Living Better for Longer

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


SPECIAL ARTICLE

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

R.G. Miller, MD, FAAN
C.E. Jackson, MD, FAAN
E.J. Kasarskis, MD, PhD, FAAN
J.D. England, MD, FAAN
D. Forshew, RN
W. Johnston, MD
S. Kalra, MD
J.S. Katz, MD

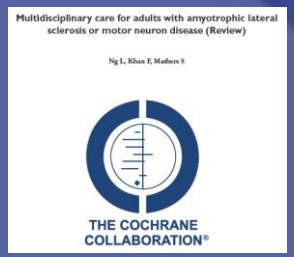
ABSTRACT

Objective: To systematically review evidence bearing on the management of patients with amyotrophic lateral sclerosis (ALS).

Methods: The authors analyzed studies from 1998 to 2007 to update the 1999 practice parameter. Topics covered in this section include slowing disease progression; nutrition, and respiratory management for patients with ALS.

Results: The authors identified 8 Class I studies, 5 Class II studies, and 43 Class III studies in ALS. Important treatments are available for patients with ALS that are underutilized. Noninvasive ventilation (NIV), percutaneous endoscopic gastrostomy (PEG), and riluzole are particularly important and have the best evidence. More studies are needed to examine the best tests of respiratory

Systematic reviews


Multidisciplinary care for adults with amyotrophic lateral sclerosis or motor neuron disease (Review)

Ng L, Khan F, Mathers S

THE COCHRANE COLLABORATION®

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

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

Expert review panel

Dr Peter Allcroft - Respiratory and Palliative Care Physician, Southern Adelaide Palliative Care Services, Repatriation Hospital MND Clinic, MND SA board member, South Australia

Jennene Arnel - MND Victoria/Tasmania Regional Advisor, Tasmania, Social Worker

Bronwyn Binnington - Occupational Therapist, Clare Holland House Hospice, ACT

Sara Feldman - Physical Therapist MDA/ALS Center of Hope Drexel University College, USA

Professor Matthew Kiernan - Neurologist, University of NSW, Prince of Wales Hospital MND Multidisciplinary Clinic, NSW

Cont'd

Expert review panel (cont'd)

Maryanne McPhee - Speech Pathologist, MND Centre, Calvary Health Care Bethlehem, Victoria

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

Home

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

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Palliative Care Victoria

Vodcast - Interview with Rod Harris: Motor Neurone Disease (MND) and palliative care. Rod Harris has been CEO of MND Victoria since 1993. read more

