



A.O.C. 7/7/08
Submission No. 569
(Inq into better support for carers)

Neuro Muscular Alliance Tasmania

President:
Joyce Abblitt
PO Box 1168
Burnie, TAS, 7320
Phone: 6431 3403
Email: joyceabblitt@bigpond.com

Secretary:
Anne Ashford
26 Goulburn Street
Hobart, TAS, 7000
Phone: 6231 3273
Email: ashfords@dodo.com.au

Parliament of Australia
House of Representatives
Standing Committee on Family, Community, Housing and Youth

Inquiry into Better Support for Carers

This submission is on behalf of the Neuro Muscular Alliance Tasmania. This Alliance represents seven not for profit organisations servicing people, state-wide, with a neuro or neuro-muscular disorder. Therefore this submission is based on experience with clients with such disorders and their carers – all have progressive physical disability and some are combined with intellectual disability or deterioration.

The majority of the Alliance members operate through a voluntary committee/board and wish to acknowledge the call for contributions to this Inquiry. Each member organisation is suggesting to its carer group that individual carers make a submission to the Inquiry. We also note that the peak bodies for each Alliance member organisation will be addressing the Inquiry. Therefore this submission covers only key points as we as a group in Tasmania see them.

We note that community consultations are planned. If a consultation is called in Tasmania we would appreciate the opportunity to send a representative.

- **The role and contribution of carers in society and how this should be recognised**

Carers play a vital role in society. They provide physical and emotional support for the person they are caring for, saving the state and/or federal governments enormous amounts of money. This care is given in return for a pension that is barely enough to meet their own needs. Carers need to feel appreciated and to be considered when decisions are made regarding any part of their care responsibilities. All too often they become involved in a merry-go-round of medical and government departments and personnel leaving them frustrated and often very angry and upset. Almost all perform their care responsibilities willingly and with love and this affects all aspects of the well being of the person being cared for. Kept in optimum health, physical and emotional, people being cared for require less other intervention options with the added financial benefit to the government. It is essential that all medical and government personnel dealing with carers value their contribution and treat them with respect.

NMAAT - the organisation representing people with neuro-muscular diseases

Alliance members:

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 barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment**

A lack of adequate respite exists that allows the carer to remain in, or find and retain, employment and to engage in social activities.

They need to be able to earn an adequate income – from employment plus from carer payments which allows them to access appropriate respite options which make working a worthwhile consideration.

Therefore

Respite

Respite needs to be meaningful and engaging for the care recipient and flexible enough to allow the carer to attend work – either full or part time as each situation requires – at a time which suits that particular household. This may even require 24 hour care options to be available as some may choose to work at night or to enable carers the freedom to attend evening functions/entertainment/family gatherings etc together with a spouse, other family member/s or friends. The respite needs to be affordable and capped so that fees do not become a burden and a disincentive for the carer to seek respite so that they can engage in employment. Work can often seem not worth the effort as caring still fills a large part of their day – before and after work. Balancing the two becomes exhausting physically and mentally.

Respite options for younger people with disabilities are particularly needed as it is inappropriate for younger people to attend day respite centres with people who are elderly and who may have an entirely different set of health issues, such as dementia.

Carer Allowance

This needs to be an adequate supplement to the carer's employment salary to enable best outcomes as they balance caring and employment. This may require each situation to be considered individually – not one package fits all.

- **The practical measures required to better support carers, including key priorities for action**

1. Provide better links for carers to information about their choices and available support for them in their caring role – perhaps at the point of contact with Centrelink if applying for a pension but available on an ongoing basis – not just a one off at first contact.
2. Provide more funding for care packages for people with disabilities and the elderly to enable carers to support the care recipient for longer
3. Provide adequate respite, particularly for young people with disabilities which will enable carers to participate in employment and social activities more easily

- **Strategies to assist carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future**

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Information and support needs to be made available at all times to carers to help them to understand what options are available to them – including the option to not continue caring if they are no longer able to.

Therefore, they need to be able to access information about assistance available to them in order to continue supporting the person they are caring for, including care packages that can provide direct care to the care recipient, counselling (including financial counselling), advocacy services for the carer, and information about their options if they do choose to not continue caring in the future – including information about what supports are available for the care recipient.

More funding is required for care packages for individuals with disabilities and the elderly as this assists the carer in their caring duties and enables them to hopefully continue for longer in their caring role.

A national project is underway in each state and territory which is jointly funded by state and federal governments to begin moving young people in nursing homes out of these facilities and into purpose built homes/accommodation where they will be living with people of their own ages and with similar goals and abilities. Although this project is in its early stages, it is imperative that funding be continued for this project when the five year timeframe has expired so that for young people who are not able to be cared for at home have options – consequently this also provides an option for the carer of a young person if they are no longer able to care for them at home.

Anne Ashford
Secretary/Treasurer
Neuro Muscular Alliance Tasmania
3rd July 2008

On behalf of Alliance members

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
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