



Welcome to the May edition of the Allied Health Hub News. The newsletter aims to keep you in touch with what's happening in palliative care and in the Allied Health Hub.

This month we celebrate both Palliative Care week and MND week by dedicating the May newsletter to Motor Neurone Disease (MND).

In recent years the role of allied health has continued to develop in the management of MND. A multidisciplinary approach has been shown to improve quality of life, not just for the patient but also for the families.

In this newsletter we are giving an over view of the role of Allied Health in the treatment of MND with articles from each of the 7 professions represented in the Allied Health Hub.



#### [Social Work \(98kb pdf\)](#)

Sue Sinclair, a social worker from Brisbane, presents a community social work perspective in MND with a case story on Alex.

#### [Psychology \(97kb pdf\)](#)

Courtney Joy, senior clinical psychologist from the Gold Coast, demonstrates the important role of psychologists in MND treatment.

#### [Dietitian \(116kb pdf\)](#)

Dr Suzie Ferrie, dietitian at Royal Prince Alfred Hospital and clinical affiliate at the University of Sydney, presents Angelo's case story.

#### [Physiotherapy \(104kb pdf\)](#)

Pip Davies, senior physiotherapist at Claire Holland House Canberra, details Sarah's case story and the role of physiotherapy.

#### [Speech Pathology \(95kb pdf\)](#)

Natalie Mohr, senior speech pathologist, and Fiona Barry, senior occupational therapist St Vincent's Health Network, Sydney, share their work on Communication Devices for MND.

#### [Occupational Therapy \(103kb pdf\)](#)

Sarah Solomon from Bethlehem Hospital, Victoria, with Rachael Russell and Stephanie Williams (occupational therapists) write on 'Best Practice Model of Care of people with MND for Occupational Therapists - Adjusting and adapting to an ever moving target'.

#### [Music Therapy \(100kb pdf\)](#)

Lisa-Marie Bartlett senior music therapist from Eastern Palliative Care, Victoria, presents information on the role of music therapists for MND patients and Logan's case story.

## WHATS NEW

### MND resources on CareSearch

[MND Aware](#) - Training for health and community care professionals in MND. Topics including swallowing, nutrition, mouth care, bowel management, and tube feeding.

[MND videos](#) - A range of videos on MND by patients, carers and families.

A list of [National and State support groups](#).

Background information on [Dysphagia](#) a major MND symptom.

[Review Collection articles](#) on MND.

[Multidisciplinary Care](#) in MND and other palliative conditions.

[PCC4U Learning modules](#) - Module 4: Optimisation. Bob's story - MND.

[The Role of RGH Day Rehabilitation Services](#) for MND patients, a video by Tamina Levy, Principal Physiotherapist, Complex Neurology Unit, Repatriation General Hospital.

### Australian MND specific websites

- [mnd Australia Inc](#)
- [mnd Queensland](#)
- [mnd New South Wales](#)
- [mnd Victoria](#) have a useful DVD for loan, on swallowing difficulties in MND
- [mnd Western Australia](#)
- [mnd South Australia](#).

These websites have useful resources. ACT and Northern Territory share the NSW website.

### International Alliance of ALS/MND Associations

The [International Alliance](#) holds an annual Allied Professionals Forum which functions as an educational and training forum for healthcare professionals who work with ALS/MND.

### Did you know

Natalie Mohr (speech pathologist) with Moira Saunders (National Relay Service) provide information on [expanding communication resources for MND and other patients \(71kb pdf\)](#).

[mnd care \(Australia\)](#) Includes On-line training (26 sessions) referral pathways and a section on living with MND.

New [Neurology Resources in Physiopedia](#) including physiotherapy information on [ALS/Lou Gehrig's/MND](#).

[Motor neurone disease: assessment and management](#) NICE - National Institute of Care Excellence (UK) guidelines February 2016.

This covers, guidance, tools and resources, information for the public, evidence and history giving a wide scope of information on MND.

[Reference guide for allied health professionals working with people with rapidly progressing neurological disease \(500kb pdf\)](#). Developed by the Herts, Essex and North East London Rapidly Progressing Neurological Disease Palliative Care Network.

[IMNDA - \(Irish MND Association\)](#) contains an excellent document on [Guidelines for the physiotherapy management of motor neuron disease \(MND\) \(1.45MB pdf\)](#) as well as other MND information.

## **Blogs**

Patients like me blog, ['Hope makes us strong'](#) - An interview with ALS caregiver Cathy.

[Neil's Blog: 'The Plattitude, post mortem'](#). A blog written by Neil and his wife during Neil's journey with MND. Neil's story has been made into a film, ['I am breathing'](#).

[MND stories](#) from mnd Australia - Includes the story of Elliott who died at 19 years of age, 8 months after an MND diagnosis.

## **Special interest groups / Facebook groups**

mnd New South Wales: [MND Special Interest Group information \(PDF 166kb\)](#) - an e-network of support and education for health and community care professionals working with MND patients.

[ComSPOT](#) - Computer Access and Communication for OT's and SP's interested in MND- a Facebook group.

[Australian MND registry](#) - a clinical database providing a research assistance registry.

For your MND patients and carers - Liz Ogg and her husband write on [Liz's MND Blog](#) and have also launched a private Facebook group [MND Together](#) for people who are affected by MND, to share their experiences.

[MND Australia](#) Facebook page with interesting posts and information on MND.

## **Video**

[Assistive equipment use by people with ALS/MND in Australia](#) - Karol Connors.

