

The MS Society of Tasmania thanks the committee for its commitment to carers and welcomes the opportunity to contribute to the Inquiry into Better Support for Carers 2008.

About the MS Society

The MS Society of Tasmania is a benevolent charitable organisation that has been part of the Tasmanian community for over fifty years.

The Society has in excess of six hundred and forty registered clients who live with a diagnosis of multiple sclerosis or another chronic, progressive neurological disease.

It also works hard to assist and represent the needs of the family members, carers, employers and others who are affected by the disease on a day to day basis. MS affects thousands of Tasmanian every day. The Society employs a range of skilled health professionals to provide a portfolio of services to Tasmanians affected by this challenging disease.

About MS

Multiple sclerosis is a chronic, progressive disease of the central nervous system affecting the brain and the spinal cord.

The average age of diagnosis is approximately 30 years with more women than men diagnosed.

We do not know the cause of MS and there is no known cure.

Our Key Points:

- The contribution of Carers in our community needs to be recognised in many ways – ways that are tailored to meet their needs/circumstances.
- Recognition needs to be flexible, responsive and commensurate with their contribution.
- Informal care and formal care must be supported to meld into a seamless and responsive framework around the needs and circumstances and choices of the individual and the family / carer.
- Respite is critical – age appropriate, flexible respite care that sustains the carers efforts and allows them to participate in the community, employment and education is fundamental.
- Carers come in all 'forms' – we cannot expect optimal care outcomes as a consequence. They are often not trained or supported to provide care support – this needs to be addressed.
- Current care packages are insufficient in number, hours and content.
- There are insufficient supports to underpin carers.
- There are inadequate models of care – in home and residential – they are also not able to respond to changes in status, not age appropriate and are inequitable across disease groups.

Inquiry into Better Support for Carers

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

Carers play a vital role in our society. They provide the physical, emotional, financial and social support for the person or sometimes persons for whom they care.

They can be the cook, the chauffeur, the cleaner, the nurse, the house manager, gardener and accountant as well as the social director and a tireless worker on all shifts day and night, seven days per week. Not a Position Description that many of us would apply for if we had the choice or the fortitude to perform for long if we were chosen.

Some do it in conjunction with additional paid employment and social contribution as well. In return they receive an allowance or a pension that is only barely enough to meet their most basic needs. And they often forego even these resources to meet the needs of their loved ones whose own meagre income is stretched by their health needs.

This care also is constant and not time limited with little or no acknowledgement of the carers own needs – they do not have access to annual leave, sick leave or long service leave – those small breaks that are so looked forward to and meaningful for and sustain us all. And there is no gold watch at 65 and an easy carefree retirement.

They are propping up a system that is unable to respond to their need and it is taking a very personal toll.

Carers experience a higher rate of depression than the average population; they have lower rates of employment and career path development; lower rates of participation in education and have less opportunities to be part of community and leisure activities. Their expendable income is usually limited as well.

An Access Economics report in 2005 estimates that the replacement cost of informal care provided to Australians with MS is over \$258m.

For people who are not fortunate enough to have a carer, a care package is provided which is funded by either the state or federal governments, depending on whether the person has a disability or if they are elderly. Their care needs have been quantified by skilled practitioners and a formal plan of care is put in place. In some ways they are the fortunate ones – as their care is in place and sustainable.

They are also on the 'radar' of care services. So many are not - until a crisis happens and a family has 'failed'. This is an unacceptable and devastating outcome for everyone involved.

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

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

Respite needs to be meaningful and engaging for the care recipient and flexible enough to allow the carer to attend work between, for example, the hours of 8am-8pm.

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 in a meaningful way.

Respite in particular needs to be available for younger people with disabilities, 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.

Steve Commane is the full time carer of his wife who has Multiple Sclerosis. He states that not only are there insufficient nursing home places, either for respite or permanent care, some residential aged care facilities even refuse to accept his wife for residential respite as her care needs are considered too high - even though the facility provides 'high care' and his wife has been assessed by ACAT as a 'high care' respite candidate.

Steve and his wife have no choice but to use residential aged care facilities for residential respite as there is no other type of facility at present in Tasmania that could accommodate her care needs.

Steve also makes the point that there are insufficient care packages and amount of care provided within these packages to care for young people with high care needs at home.

The MS Society literally watches its families go under – young carers balancing care of babies / children and their partner to elderly parents looking after their children who are progressively debilitated due to the nature of the disease. We see our carers sustain injuries and put their loved ones at risk.

No one plans for a disease such as MS and its unpredictable disease course undermines all efforts to do so.

- **The practical measures required to better support carers, including key priorities for action**
 1. Demonstrate that this community values its carers and acknowledges their challenges – both financially and practically.
 2. Provide better links for carers to information about their choices and available support for them in their caring role – at each step of the journey including perhaps at the point of contact with Centrelink if applying for an allowance / pension.
 3. Provide more funding for care packages for people with disabilities and the elderly to enable carers to support the care recipient for longer. With mechanisms in place that are responsive to changes in either the status of the person requiring care and/or their carer.
 4. Provide adequate, flexible, age appropriate respite opportunities, particularly for young people with disabilities which will enable carers to participate in employment and social activities more easily. Do not allow them to disengage with the community and the 'future' that they had planned.
 5. Providing an employment support framework whereby carers do not spend their annual leave caring so that they can 'bank' hours to cover the next period of work and also extend their access to sick leave/carers leave. Even recognise their role in real terms by legislating special entitlements for working carers – extra annual leave / subsidised part time employment etc.
 6. Extend the opportunities for carers to pursue training activities – including non vocational streams.
- **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**

Information and support needs to be made available 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 do so.

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.

Significantly 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 age group and with similar goals and abilities or to divert people from this path. (YPIRAC)

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.

This project is currently aimed at people under 50 years of age. The average age of people in residential aged care is 85 years. So the current focus is a start however it is not acceptable to limit the project to this age range.

Our families are providing the 'home' – often sustaining the roof over the person's head, the love, attention and care – those things that make life valuable and are the important determinants of quality of life.

We as a 'care system' cannot provide these things > we surely have a responsibility however to assist by providing appropriate support and a sufficient level of direct care services.

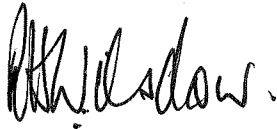
We need to make the 'entry' into the care continuum less daunting and crisis focussed and reactive. Our families initially view the commencement of external care services in their home as a 'home invasion'! All these people in their home telling them what to do! And yet feeling that they should be grateful.

They need to be supported to develop timely relationships with skilled care services > initially based on advice and support then seamlessly offering direct services as required and based on trust and consultation over time.

Services that integrate acute, rehabilitation, GP, continence and other allied health input within a whole focussed on optimal care outcomes and carer needs.

Carers are taking the pressure off the system and placing it squarely on their own shoulders.

On behalf of our clients; current and future; their families and others with these challenging diseases and disabilities, thank you for the opportunity to contribute to this inquiry and we would value the opportunity to present to the inquiry if we can add value to this valuable process.



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