



MND Tasmania News

September - October 2009

MND Tasmania
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State Committee

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Public Officer: John Hughes OAM

Northern Support Group: Mary Erickson

Southern Group: Anna Nicholas

Lyle Sydes

Kate Barnett

Denis Lyne

Regional Advisor

Jennene Arnel: ra_tasmania@mnd.asn.au

(note the underscore between ra and tasmania)

Support service

The MND Associations of Victoria and Tasmania work together to provide:

- Information and support by telephone on 1800 806 632, Monday-Friday, 9 am -5 pm.
- Referral to Tasmanian support services.
- Information kits.
- Free membership of MND Victoria and MND Tasmania for people living with MND.
- Victorian Newsletter with Tasmanian News insert for members living in Tasmania.
- Telelink meetings for people with MND, carers and past carers.

New Members

We welcome new members: R.Durant (NW), K.& N.Gatehouse (S), S.& T. McMurtrie (S), S.& M. Newton (S), L.& W. Parsons (S) and H.& R. Svennsen (S).

Vale

Our sympathy is with the families and friends of S. Eriksen and Dr Stan Siejka. Dr Siejka was the first neurologist in Tasmania. He worked hard to increase neurology services in the State, fought for the Launceston General Hospital to have better services and initiated research into neurological diseases. He believed passionately that neurology is an essential discipline to which the people of Tasmania are entitled.

Regional Advisor's Report

Since the last Newsletter I have made three visits to Tasmania. The first, in July was for nine days. On this trip, I visited eight people with MND and met with a number of health professionals in the North and South. A highlight of the trip was presenting a paper on MND to the Palliative Care Study Day on Neurology in Hobart.

The second visit was in August when I was asked to visit a large organization in Hobart where an employee has been diagnosed with MND. The all day visit involved meeting with the newly diagnosed person and their family, meeting with managers and presenting an information session on MND to approximately 40 fellow employees. All expenses were covered by the organization and it is impressive to work with a group that shows such concern and care for their staff. I look forward to continuing my relationship with the family and the organization.

In September, I visited 12 people living with MND in the North West and South and once again met with a number of health professionals. In the North West, I was invited to make a presentation on MND to palliative care volunteers. Palliative Care provides a number of significant services to people living in the North West and volunteers are an essential part of the service.

The First Year

With the end of September, the first year of the RA Project in Tasmania is completed. It has been a busy and productive year, and I believe the outcomes for people living with MND have been enhanced access to timely services and staff who are well informed about MND. The general profile of MND in the community has also been raised.

Some data on the year to 30 September 2009 is as follows

Number of visits to Tasmania	6 (+ 1 extra visit in Aug)
Number of home visits	75
Total number of contacts with clients/health professionals	154
Number of Information Sessions conducted	14 (255 people)
Total number of days worked	86
Number of people with MND registered at 30/09/09	33

It has been a challenging and rewarding year for me and I thank members and health professionals for the warm welcome you have given me to Tasmania and the role of Regional Advisor. I look forward to continuing our work together next year.

My next visits will be in October to the Northern region (which will include participation at the MND Forum in Launceston on 23 October 2009) and then again in November.

If you wish to contact me at any time please phone 1800 806 632 (leave a message and I will return your call) or email ra_tasmania@mnd.asn.au

Jennene Arnel
Regional Advisor, Tasmania

Freecall 1800 806 632

Calls to this number go directly to the MND Victoria office. To assist the volunteer receptionist, please identify at the outset that you are calling from Tasmania. If you wish to speak to a specific person such as a committee member or Jennene Arnel, please say so and you will be asked for your contact details. Your call will be returned by that person as soon as possible.

Donations

Donations have been gratefully received from L.&W.Parsons, R.Minchin, H.&R.Svenssen and in memory of I.A.Smith and S.Eriksen.

Northern Support Group

The contact person for this group is Mary Erickson who may be contacted on 1800 806 632 (message).

Meetings are held on the last Monday of each month at 11am at the John Grove Centre, Howick Street.

Southern afternoon tea

Anna Nicholas is the contact person for this group. She may be contacted on 1800 806 632 (message).

North-west Group

Contact Jennene Arnel on 1800 806 632.