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New

- McCabe and O'Connor 2010
- Palliative Care Australia 2008

Updated

- MNDcare approach
- Getting started
- Overview

Referral Pathways

click on a state or territory

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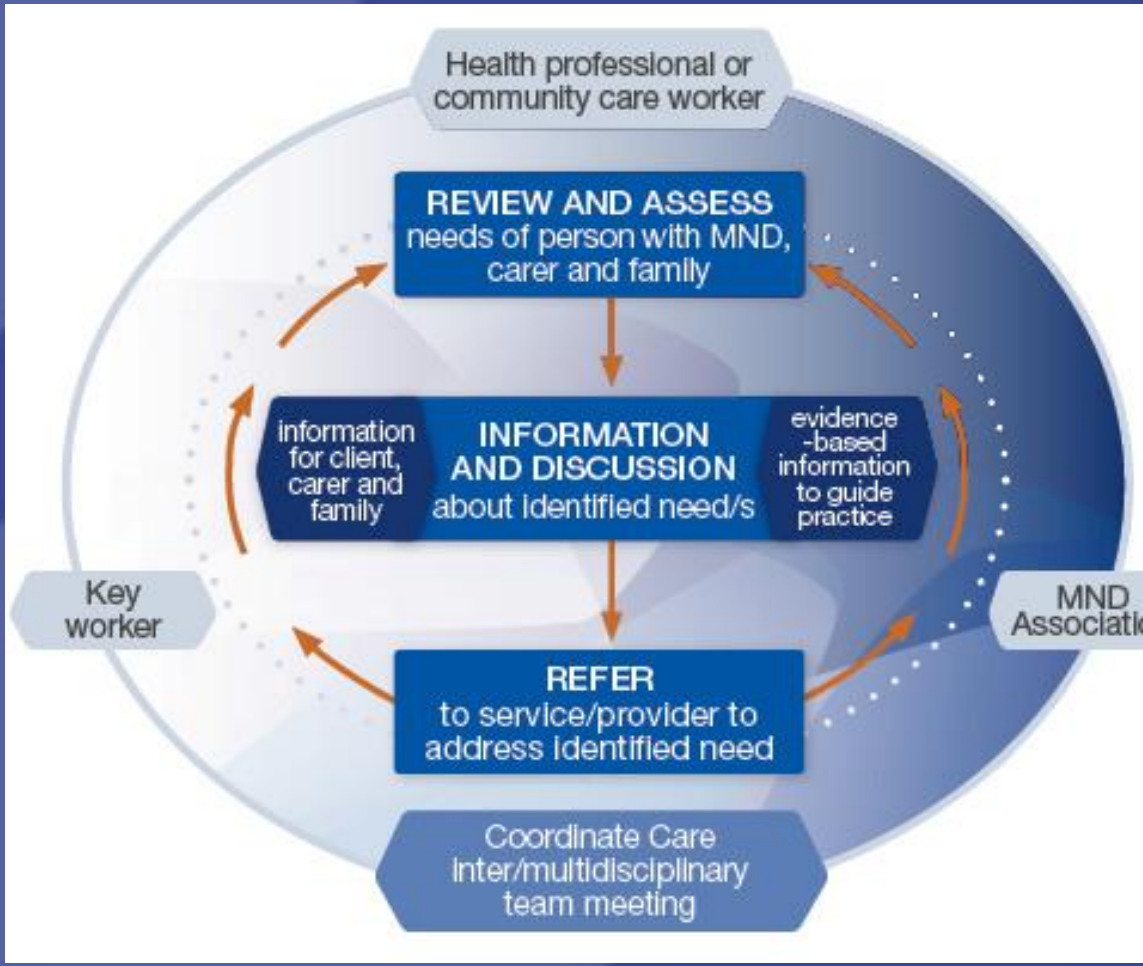
www.mndcare.net.au

1. assess the needs of the person with MND and their carer
2. get evidence based and best practice MND information



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  - Respiratory
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    - Dyspnoea
  - Swallowing
  - Communication
  - Movement and joints
  - Cognition
  - Emotional lability
  - Fatigue
  - Insomnia
- Wellbeing and support needs

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

Respiratory

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

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 that time include:

- breathlessness on exertion, sometimes just the exertion of speaking or eating
- sleep disturbance, anxiety and panic
- orthopnoea - breathless lying flat
- hypoventilation is worse during sleep. Upper airway may also be partially obstructed due to bulbar and laryngeal muscle weakness
- increasing blood C02 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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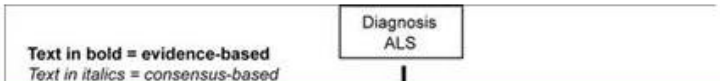

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- Insomnia
- Podcast - Dr Amanda Piper, Ask the Experts, Breathing Under Pressure
- Saliva management

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
- MND Australia 2008 Motor neurone 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. EALSC Working Group
- Miller and others 2009a Practice parameter update: The care of the patient with amyotrophic lateral sclerosis: drug, nutritional, and respiratory therapies

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explanation about the symptom

link to respiratory assessment information and detailed information about dyspnoea

Related content

Related documents

Related external links (usually the review or evidence)

Respiratory

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.