Presented at the 13th International Alliance of ALS/MND Associations (2015) Annual Allied Health Professionals Forum, U.S.A.

[Tim Minchin singing Don't Dream it's Over](#) - uploaded to YouTube by MND Australia.

This is an amazing use of analogy for MND.

[Living with ALS: Stories of strength](#) - video highlighting MND patients.

## FREE ARTICLES TO READ

### Journal Articles

Henderson RD, Hutchinson N, Douglas JA, Douglas C. [Telehealth for motor neurone disease](#). Med J Aust. 2014 Jul 7;201(1):31.

This letter to the editor, documents the use of Telehealth for MND and home mechanical ventilation patients in Queensland.

Lerum VS, Solbrække KN, Frich JC. [Family caregivers' accounts of caring for a family member with motor neurone disease in Norway: a qualitative study](#). BMC Palliat Care. 2016 Feb 24;15:22.

An interesting article detailing the emotions and responsibility when providing care for MND family members. This is based on interviews with 25 carers and finds they experience 5 lines of care work.

Pagnini F, Phillips D, Bosma CM, Reece A, Langer E. [Mindfulness as a protective factor for the burden of caregivers of amyotrophic lateral sclerosis patients](#). J Clin Psychol. 2016 Jan;72(1):101-11. Epub 2015 Oct 20.

A survey report on the effect of Mindfulness for carers of MND family members.

Allen C, Vassilev I, Kennedy A, Rogers A. [Reaching the parts offline support can't: Long-term condition illness work in online communities. A meta-synthesis of qualitative studies](#). J Med Internet Res. 2016.

Research on the effect of on-line support for people living with a long term condition. Results show that symptom management for patients, is often assisted by on-line resources which include blogs and support groups.

Zoing M, Kiernan M. [Motor neurone disease - caring for the patient in general practice](#). Aust Fam Physician. 2011 Dec;40(12):962-6.

This article describes the role of the doctor in treating MND patients in general practice.

Simon NG, Huynh W, Vucic S, Talbot K, Kiernan MC. [Motor neuron disease: current management and future prospects](#). Intern Med J. 2015 Oct;45(10):1005-13.

This article covers both clinical care and scientific developments in MND. Multidisciplinary care is seen to prolong survival and improve quality of life and is the most appropriate care for patients with MND.

Peters M, Jenkinson C, Doll H, Playford ED, Fitzpatrick R. [Carer quality of life and experiences of health services: a cross-sectional survey across three neurological conditions](#). Health Qual Life Outcomes. 2013 Jun 25;11:103.

This study investigated the relationship between carer well-being and experiences with health and social services.

## Other Articles

[mnd New South Wales](#) has information about primary, community and residential, reading lists and free online presentations including [Motor neurone disease aspects of care: community care](#).

A book compiled following many requests from community care providers, case managers and from people with motor neurone disease and their carers for information about caring for people with MND in the community setting.

mnd Australia booklet, [Motor neurone disease aspects of care: for the primary health care team](#). Gladesville (NSW): MND Australia; 2014.

Morse A. [When I'm dying, will you sing to me? The therapeutic use of music in end-of-life aged care \(1.20MB pdf\)](#). Hobart: Tasmanian Association for Hospice and Palliative Care (TAHPC); 2016.

## INTERESTING ARTICLES THAT ARE NOT 'FREE ACCESS'

Fullam T, Stephens HE, Felgoise SH, Blessinger JK, Walsh S, Simmons Z. [Compliance with recommendations made in a multidisciplinary ALS clinic](#). Amyotroph Lateral Scler Frontotemporal Degener. 2016 Jan-feb;17(1-2):30-7. Epub 2015 Oct 29.

Factors affecting compliance in respect to recommendations made by the multidisciplinary team.

Pavey A, Warren N, Allen-Collinson J. ["It gives me my freedom": technology and responding to bodily limitations in motor neuron disease](#). Med Anthropol. 2015;34(5):442-55. Epub 2015 Jun 17. A review of 42 MND patients and their use of technologies and technical aids.

Chhetri SK, Bradley BF, Callagher P, Addison-Jones R, Bennett W, Gardham J, et al. [Choosing the place of death: Empowering motor neurone disease/ amyotrophic lateral sclerosis patients in end-of-life care decision making](#). Palliat Med. 2015 Jul;29(7):667-8

Article discussing preferred place of death and advanced care planning for MND patients.

Arbesman M, Sheard K. [Systematic review of the effectiveness of occupational therapy-related interventions for people with amyotrophic lateral sclerosis](#). Am J Occup Ther. 2014 Jan-Feb;68(1):20-6.

A systemic review of literature on occupational interventions for MND patients.

## CONFERENCES OF INTEREST

A list of [general palliative care conferences](#) can be found on the CareSearch website.

### 2016

#### [Australian 8th National MND Conference 2016](#)

Care, Collaboration, Communication

12 September 2016

Melbourne, Victoria

Full program will be available in July 2016.

Abstracts close 30 May

There will be an education day run by Bethlehem Hospital the day after the conference but these details are still being finalised. The registration for this will be offered with conference registration.

#### [The MND Association - 27th International Symposium on ALS/MND](#)

7-9 December 2016

Dublin, Ireland.

Abstracts close, 27 May 2016

#### [A one-day pre-conference Allied Professionals Forum.](#)

Dublin, Ireland

6 December 2016.

## NEWSLETTER BASICS

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