSW)

- community/aged care worker and case manager
- dietitian
- general practitioner
- MND Association regional/care advisor
- neurologist
- occupational therapist

- palliative care team
- physiotherapist
- respiratory specialist
- registered nurse, MND nurse, clinical nurse consultant or clinical nurse specialist
- social worker, psychologist, counsellor
- speech pathologist
Objectives:

To assist people living with ALS/MND to live better for longer by providing:

1. ‘one stop shop’ ALS/MND online resources:
2. easily accessible referral pathways
3. easily accessible ALS/MND information to health and community care professionals working in Australian regional and remote areas.
Sources of evidence

Timely intervention and referral improves survival and quality of life of people living with MND

Evidence-based guidelines

Andersen and others 2007, Chio and others 2009, Miller and others 2009, Orrell 2010

Systematic reviews
Getting research into practice

- MND Australia
  - Living Better For Longer project
- Funder
  - Australian Government Department of Health and Ageing
Steering committee

Carol Birks - Project Manager, National Executive Director, MND Australia

Rod Harris - CEO, MND Victoria

Graham Opie - CEO, MND NSW

Penny Waterson - Project Officer, Information Resources Coordinator, MND NSW
Dr Peter Allcroft - Respiratory and Palliative Care Physician, Southern Adelaide Palliative Care Services, Repatriation Hospital MND Clinic, MND SA board member, South Australia

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Nicole Hutchinson - Clinical Nurse Consultant, Royal Brisbane and Women’s Hospital MND Clinic, Queensland
Margherita Nicoletti - Palliative Care Physician, WA Neurosciences network and WA MND Model of Care, MNDWA board member, Palliative Care Australia, Western Australia
Heather Wieland - National Rural Health Alliance and National President of the Country Women's Association of Australia
Welcome to MNDcare - the website for Australian health and community care professionals involved in motor neurone disease care and support.

No matter where you work, MNDcare will help you to:
- assess the needs of the person with MND and their carer
- get evidence based and best practice MND information
- make referrals to the right provider at the right time
- provide a coordinated, multidisciplinary team approach to MND care

Find out more about motor neurone disease...
Motor neurone disease (MND) which is known as amyotrophic lateral sclerosis (ALS) in many other parts of the world, and as Lou Gehrig's disease in the USA, is a progressive neurological disease. read more

What is the MNDcare approach?
Motor neurone disease is very different for every person diagnosed. MND may start in different areas of the body and progress in different patterns and at different rates. read more

Strategies you can use to sensitively communicate the diagnosis of motor neurone disease
Prognostic and end-of-life communication is a vital skill for health care professionals caring for patients with progressive life-limiting illnesses, and their families. read more

Is non-invasive positive pressure ventilation beneficial for people with MND?
An important intervention, which clinical experience suggests is beneficial for patients with ALS/MND, is non-invasive ventilation (Orrell 2010). read more
1. assess the needs of the person with MND and their carer
2. get evidence based and best practice MND information
Respiratory

Respiratory weakness can develop at any stage of disease progression and may cause shortness of breath with impaired quality of life and somnolence. Dyspnoea is caused by weakened respiratory muscles – intercostals, diaphragm and abdominal muscles.

The diagnosis and management of respiratory insufficiency is critical because most deaths from ALS are due to respiratory failure (Miller and others 2009a).

**MND Australia 2008**

Early in the course of the disease nocturnal hypoventilation may not be manifest by obvious shortness of breath but more by headaches or general tiredness.

Later, more marked shortness of breath may appear but this tends to be at the time when the person living with MND has severe generalised weakness which may affect the throat and limb muscles. Symptoms at this time include:

- breathlessness on exertion, sometimes just the exertion of speaking or eating
- sleep disturbance, anxiety and panic
- orthopnoea - breathlessness lying flat
- hypoventilation is worse during sleep. Upper airway may also be partially obstructed due to bulbar and laryngeal muscle weakness
- increasing blood CO2 levels result in headaches, nausea and somnolence, especially on waking
- hypoxia, especially if there is coexisting lung disease

**Respiratory management algorithm (Miller and others 2009a)**

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**Related content**
- Fatigue
- Insomnia
- Podcast - Dr Amanda Piper, Ask the Experts, Breathing Under Pressure
- Saliva management

