MULTIPLE SCLEROSIS AUSTRALIA

Submission on Increasing Choice in Home Care – Stage 1 Discussion Paper

27 October 2015

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Multiple Sclerosis Australia
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About Multiple Sclerosis Australia

MS Australia (MSA) is the national peak body for people living with multiple sclerosis (MS) in Australia. Our role is to work on behalf of all state and territory based member organisations to provide a voice for people living with multiple sclerosis across the country to support the development of:

- Advocacy and awareness
- Communication and information
- Services provided by our member organisations
- International collaboration
- Research

MSA advocates across all stakeholders, governments and communities, on behalf of our members, to represent people who are diagnosed with MS, their carers and the broader MS community.

Our Vision

Is consistent with the vision of the Multiple Sclerosis International Federation – **'A world without MS'**

Our Mission

MSA will support our members and work towards meeting the needs of people with MS, their families and carers. We will facilitate a national comprehensive representation of the Member organisations through advocacy and communication.

Our Purpose

On behalf of our members and people with MS, our purpose is to develop:

- **Research:**
  Supporting ongoing research to pursue further knowledge in targeting prevention, improving treatment, enhancing quality of life and ultimately, to find a cure.
- **Advocacy and Awareness:**
  Although MS impacts people differently, there are common, fundamental issues for people affected by the disease. We are steadfastly committed to giving these people a voice and remain willing and able to work with government and the Australian society to champion issues in a dynamic policy environment to bring about change to the lives of people living with MS.
- **Communication and Information:**
  Utilising traditional, contemporary and innovative channels to source information and share it with people with MS, our member organisations and our key stakeholders.
- **Support for our member organisations:**
  As MS specialists providing and facilitating high quality services that span the life-time needs of people affected by MS and other degenerative neurological conditions, their families and carers – from the point of early symptoms and pre-diagnosis, that addresses their changing needs.
- **International Collaboration:**
  Representing the MS cause and promoting collaboration with our domestic and international partners.

Introduction

MS Australia (MSA) is pleased to provide a submission on the Increasing Choice in Home Care – Stage 1 Discussion Paper.

The focus of the comments, suggestions and recommendations provided in this submission is on key areas that will impact on people affected by MS.

Multiple Sclerosis (MS) is a debilitating disease of the central nervous system that affects more than 23,000 people throughout Australia with a further 1,000 people diagnosed every year. It is the most common chronic neurological condition affecting young adults. The average age of diagnosis is between 20 and 40, and 75% of people diagnosed are women.

MS varies significantly from person to person. For some people, it is a disease that comes and goes in severity with periods of unpredictable relapse and remission. For others it is a progressive decline over time. For all, it is life changing.

Symptoms can include severe pain, walking difficulties, debilitating fatigue, partial blindness or thinking and memory problems.

There is no known cause or cure.

An Economic Impact study of MS conducted by A. Palmer in 2011 stated that, "the typical course of MS is initially relapsing-remitting, with symptoms partially or completely disappearing during remissions. However, after about 10 years, the majority of people enter a secondary progressive phase and disability gradually accumulates. For a smaller group, the disease course is primary progressive, with ongoing worsening of the initial presentation. Many of these people with MS develop other chronic conditions in the course of the disease."[1]

In terms of people with MS who may be seeking services and support from the aged care sector, it is estimated that approximately 28% of all MS Society clients across Australia are aged over 65, with some variation on a state by state basis, as set out in Table 1.

Table 1. Estimated percentage of MS Society clients aged over 65 by state

ACT	**13%**
Tas	**20%**
Vic	**20%**
NSW	**19%**
WA	**22%**
SA	**22%**
NT	**16%**
Qld	**29%**
Total	**28%**

To ensure people with MS who become disabled after age 65 are able to maintain their well-being and live a fulfilled life, it will be necessary to ensure that adequate support is provided for them to stay at home for as long as possible, engage in the community, stay at work for as long as possible with appropriate support in the workplace and ensure their financial security is maintained to cater for such things as housing, aids and equipment and a quality social life. In general, aged care support has a much greater focus on personal care and in-home support rather than community participation – an important, often vital aspect of life for a person affected by MS.

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[1] Palmer A., *Economic Impact of MS in 2010 Australian MS Longitudinal Study, September 2011*, page 7.

Our submission is framed around the concerns that MSA has for how the disability needs for people with MS aged over 65 will be met.

At MSA we believe that people with a disability should be able to access whichever support system, the NDIS or aged care, which best meets their needs. Currently, these is inequity in government support of people living with MS. For people diagnosed with MS when under the age of 65, the NDIS, will, when fully rolled out, provide access to supports to meet individual needs, but people aged 65 and over must rely on the aged care system which is designed primarily to address ageing, not disability. For example, the NDIS is not means tested, eligibility is determined on need rather than capacity to pay whereas consumers of home care are expected to contribute to the cost of care.

(a) **Overall, what do you believe will be the impact of the proposed changes in Stage 1 on consumers and providers?**

Your feedback is sought on the proposed national approach for making packages available to consumers based on individual needs. This would replace the current system of planning and allocating home care places to providers at the regional level.

MSA agrees with the objectives of the Home Care Packages Programme as set out on page 5 of the Discussion Paper, i.e.

- to assist people to remain living at home; and
- to enable consumers to have choice and flexibility in the way that the consumer's aged care and support is provided at home.