Advocacy

NMAT Statewide survey

The Neuromuscular Alliance of Tasmania (NMAT) consists of MND Tasmania, Alzheimer's Australia (Tas), Australian Huntington's Disease Assoc. (Tas), Multiple Sclerosis Tas., Muscular Dystrophy Assoc. of Tas., Parkinson's Tas. and the Spina Bifida Assoc. of Tas. In collaboration with MS Tasmania as the project leader, NMAT has received a grant from the Community Support Levy, Charitable Organisations Grant Program for resources to develop and utilise a survey for obtaining the demographic profile of the population represented by NMAT in Tasmania. This will provide the first set of benchmark information about the prevalence of these complex diseases in Tasmania and the needs of the people who live with them.

Current information is that over 2,000 clients of the members of NMAT have newsletter or direct contact with their known clients or their carers, i.e. Alzheimer's: 1,664+, Huntington's: 70, MND: 31, MS: 732, MD: 80, Parkinson's: 750, SB: 36.

Dying with dignity

The Neuromuscular Alliance of Tasmania (NMAT) presented their case to the Legislative Council Joint Standing Committee into Community Development on August 31 with regard to the Dying with Dignity Bill. NMAT Chairman Lynsey Spaulding spoke to the Committee about the position of the Associations within NMAT with respect to euthanasia. It was recognised that the Bill's criteria with respect to pain and time spans are not relevant to most neuromuscular disorders. It was observed that there is a general lack of understanding in the community about current options related to dying with dignity such as the role of palliative care services and the effective planning of care issues utilising enduring power of attorney, advanced care directives and other modalities. NMAT Associations aim to

provide their members with information and support with respect to such issues.

MND Regional Advisor

MND Tasmania has been successful in receiving a grant from the Community Support Levy, Charitable Organisations Grant Program for increasing the hours that Jennene Arnel can work with our members. This will supplement the income for the Regional Advisor project for 12 months. (This project has been funded for three years by MND Tasmania and by a philanthropic donor accessed by MND Victoria.)

MND National Conference

Report from the 2009 National MND Conference
*Motor Neurone Disease - Care, Advocacy,
Research, Excellence*

In June 2009, I attended the National MND Conference in Sydney after becoming a recipient of the 2009 Nina Buscombe Award. As an Occupational Therapist working in the Community in Launceston and the surrounding area, I found the conference most informative and insightful and the knowledge gained will assist me when working with my clients with MND.

The themes of the conference were care, advocacy, research and excellence and a wide range of presentations were presented upon these topics from all over Australia.

A carer of a 36 year old man with MND presented her perspective on how her life had changed once her husband received his diagnosis. Her role of wife and mother had extended to carer and she gave a touching account of how their family, community and the strength of their relationship allowed her husband to maintain a quality of life. As this family was Aboriginal some cultural issues also were raised and discussed.

There is still no cure for MND but developments in research and treatment were presented. A neurologist spoke about advancements in medication used to treat the symptoms of MND such as Rilutek. Rilutek has been found to slow the progression of the disease by about 12 months improving quality of life for longer, yet not cure the condition. The overlap between MND and front

temporal dementia was discussed at a clinical and pathological level as there is a growing body of evidence to support this link. The presence of the front temporal dementia can in turn increase the burden on the carer and the individual.

The importance of early intervention soon after diagnosis is paramount considering the unpredictable nature of the condition. Each individual is different so a client-centred approach needs to be taken. Health professionals including the occupational therapist, physiotherapist and speech pathologist, benefit by working together with the client to develop an intervention plan which allows the client and family to be involved in the care. The client-centredness is paramount to maintaining the therapeutic relationship. The multidisciplinary team based at Bethlehem Hospital in Victoria presented an overview of their service describing the journey of one of their MND clients.

Whilst practical solutions such as home modifications, communication devices, and manual handling/equipment provision need to be timely, therapists and health care workers need to be sensitive to the emotional and psychological needs of the client.

Petrea King, founder of the Quest for Life Centre in Bundanoon, NSW presented "The heart of caring", a talk which spoke about how we as carers can have the strength to maintain our physical, mental, emotional and spiritual health, and how this approach can help our clients. Petrea provided practical solutions and strategies to help us as health professionals deliver the best quality care without becoming overwhelmed ourselves.

The conference provided a great opportunity for networking and helped to affirm my own practice and intervention with my MND clients in Tasmania as well as providing me with strategies and techniques to enhance my practice. I look forward to attending the conference again in 2010.

Carolyn Mills
Occupational Therapist
Launceston General Hospital Tasmania
2009 Nina Buscombe Award Recipient