**Related documents**
- Breathing and MND: an introduction - for people living with MND
- Breathing and MND: medications and non-invasive ventilation - for people living with MND
- Breathing and MND: what you can do - for people living with MND
- NMD Australia 2008 Motor neuron disease: A problem solving approach - A guide for general practitioners

**Related external links**
- Andersen and others 2007 Good practice in the management of amyotrophic lateral sclerosis: clinical guidelines. An evidence-based review with good practice points, EAESC Working Group
- Miller and others 2009a Practice parameter update: The care of the patient with amyotrophic lateral sclerosis: drug, nutritional, and respiratory therapies
Respiratory weakness can develop at any stage of disease progression and may cause shortness of breath, fatigue, impaired quality of life and somnolence. Dyspnoea is caused by weakened respiratory muscles – intercostals, diaphragm and abdominal muscles.

The diagnosis and management of respiratory insufficiency is critical because most deaths from ALS are due to respiratory failure (Miller and others 2009a).

MND Australia 2008

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Communication

Dysarthria (impairment of speech production) is caused by weakness and paralysis of the lips, facial muscles, tongue, larynx, and pharynx resulting from affected trigeminal, facial, glossopharyngeal, vagus, accessory and hypoglossal cranial nerves. Weakness of the muscles of respiration will also impact on speech volume. These symptoms require a coordinated, multidisciplinary approach and regular review (MND Australia 2008).

MND Australia 2008

Effects of dysarthria
- slurring, hoarseness and weak voice which may progress to total loss of speech (anarthria)
- poor communication ability can lead to:
  - isolation - communication inadequate or avoided
  - frustration - for both communication partner and person with MND - communication may need extra need time which may not be available
  - fear and anxiety - unable to discuss their fears and concerns
  - low self-esteem - others assume deafness and shout or assume intellectual impairment
  - loss of control and increasing vulnerability - because misunderstood
Cognitive assessment

A fuller characterisation of the extent of cognitive and behavioural dysfunction in MND is not simply of academic interest but has important implications given that the burden and stress for carers of patients with FTD is very great. It also has relevance to effective communication, legal issues and end-of-life decision making by patients with MND (Lillo and Hodges 2009).

Miller and others 2009b Practice parameter update: The care of the patient with amyotrophic lateral sclerosis: multidisciplinary care, symptom management, cognitive/behavioral impairment


Strong and others 2009 Consensus criteria for the diagnosis of frontotemporal cognitive and behavioural syndromes in amyotrophic lateral sclerosis

Miller and others 2009b Practice parameter update: The care of the patient with amyotrophic lateral sclerosis, multidisciplinary care, symptom management, cognitive/behavioral impairment


Free full text access online.

www.neurology.org/cgi/content/full/73/15/1227
Special Article

Practice Parameter update: The care of the patient with amyotrophic lateral sclerosis: Multidisciplinary care, symptom management, and cognitive/behavioral impairment (an evidence-based review)

R. G. Miller, MD, FAAN, C. E. Jackson, MD, FAAN, E. J. Kasarskis, MD, PhD, FAAN, J. D. England, MD, FAAN, D. Forshey, RN, W. Johnston, MD, S. Kalra, MD, J. S. Katz, MD, H. Mitsumoto, MD, FAAN, J. Rosenfeld, MD, PhD, FAAN, C. Shesmith, MD, BSc, M. J. Strong, MD and S. C. Woolley, PhD

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Address correspondence and reprint requests to American Academy of Neurology, 1080 Montreal Avenue,
3. make referrals to the right provider at the right time

4. provide a coordinated, multidisciplinary team approach to MND care
Communication

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MND Australia 2008

Effects of dysarthria

- slurring, hoarseness and weak voice which may progress to total loss of speech (anarthria)
- poor communication ability can lead to:
  - isolation - communication inadequate or avoided
  - exclusion from social interaction - as speech becomes difficult/impossible to understand
  - frustration - for both communication partner and person with MND - communication may need extra need time which may not be available
  - fear and anxiety - unable to discuss their fears and concerns
  - low self-esteem - others assume deafness and shout or assume intellectual impairment
  - loss of control and increasing vulnerability - because misunderstood or opinion ignored or not sought