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MND Australia 2008

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http://www.mndcare.net.au/living-with-mnd/symptom-management/communication

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Communication - MND Care

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- Wellbeing and support needs

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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
  - 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

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

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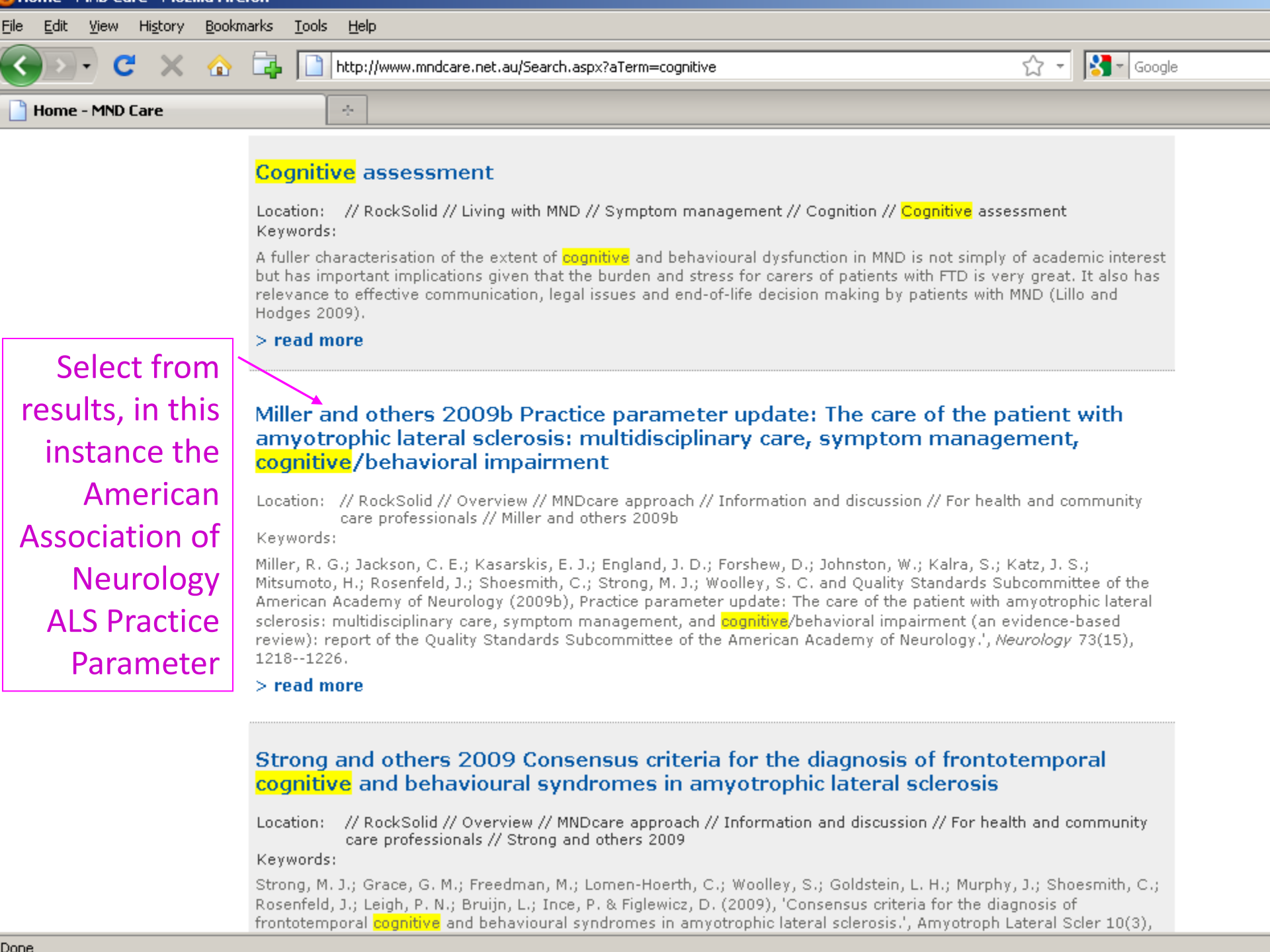
- Tomik and Guiloff 2010 Dysarthria in amyotrophic lateral sclerosis: a review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Cognitive assessment
Location: // RockSolid // Living with MND // Symptom management // Cognition // Cognitive assessment
Keywords:
A fuller characterisation of the extent 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).
> read more
Select from results, in this instance the American Association of Neurology ALS Practice Parameter
Miller and others 2009b Practice parameter update: The care of the patient with amyotrophic lateral sclerosis: multidisciplinary care, symptom management, cognitive/behavioral impairment
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Keywords:
Miller, R. G.; Jackson, C. E.; Kasarskis, E. J.; England, J. D.; Forshew, D.; Johnston, W.; Kalra, S.; Katz, J. S.; Mitsumoto, H.; Rosenfeld, J.; Shoesmith, C.; Strong, M. J.; Woolley, S. C. and Quality Standards Subcommittee of the American Academy of Neurology (2009b), 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.', Neurology 73(15), 1218--1226.
> read more
Strong and others 2009 Consensus criteria for the diagnosis of frontotemporal cognitive and behavioural syndromes in amyotrophic lateral sclerosis
Location: // RockSolid // Overview // MNDcare approach // Information and discussion // For health and community care professionals // Strong and others 2009
Keywords:
Strong, M. J.; Grace, G. M.; Freedman, M.; Lomen-Hoerth, C.; Woolley, S.; Goldstein, L. H.; Murphy, J.; Shoesmith, C.; Rosenfeld, J.; Leigh, P. N.; Bruijn, L.; Ince, P. & Figlewicz, D. (2009), 'Consensus criteria for the diagnosis of frontotemporal cognitive and behavioural syndromes in amyotrophic lateral sclerosis.', Amyotroph Lateral Scler 10(3),
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Free full text access online.

