MNDcare Latest News - April 2015

April Highlights

- New information resource – Planning Ahead Fact Sheet
- Latest research – March International Research Update
- Advocacy update
- Conferences/workshops

New Information Resource

Starting difficult conversations

People living with MND are likely to feel particularly concerned about what lies ahead and how decisions about their future will be made. The latest addition to the series of MND Australia Fact Sheets explores the topic of planning ahead and Advance Directives.

This Fact Sheet provides a catalyst for the person with MND to begin discussion with family and health care providers and to set in place arrangements for health, lifestyle and financial decision-making. Although it can be difficult to begin this conversation planning ahead is likely to result in empowerment for the person with MND and clarity and support for the family in decision making. Read more....

This Fact Sheet may also help initiate discussions between the person with MND and the multidisciplinary team about this important topic. The health care team may feel reluctant to start the conversation about future planning. This may be due to a lack of confidence in raising this topic, insufficient appropriate time to start the conversation or perceived barriers presented by the person with MND. However, it is important for the most appropriate person on the team to ‘sow the seeds’ for this conversation and once started these discussions are likely to evolve over time.

If you would like more help in understanding and addressing future planning see:-
MND Aware Session 6: Planning for future care needs - advance care planning

This training module provides health and community care professionals with an overview of the advantages of introducing this topic as well as the barriers. It also offers some practical strategies on how to start the conversation.

Latest Research

The March 2015 edition of the International Research Update by Isabella Lambert-Smith, (Rotary Health PhD Scholar, University of Wollongong) is now available.

Recent research outlined in this latest edition includes:-
- Getting personal: the future of medical research

Most people with MND have no previous family history of the disease and the main line of thinking is that multiple factors, both genetic and environmental, contribute to the development of this sporadic MND (sMND). This occurs in many other human diseases, and research has entered a new and unprecedented molecular era with the availability of DNA sequence data.
Techniques used to measure changes in everything from the DNA sequence itself to the actual expression of genes and the levels and activity of the proteins they encode continue to be developed. These developments are leading the way to the personalisation of treatment, catering to the individual’s specific biological dysfunction.

- The importance of gene cluster analysis in managing the volume of data evolving from the increasing scale of genetic studies
- Helping a nerve growth factor (GDNF) to slow degeneration
- Controlling the toxicity induced in motor neurones by glutamate excitotoxicity

**Advocacy update**

**MND Week 2015 – 3 to 9 May 2015**

This important week on the advocacy calendar for the MND community is fast approaching and we look forward to building on the increased profile of MND resulting from last year’s Ice Bucket Challenge. This year the advocacy focus for MND Australia and the state based associations is:

*’Let's make the system fair for all people with MND’*

On 1 July 2015 the Australian Government will release the latest Aged Care Reforms to give older people more choice, more control and better access to a wider range of aged care services. The crucial issue is whether people with a disability over the pension age will have access to adequate supports to meet their individual needs. This MND Week we will be appealing to parliamentarians to act to ensure that the reforms create a fair care system for the 50% of people diagnosed with MND when over the age of 65.

Health care providers can help us to champion the rights of people living with MND. As we finalise the MND Week campaign, let us know if there are existing gaps in services for your clients with MND.

People living with MND can share their experiences of service provision by emailing their story to iwanttotellmystory@mnd.asn.au or by contacting their state MND association. More details on the [2015 MND Week campaign here!](#)

**MND Australia government submission update:**

This year MND Australia has made three new submissions to support the rights of people living with MND:

- Submission to the Senate Community Affairs Reference Committee Inquiry into residential care for young people with severe physical, mental or intellectual disabilities
- Feedback on the National Disability Insurance Scheme Information, Linkages and Capacity Building Policy Framework
- Feedback to the National Disability Insurance Agency on assistive technology

Read the full submissions [here.](#)

Evidence provided by health and community care professionals can offer invaluable support for our submissions. Please let us know if you have experiences with MND clients that support the above submissions or if you have other issues of service provision for MND clients that you feel need to be addressed.

**Conference and Workshop update**
Allied Professionals Forum – Orlando USA - 10 December 2015

The Allied Professionals Forum (APF) which each year accompanies the International Symposium of ALS/MND provides an opportunity for health professionals to share their experiences, knowledge and strategies of caring for people with ALS/MND with their international peers. The call for Abstracts will be available after the 27 April. [More information...]

Nina Buscombe Awards 2015 – call for applications

If you are thinking of attending the International meetings in Orlando this year or another MND related conference or workshop the Nina Buscombe awards are available to support the costs of your attendance. ‘Nina’s’ are awarded to celebrate the contribution and commitment demonstrated by Nina Buscombe to the improvement of services, management and research for people with motor neurone disease. The Award is presented and administered by MND Victoria. It is intended to provide funds for attendance at training courses, conferences or seminars within Australia or overseas.

The training course, conference or seminar attended must have content that will help to improve the quality of services, management or research for people living with MND. The value of each Award will reflect the projected costs of travel, accommodation and registration for the applicant. [Applications close 8 May 2015.]