MNDcare Latest News - June 2014

October Highlights:

Good reviews from MND Australia National Conference delegates
Links to MND National Conference presentations
The value of multidisciplinary care in managing MND
Research updates


The extent of positive feedback for the National Conference was rewarding. All aspects of the program were rated by delegates as being predominantly ‘good’ to ‘excellent’. MND Australia is grateful to MND South Australia for hosting this important meeting.

Quotes from the evaluations included:

“This was a very well-run conference with interesting speakers and good choice of venue. Everything ran very smoothly and all speakers were of relevance to people in the MND service and support community”.

“Everything was expressed in a way that someone without medical credentials could grasp and this was much appreciated! All of the speakers were most engaging.”

We would like to thank the speakers for the high standard of their papers and for making them available post conference. Highlights from some of the papers below - all presentations are available here

Themes for the conference included:

- A personal experience of caring for a spouse with MND
- Communication technology and its relevance for MND clients
- Aspects of multidisciplinary care in managing MND
- Research summary and updates

A personal experience of caring for a spouse with MND

The first keynote speaker was Sue Craig, who lost her husband Derek to MND in 2011. Ms Craig spoke with poignant honesty about the “journey beyond your wildest nightmare” embarked upon by families affected by MND. Several positive comments regarding this address appeared in the evaluations including the following quote:
“It was extremely evocative and powerful to hear her first-hand experience of caring for someone with Motor Neurone Disease and her thoughts and recommendations regarding service delivery”

The complexity of evolving communication technology and its application to MND

Communication technology is evolving rapidly and it is a challenge for service providers and people with MND to keep abreast with changing technology and to evaluate the most relevant of current options.

Anna Love, Master of Occupational Therapy student from the University of Sydney, spoke about communication technology for people with MND. Ms Love and her colleagues surveyed 79 people with MND and identified opportunities for greater use of telehealth as well as greater training for people with MND in areas of communication technology.

Take home message: health professionals should initiate discussions about communication technology early after diagnosis, and provide ongoing support with changing client needs.

Rachelle Baldock, TASC, Cerebral Palsy Alliance, Sydney, outlined a new model for assistive technology intervention for communication difficulties in MND.

Take home message: an identified need for centralised education and support for local therapists, and greater collaboration between professionals involved in communication interventions for people with MND.

Aspects of multidisciplinary care

Several papers at the National Conference outlined different approaches towards multidisciplinary care using locally available resources and areas of expertise:

Dr Peter Allcroft, Respiratory and Palliative Care Physician from Daw Park Repatriation Hospital, Adelaide spoke about symptom management for people with MND. Dr Allcroft focused on a team approach to respiratory management including non-invasive ventilation. He also discussed Advanced Directives and terminal care.

Helen Brown, Dietitian, Nurse Maude Hospice, Christchurch, NZ spoke about Canterbury Health Pathways. This MND Health Pathway provides an information hub for health professionals to assist the multidisciplinary team in navigating the complexities of the health system. Local GPs provide a pivotal role in delivery of this service.

People with MND frequently identify a lack of MND specific information and guidance with relevant legal issues. Alexandra Jessop from the Benevolent Society summarised the innovative Planning Ahead project in southern Sydney. In partnership with Legal Aid NSW, the project provides people with MND with free legal advice and tools for future decision-making.

The presentation by Mount Gambier Palliative Care Occupational Therapist, Kathy Miles, demonstrated how COAG funding had enabled flexible care packages and appropriate equipment provision for people with MND in the Mount Gambier area.
She highlighted innovative solutions to enable people with MND to be supported in their home.

MND Victoria Regional Advisor, Eric Kelly, discussed the benefits of multidisciplinary team planning meetings which involve the multidisciplinary team as well as people with MND and their families in the process of planning care.

Anne Hogden, Speech Pathologist, PhD student, UNSW shared highlights from her study examining perspectives of people with MND a multidisciplinary clinic setting. Ms Hogden discussed the tensions between patients’ focus on living in the present and the need for the multidisciplinary team to plan for future care. She advised health professionals to create sound decision-making environments.

**Are you interested in establishing an MND multidisciplinary team or currently working within one?**

A useful tool can be found in the MND Association of England, Wales and Northern Ireland booklet:

**Best Practice Guide - Multidisciplinary Team (MDT) Working**

This booklet is a useful guide for care professionals wanting to establish an MND multidisciplinary team using the resources available in their specific health area or to refine the processes involved within an existing team. It provides an excellent introduction to the core principles of working in a MDT. It outlines how professionals can work together to pool their skills, knowledge and commitment to achieve the best possible outcomes care for people affected by MND. Best practice care requires team members to participate in regular meetings, to share information and influence decisions about care. Determining appropriate services that already exist in area and targeting those that can be adapted to incorporate into an MND specific service is an essential first step towards establishing the MDT. The right mixture of expertise may well exist in an established team such as a community rehabilitation team and specialised MND care can be assimilated into this structure. This guide also addresses team leadership, team sustainability and care principles.

**Research updates presented at the National Conference**

Dr James Burrell, Neuroscience Research Australia, provided a fascinating summary of the latest research relating to links between MND and frontotemporal dementia (FTD). Dr Burrell and colleagues are focusing on the incidence and characteristics of cognitive and behavioural disturbance in MND. He discussed the complexities of cognitive assessments including the use of eye movement tracking tools. Dr Burrell reported on studies that suggest caregiver burden in MND depends more on the extent of patient behaviour changes than on the level of physical disability.

The recent discovery of the C90RF72 gene expansion has provided a great step forward in MND research. This is the most common genetic cause of MND to be identified so far. It offers a common and relevant target for treatment development. Yet there are several other genes affecting a variety of neurological processes involved in MND. Neuroscientist Dr Bradley Turner from the Florey Neuroscience Institutes at the University of Melbourne captivated the audience with his summary of research
on causes and potential treatments for MND.

**MND Australia International Research Update - September 2012**

In this quarterly newsletter Dr Catherine Blizzard reports on the latest research discoveries in MND.

For some people MND can progress at a devastatingly rapid rate while others can survive for a lot longer. A paper published in August in the journal Nature, Medicine, sheds some light on this puzzling variation in disease outcome. Research lead by Professor Wim Robberecht at the University of Leuven, Belgium has identified a previously unknown role in MND progression for a cell receptor called Ephrin receptor A4. Cell receptors are positioned on the surface of cells and help cells to interact with their outside environment. This research demonstrated that reducing the amount of the EphA4 increased the survival rates and delayed the onset of symptoms in these animal models.

Other research discussed in the International Update includes:

- Can we vaccinate against motor neurone disease?
- From jellyfish to jumping muscles
- A little protein with a big reputation - Transmembrane glycoprotein NMB (GPNMB)
- Spinal muscle atrophy
- The protein, TDP-43, which is implicated in MND in humans, may also play a role in MND in horses. Their findings indicated that the human and horse forms of MND

**Stop Press:**

Final opportunity to register for the International ALS/MND Symposium, Chicago, USA!

At the Allied Professionals Forum Kristina Dodds, MND NSW, will be presenting on the MND Aware training program for frontline staff and Anna Love’s colleague Kim Ruston will present ‘Communication technologies for people with MND: current picture and future directions’.