URL www.neurology.org/cgi/content/full/73/15/1227

NEUROLOGY 2009;73:1227-1233

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)

Report of the Quality Standards Subcommittee of the American Academy of Neurology

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

From the Department of Neurology (R.G.M., D.F., J.S.K., S.C.W.), California Pacific Medical Center, San Francisco; University of Texas Health Science Center of San Antonio (C.E.J.); University of Kentucky (E.J.K.), Lexington; Louisiana State University Health Sciences Center (J.D.E.), New Orleans; Department of Neurology (W.J., S.K.), University of Alberta, Canada; Neurological Institute (NI-9) (H.M.), New York, NY; Division of Neurology (J.R.), UCSF, Fresno, CA; and London Health Sciences Center (C.S., M.J.S.), London, Ontario, Canada.

Address correspondence and reprint requests to American Academy of Neurology, 1080 Montreal Avenue,

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3. make referrals to the right provider at the right time
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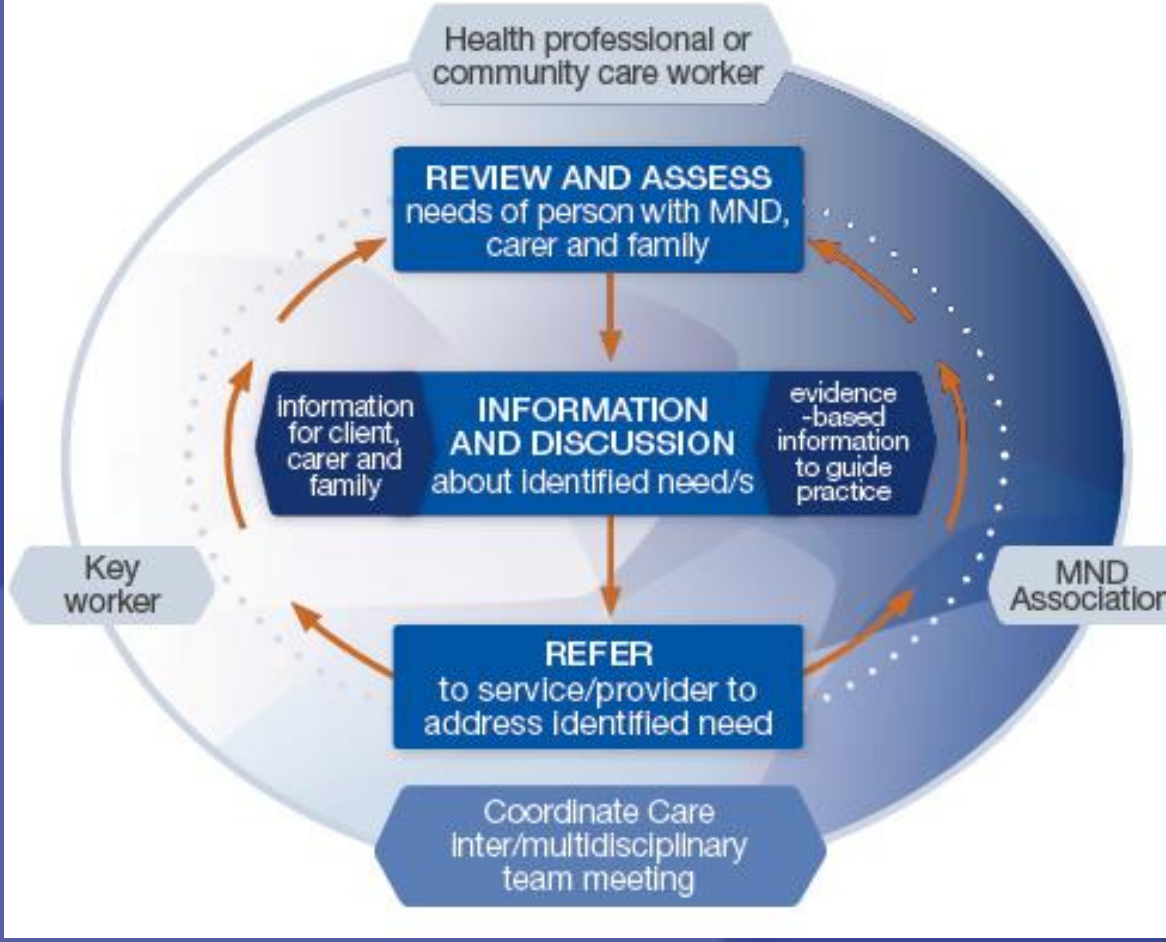