You are here: Living with MND > Symptom management > Communication

Click to edit Master title style

Related content
- Augmentative and assistive communication (AAC) devices
- Communication assessment
- Communication support strategies
- Swallowing

Related documents
- MND Australia 2008 Motor neurone disease: A problem solving approach - A guide for general practitioners

Related external links
- Tomik and Guiloff 2010 Dysarthria in amyotrophic lateral sclerosis: a review
Referral Pathways

Search By Map

OR

Search by criteria selection

State: *
New South Wales / Australian Capital Territory

Issue: *
Northern Territory
Queensland
South Australia
Tasmania
Victoria
Western Australia

Need:
Communication

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OR

Search by criteria selection

State: *
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Issue: *
Symptom management
Diagnosis
Psychosocial
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Information and education
Equipment
Personal care
Community engagement
Respite
End of life

Need:
Referral Pathways

New South Wales & Australian Capital Territory selected

Step 1 - Select the issue: *

Symptom management

Step 2 - Select the need: (Optional)

Communication

Update Search

MND New South Wales
Phone: 02 8877 0999
Fax: 02 9616 2077
info@mndnsw.asn.au
www.mndnsw.asn.au
Building 4, Gladesville Hospital, Victoria Rd Gladesville NSW 2111

MND NSW is a registered charitable not-for-profit organisation providing support and information to people with all types of motor neurone disease, their families and carers in NSW, ACT and NT.

MND NSW provides a range of aids and equipment to people living with MND in NSW and ACT following assessment by an appropriate health professional.

The MND Association can provide information on local services and providers.
Multidisciplinary MND Clinics

Phone: 1800 777 175

There are several motor neurone disease specific clinics and programs of care in New South Wales. These specialised clinics provide an integrated approach to the management and clinical care of the person with motor neurone disease.

The multidisciplinary clinics give the person with motor neurone disease access to a range of health professionals who work together to provide a coordinated response to care.

Team members may include the neurologist, rehabilitation specialist, palliative care specialist, respiratory specialist, physiotherapist, dietitian, social worker, occupational therapist, speech pathologist and clinic nurse coordinator. MND Association regional advisors also attend these clinics to provide information and support.

MND clinics and services in New South Wales are located at:

- Prince of Wales Hospital MND Clinic, Randwick
- Sydney West MND Clinic, St Joseph’s Hospital, Auburn
- Macquarie Neurology, Macquarie University Hospital
- Calvary Health Care MND Service, Kogarah

For contact details of these clinics use the freecall number, if you are located in NSW, to contact MND NSW.

Speech Pathologist

Phone: 03 9642 4899

www.speechpathologyaustralia.org.au/about-spa/find-a-speech-pathologist

Level 2 / 11-19 Bank Place

The speech pathologist (SP) is an integral part of the multidisciplinary team. SPs may be accessed from local hospitals or community health, aged care or palliative care services.
Referral Pathways

New South Wales & Australian Capital Territory selected

Step 1 - Select the issue: *

Symptom management

Step 2 - Select the need: (Optional)

Communication

Update Search

Technology solutions for computer Access, Seating and Communication (TASC)

Phone: 02 9975 8469
www.thespasticcentre.org.au/services/services-tasc/services-tasc.htm
189 Allambie Road, Allambie Heights
NSW 2100

TASC is a consultancy service which meets the technology, seating and mobility needs of people with disabilities in NSW.

TASC services include the following:

- identification of client needs and recommendations in relation to technology for communication, computer access, seating/wheelchairs and environmental control
- alternatives to handwriting
- assistance with the trial of recommended equipment
- assistance with preparing funding submissions for recommended equipment
Referral Pathways

• simple tool
• more than 1200 potential pathways
• Australian health professionals and community care workers can – locate the appropriate health professional, community care worker, agency or other service for the person living with MND – as soon as the need is identified
Information about motor neurone disease

Phenotypes

Motor neurone disease can be categorised on the basis of sites of involvement at presentation and the balance between lower motor neurone (LMN) and upper motor neurone (UMN) features (MND Australia 2008).

