Welcome

The WA lcp Project Team would like to welcome you to Omega – The Last Word the fourth state wide e-newsletter for health workers with an interest in end of life care. This month our focus is on a group of diseases known collectively in Australia as Motor Neurone Disease (MND) and which have been the subject of recent attention in international and local press and social media.

MND is a terminal, progressive, degenerative, neurological disease affecting an estimated 170 West Australians at any given time. Some live a long time but the majority 2 to 3 years, with average survival of 27 months. With curative treatment not currently available access to optimal, timely, care which supports quality and length of life is imperative.

On 27 August 2014 the Motor Neurone Disease Association of WA (MNDAWA Inc.) and Omega will hold Motor Neurone Disease – A Palliative Approach, presented by Sarah Pickstock and Julie Craig Smith. They will present an overview of MND, the palliative course of disease from diagnosis to death and explore the vital role of front line health professionals in supporting individuals and families with this devastating disease.

Remember the next Omega meeting is:

**Motor Neurone Disease – A Palliative Approach**

*Wednesday 27 August 2014 (4.30 – 6.00 pm)*

**Presenters:**

*Dr Sarah Pickstock*

Palliative Care Consultant, Director of Medical Training Silver Chain

*Julie Craig Smith*

Care Advisor, MNDAWA Inc.

**Venue:**

Brian Vivian Seminar Room, Level 4 Nicolay Block, Royal Perth Hospital

RSVP or organise to Videoconference by Monday 25 August 2014 with Lorna Hurst on (08) 9222 4108 or walcp@health.wa.gov.au

"You matter to the last moment of your life and we will do all we can, not only to let you die peacefully, but to help you live until you die."

– Dame Cicely Saunders (1918–2005)
The session will appeal to all health professionals who care or will care for people with MND, whether working in acute, community, residential aged care or specialist palliative care or MND services. It will provide a greater understanding of the impact of MND on the individual’s life and family life and focus on living with rather than dying from MND.

MNDAWA Inc. is the specialist organisation which provides support to people living with MND in WA. It is partially funded by the Health Department of WA and extends no charge for its services. MNDAWA Inc with the other State MND Associations advocates for a palliative approach from diagnosis through to the terminal phase. The organisation provides support, information and equipment to people with MND, their families and carers across WA. Education is provided to all health professionals and disability workers and has a strong focus on advocacy on behalf of all people affected by MND.

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The team from the Motor Neurone Disease Association WA

A look at news and research from home and abroad

International News

You will probably be aware of the social and public media frenzy called the Ice Bucket Challenge which started in America, where Motor Neurone Disease is known as ALS or Amyotrophic Lateral Sclerosis. The idea is a simple one - it involves being challenged by someone to empty a bucket of ice cold water on your head, while taking a video of yourself, which you then post on social media such as Facebook or Twitter and dare others to take the challenge. If you fail to do the Ice Bucket Challenge you pay a donation to the MND/ALS charity of your choice.

The recent involvement of high profile celebrities such as Bill Gates, Oprah Winfrey and Taylor Swift in the challenge has created a great deal of momentum for the challenge which has now gone viral, spreading through the Americas to Europe and internationally.
Although the campaign has received some criticism, with celebrities accused of getting on the bandwagon for publicity rather than doing it for the right reasons, there have been clear benefits with donations to the US ALS Association increasing four fold since last year and awareness of the disease’s spread across the globe.

Do you want to support people living with motor neurone disease by taking up the Ice Bucket Challenge? To take this step go to: http://www.everydayhero.com.au/event/icebucketchallenge

**National News**

The well known former Essendon footballer and Melbourne coach, Neale Daniher, has publicly spoken this week of his diagnosis with MND. Mr Daniher, 53, said that he had noticed some arm weakness while hanging out washing. However it had taken a many investigations and a further 9 months for his diagnosis to be revealed.

During his television interview he discussed his plans to battle the terminal disease with the same determination he harnessed during his career and to spend as much time as possible in the time left to him to educate the community about the deadly disease.

**Local News**

Pilot testing has commenced on the newly developed care plan to guide care of the dying in West Australian health services. The document, developed by a group of expert clinicians from across the state following a state-wide review of the WA LCP, is currently being used in four Metropolitan and rural health services.

**In the Spotlight**

Omega would like to congratulate 2014 WA Social Worker of the Year, Pippa Blackburn, from the South West Palliative Care Service. Pippa is a deserved winner of the prestigious award which is a joint initiative by the Australian Association of Social Workers, the University of WA and Curtin University.

The WA Social Worker of the Year Award is presented to the social worker judged most outstanding of the five Award category winners. **Omega invited Pippa to speak in this edition about her emotional win on a day which meant so much more to her than the organisers and attendees of the awards could have ever realised.**
As a Palliative Care Social Worker, I was awarded the Rural and Remote Practitioner award and the WA Social Worker of the Year award at a state-wide ceremony on the 9th June 2014.

For me, what was special was that the awards helped to raise awareness of palliative care, particularly the role of social workers in palliative care. I am very passionate about my profession, rural practice and palliative care and feel very privileged to be working my role with WA Country Health Service (WACHS) as Regional Palliative Care Social Worker in the South West of WA.

Being a winner of the Rural and Remote Practitioner award was very exciting and was a great opportunity to promote rural practice and the contribution social workers make in their local communities.

To be announced as the overall winner and be awarded the WA Social Worker of the Year was very overwhelming but also very humbling to be recognised by peers, industry partners and consumers.

When the announcement came that I was the overall winner for the WA Social Worker of the Year awards, I looked over at my husband and he nodded at me. The look we shared was understood only by a few in the audience who knew our story.

That look conveyed an intimate moment between us, we shared the same thoughts….perhaps she has played a role in this somehow? Some kind of divine intercession?

I choked my tears back as I approached the podium, tears that were not for winning an award per se, but for winning an award on the anniversary of our daughter’s death, a serendipitous significance with poignancy too profound for words…..

Please click here to continue reading Pippa’s story.

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