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Symptom management
- Respiratory
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- Communication
  - Communication assessment
  - Dysarthria
- Movement and joints
- Cognition
- Emotional lability
- Fatigue
- Insomnia

Wellbeing and support needs

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Communication

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MND Australia 2008

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  - 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

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State: * New South Wales / Australian Capital Territory

Issue: * Symptom management

Need:

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- Psychosocial
- Carer
- Information and education
- Equipment
- Personal care
- Community engagement
- Respite
- End of life

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State: * New South Wales / Australian Capital Territory

Issue: * Symptom management

Need: Communication

- Select
- Regular review and assessment
- Mobility
- Respiratory assessment and support
- Saliva and swallowing
- Nutrition and PEG
- Communication
- Cognition and emotional lability
- Fatigue
- Pain management

Referral Pathways

Search By Map

OR

Search by criteria selection

State: * New South Wales / Australian Capital Territory

Issue: * Symptom management

Need: Communication

Search

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

New search

4 service(s) found. 1 2

Current as at 11 Jun 2010

MND New South Wales

Phone: 02 8877 0999

Fax: 02 9816 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.

Current as at 17 Jun 2010

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.

Current as at 06 Jun 2010

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

New search

4 service(s) found. 1 2

Current as at 02 Jun 2010

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

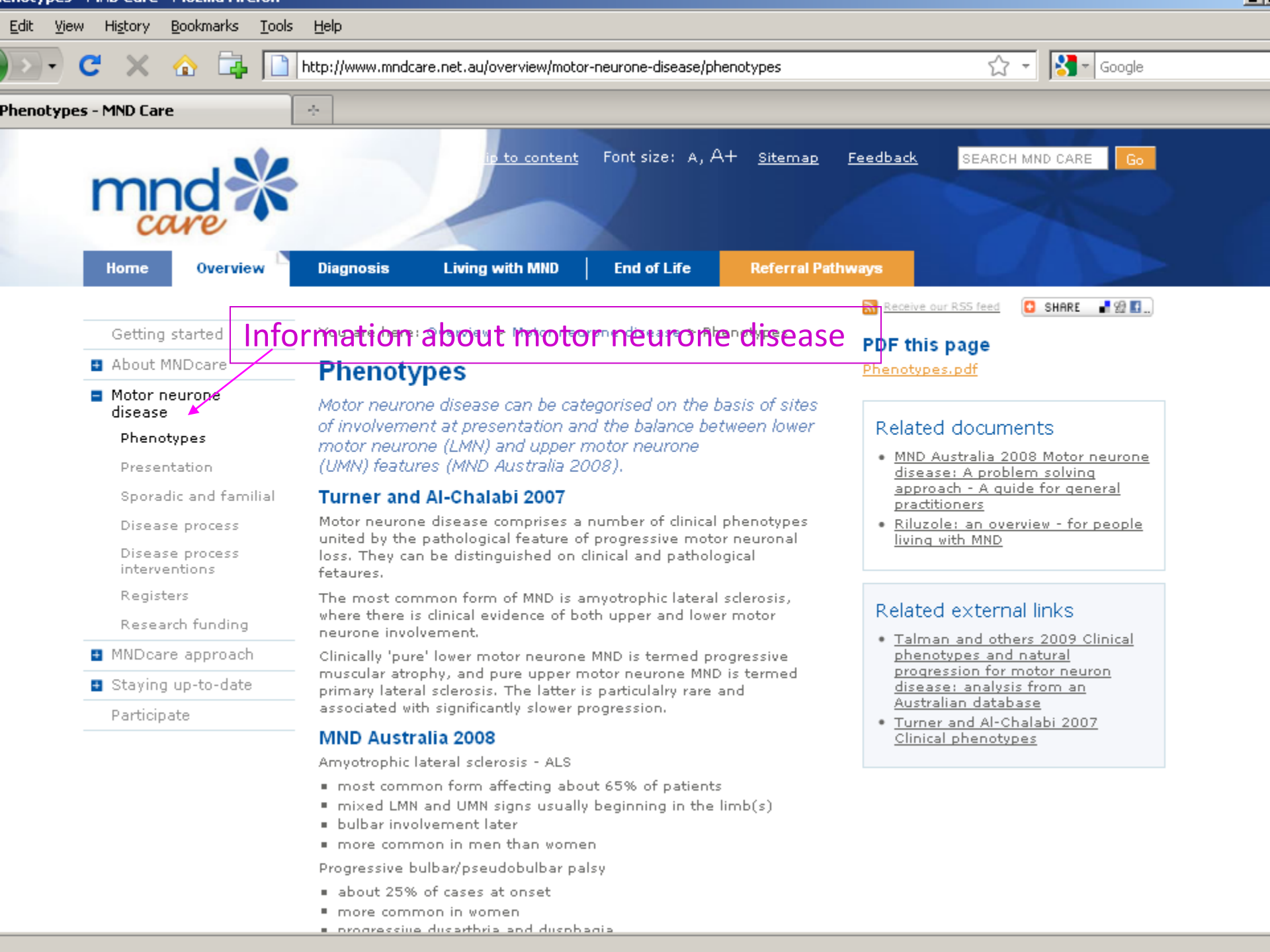
TASC is a consultancy service which meets the technology, seating and mobility needs of people with disabilities in NSW.

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**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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 fetaures.
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 particulalry 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
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Phenotypes.pdf
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MND Australia 2008 Motor neurone disease: A problem solving approach - A guide for general practitioners
Riluzole: an overview - for people living with MND
Related external links
Talman and others 2009 Clinical phenotypes and natural progression for motor neuron disease: analysis from an Australian database
Turner and Al-Chalabi 2007 Clinical phenotypes

Disease process interventions

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Disease process interventions

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

Riluzole

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).

Read more

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).