**Turner and Al-Chalabi 2007**

Motor neurone disease comprises a number of clinical phenotypes united by the pathological feature of progressive motor neuronal loss. They can be distinguished on clinical and pathological features.

The most common form of MND is amyotrophic lateral sclerosis, where there is clinical evidence of both upper and lower motor neurone involvement.

Clinically 'pure' lower motor neurone MND is termed progressive muscular atrophy, and pure upper motor neurone MND is termed primary lateral sclerosis. The latter is particularly rare and associated with significantly slower progression.

**MND Australia 2008**

Amyotrophic lateral sclerosis - ALS
- most common form affecting about 65% of patients
- mixed LMN and UMN signs usually beginning in the limb(s)
- bulbar involvement later
- more common in men than women

Progressive bulbar/pseudobulbar palsy
- about 25% of cases at onset
- more common in women
- progressive dysarthria and dysphonia
Disease process interventions

Riluzole

Riluzole is the only medication approved by regulatory authorities for the treatment of ALS, including Europe, the USA, and Australia (Orrell 2010).

Riluzole is an anti-glutamate medication manufactured by Sanofi-Aventis under the name Rilutek™. Riluzole appears to block the release of glutamate from nerve cells (neurones).

Riluzole is safe and effective for slowing disease progression to a modest degree in ALS (Miller and others 2009a). It helps people remain in the milder or moderately affected stages of the disease for longer than those not taking riluzole, if they start on the medication early in the disease progression (Miller and others 2007).

Other disease process interventions

Riluzole remains the only medication to have shown benefit which has stood up to the methodology of the Cochrane review process (Orrell 2010).
Staying up-to-date
subscribe to email updates
conferences and events
RSS feeds (content from other MND/ALS sites)
You are here: Overview > Staying up-to-date > The ALSUntangled Group

The ALSUntangled Group

ALS-U is a new and exciting initiative. Driven from the ‘ground up’ it will provide a timely, accurate and scientifically valid analysis of alternative and off-label treatments. This in turn helps people with ALS/MND and their families to make informed decisions. For more information on ALSUntangled visit http://www.informaworld.com/smpp/content?content=a911419844&fulltext=713240928

**ALSUntangled No. 5: Investigating the Stowe/Morales ALS Protocol**
Amyotrophic Lateral Sclerosis, August 2010, Vol. 11, No. 4, Pages 414-416.

**ALSUntangled Update 4: Investigating the XCell-Center**

**ALSUntangled Update 3: Investigating stem cell transplants at the Hospital San Jose Tecnologico de Monterrey**

**ALSUntangled Update 2: Investigating The Hickey Wellness Center**
Amyotrophic Lateral Sclerosis, 2009, Vol. 10, No. 5-6, Pages 490-491.

**ALSUntangled Update 1: Investigating a bug (Lyme Disease) and a drug (Iplex) on behalf of people with ALS**
Feedback and submit site content

Participate

MNDcare welcomes your feedback and suggested site content items.

Feedback
Read more

Submit site content
Read more
Content development

• ongoing
  – monthly e-newsletters for subscribers
  – images
  – checklists, assessment tools
  – podcasts, vodcasts
  – case studies, local care pathways
  – fact sheets for people living with MND
  – evidence updates
Outcomes

• ‘One-stop shop’ website – for health professionals and community care workers

• facilitate and promote best practice coordinated multidisciplinary MND care – timely interventions and appropriate referrals

• for all people with a diagnosis of MND in Australia – especially in regional, rural and remote areas
Acknowledgements

www.mndcare.net.au

• MNDcare Expert review panel
• Australian Government Department of Health and Ageing
• RockSolid Consulting
• MNDcare Steering committee
• Tomik and Guiloff, 2010 Dysarthria management algorithm
• Anita Richter, Project Officer, MNDcare audit

See poster: CW248

Helping people living with motor neurone disease to live better for longer
MND Australia Invites you to Sydney next year

- Hilton Hotel, Sydney  
  www.hiltonsydney.com.au

- 29 November  
  - Allied Professionals Forum

- 30 November to 2 December  
  - ALS/MND Symposium  
  - Scientific and Clinical streams

- More details  
  - www.mndaust.asn.au  
  - www.mndassociation.org