



MND Tasmania News

September – October 2007

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Northern Support Group: Bill Braithwaite

Care Advisor: Anna Nicholas

Kate Barnett

Lyle Sydes



New initiative - 2007

This broadsheet is the result of an initiative by the MND Associations of Victoria and Tasmania. In addition to this News, a Motor Neurone Disease Information and Telephone Support Service for people living in Tasmania became available on April 1 2007. MND Victoria and MND Tasmania are working together to improve support for people with MND.

Support service

- Access to information and support, by telephone (1800 806 632), Monday to Friday, 9 am – 5 pm.
- Referral to Tasmanian support services.
- Information kits for:
 - people living with MND, family and friends;
 - general practitioners;
 - health professionals.

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- Free membership of MND Victoria and MND Tasmania for people living with MND.
- Victorian Newsletter with Tasmanian News insert for members living in Tasmania.

MND Week: May 6 - 12

This year's MND Awareness Week saw lots of activity around the State. A heartfelt thank you to all those who gave of their time!

A total of \$2,728.70 has been received from collectors in Devonport, Ulverstone, Hobart, Latrobe and Launceston.

New Members

We welcome the following new members:

Mr & Mrs Terence & Elaine Hansson, Mr Peter van der Pluym, Mr & Mrs Couzins, Mr & Mrs Charles & Doreen Henry, Mrs A. Williams, Ms L. Crosswell.

Thank you to those members who have renewed their membership.

Donations

Memorial donations have been received in memory of: Mr Alan Peattie; Dr Kate McPherson; Mr Gilbert Smedley; Susan Robertson. A donation has been received from the Huon Valley Rotary Club.

Northern Support Group

Bill Braithwaite organises the monthly meetings in Launceston. At the June meeting about 15 people enjoyed getting together and a similar number attended the July gathering. The trade table always adds to the Association's funds and we appreciate the gifts and effort that people put in to this time of mutual support.

Baby News

A new dimension has been added to MND Tas with the safe arrival of Kate Hynes. Emails flew around the country as the Committee and members of other MND associations asked each other if anyone had heard if Baby Hynes had arrived yet. Contingency plans were put into place by an expectant father so that donations from the Huon Valley Rotary Club could be received even if he was in the birthing unit and meetings would be held even if he was suddenly unavailable to chair. Finally we all received THE email and we rejoice with Tim and Carolyn at the wonderful Tasmanian addition to their family.

Publications

mndAustralia: Motor Neurone Disease – A Problem Solving Approach. The new edition of this booklet for medical and other health professionals is now available from MNDTas or MNDVic.

The Motor Neurone Disease Handbook. This Australian publication has been edited by Matthew C. Kiernan and contains 16 papers on the latest research into MND. Topics include MND epidemiology, pathogenesis, diagnosis, respiratory function and the disease-modifying drug riluzole. Personal accounts are written from the perspective of Margie Zoing, a nurse, and Roderick McKenzie, a Sydney neurologist who was himself diagnosed with MND. There's also a paper on palliative care by well-known British palliative care specialist David Oliver. It is available on loan from MNDTas and we have donated a copy to each of the four neurologists in Tasmania.

Communicating the diagnosis

In June 2007 the first comprehensive set of guidelines for how doctors should communicate bad news to dying patients was published in the *Medical Journal of Australia* (2007; 186(12): S7-S108). The guidelines were funded and released by the NHMRC. They make it clear that talking to people about their diagnosis is a very personal thing. Until recently there has been little guidance in the literature on how best to discuss such issues with patients and their families. A result is that many doctors lack confidence and trained skill in discussing end-of-life issues. The guidelines can be viewed at www.mja.com.au/public/issues/186_12_180607/cl11246_fm.html#0_i1093824

Equipment: Lightwriter

There are many types of communication devices suitable for use by people with MND.

The Lightwriter is a communication device supplied by Zygo Australia. It is small enough to be hand-held and has a keyboard, a display screen and a voice output. MNDTas has four of these and two are currently out on loan. They were purchased with donations and grants received from the Allport Bequest. The Lightwriter has a variety of accompanying modules and the Association has recently purchased a Lightwriter Scanner **with** funds

donated in memory of Alan Peattie. The scanner enables a person to communicate without typing onto the keyboard.

Neuro-Muscular Alliance Tasmania

The Neuro-Muscular Alliance Tasmania was officially launched on August 20. The membership is an alliance of Tasmanian not for profit organisations which support people who have chronic progressive muscular or neurological conditions. The membership consists of but is not restricted to: Alzheimer's Australia, Tasmania; Australian Huntington's Disease Association (Tas) Inc.; Motor Neurone Disease Association of Tasmania Inc.; Multiple Sclerosis Society of Tasmania Inc.; Muscular Dystrophy Association of Tasmania Inc.; Parkinson's Tasmania Inc.; Spina Bifida Association of Tasmania Inc.

The Alliance intends to improve the lives of people who have chronic progressive muscular or neurological conditions by:

- working towards having a community, including health professionals, which understands and is aware of the implications of these conditions for those who have them, their carers and families;
- promoting active cooperation between the members which will lead to "best practice";
- attracting resources to enable the Alliance and the individual organisations to meet their stated aims in support of people who have these conditions.

Continuity and your newsletter

The Association in Tasmania depends on volunteers to make things happen. The Committee is grateful for those members who continue to faithfully attend Support Group meetings, to support MND Awareness Weeks, to send in donations and to circulate equipment. We also appreciate the new members who have joined and who are willing to continue the work of supporting people who have MND and of increasing the knowledge and awareness of MND in our communities and among health service providers.

Please let us know if we have omitted key points or made errors in any of the information presented in this news sheet. We welcome your ideas, thoughts and questions to MND Tasmania News. Write to us at our email or PO Box address.