Read more

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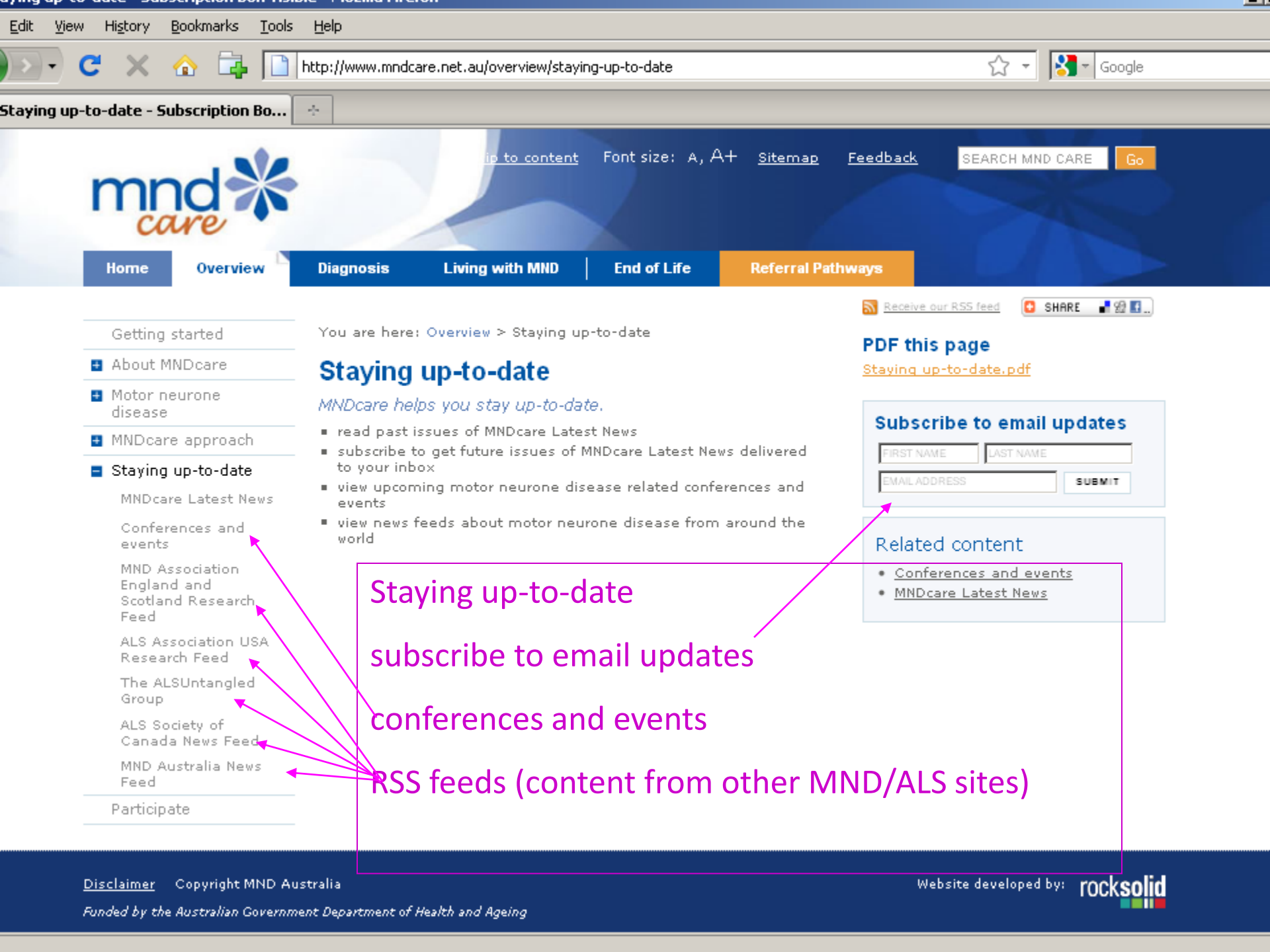
Related external links

- Orrell 2010 Motor neuron disease: systematic reviews of treatment for ALS and SMA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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/section?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
Amyotrophic Lateral Sclerosis , May 2010, Vol. 11, No. 3, Pages 337-338.

ALSUntangled Update 3: Investigating stem cell transplants at the Hospital San Jose Tecnologico de Monterrey
Amyotrophic Lateral Sclerosis , 2010, Vol. 11, No. 1-2, Pages 248-249.

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
Amyotrophic Lateral Sclerosis , 2009, Vol. 10, No. 4, Pages 248-250.

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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
- Miller, R. G.; Jackson, C. E.; Kasarskis, E. J.; England, J. D.; Forshew, D.; Johnston, W.; Kalra, S.; Katz, J. S.; Mitsumoto, H.; Rosenfeld, J.; Shoesmith, C.; Strong, M. J.; Woolley, S. C. and Quality Standards Subcommittee of the American Academy of Neurology (2009a) and (2009b), Practice parameter updates
- 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

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