Further, MSA is highly resistant to any mechanisms that lead to people with MS moving into residential care except when all other support systems have been exhausted and as a choice of last resort.

On page 5 of the Discussion Paper it is stated that, "a package may include a range of co-ordinated personal care, support services, clinical care and other services tailored to meet the assessed needs of the consumer, including people with dementia and other special needs".

It is essential that these "assessed needs" and "special needs" include the disability needs of people aged over 65 with MS and that they include items such as:

- Aids and equipment and assistive technology
- Flexible respite options (for the person with MS and their carer(s))
- Appropriate therapy/health service supports with a level of hours of support to ensure a person can remain at home
- Medical cooling (90% of people with MS are heat intolerant and run their air conditioners 15 times more than average households)

It is also essential that a system for ensuring changing and complex needs are assessed adequately and regularly enough to address periods of unpredictable relapse and remission.

MSA welcomes the statement (on page 12) that "consumers with special needs will continue to access subsidised home care services and there will be greater choice for consumers when selecting a provider. Once an eligible consumer has been assigned a package, the consumer will be able to take their package to any approved provider with capacity to meet the consumer's needs", providing these special needs include attention to the disability and special needs of people with MS and other degenerative neurological conditions. These needs are illustrated in the case study below.

Case study 1:
ALEX is 66; she lives with her 75 year old husband (who is her main carer) and their daughter. Alex mobilises with a stick, she finds shopping and domestic tasks challenging due to a lack of mobility and the level of fatigue she experiences. Alex's husband has chronic heart failure, is not in good health and has limited capacity to undertake these tasks. Alex's daughter also has serious health issues and has limited capacity to assist.
Alex reports that they are socially isolated. There are home modifications that are required – ramps at front and back doors and rails in the bathroom. Alex has had several falls recently and she experiences lower limb and upper arm weakness, she is a 'falls risk'.

Alex is on a Disability Support Pension, her husband receives the Aged Pension and they live in rental accommodation.

Alex was in receipt of an Attendant Care Package but this has now ceased as she is over 65 and she is receiving a lower level of domestic assistance through the aged care system; this is not meeting her needs.

Prioritisation (assignment of a package)

Where there is a limited number of home care packages available, what factors do you believe should be taken into account in prioritising consumers to access a package?

MSA agrees that the current system of allocation is not effective due to lack of transparency and inability for the system to be monitored effectively.

The factors set out in the Discussion Paper on page 15 appear reasonable. They should also include an assessment of a person's disability needs, any functional impairment, the progress of any chronic illness they may have and the likelihood of a crisis situation developing, especially if this is likely to lead to a person ending up in a nursing home.

We are working hard to ensure people living with MS are supported to stay at home for as long as possible and are only recommended for residential care when every other possible avenue of care and support has been exhausted. This is essential to maintaining independence and quality of life. This may require, for example, an intervention in current Aged Care Assessment Team processes to ensure a person's functional impairment and any disability needs are accurately assessed and appropriate recommendations are made for their care and support. We are keen to minimise any risk that someone with MS is admitted to residential or aged care facilities any earlier than is absolutely necessary. This is further illustrated in the case study below:

Case study 2:
MARGARET a 68 year old woman with Primary Progressive MS was living alone and finding it increasingly difficult to manage living independently in her own home. In 2014, after a significant deterioration in function, Margaret received a Home Care Package, however she was initially only able to access eight hours of service (Level 3). This meant that if she was unable to get a friend or family member to help her get ready and into bed in the evenings, she was being put to bed in the afternoon by her service provider, as there was little ability to access flexible hours of care.

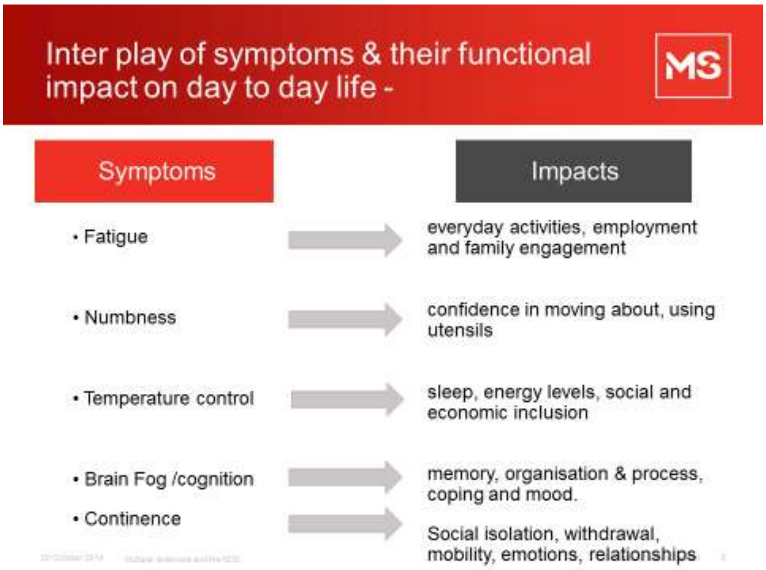
After some months Margaret's package was increased to Level 4 – equating to 12 hours of care per week, unfortunately the provider she was using did not have capacity to provide her with the total number of hours in her package. Consequently Margaret moved providers to one she thought would be able to give her the increased hours more quickly. At this time she developed a pressure area which necessitated her package having to pay for community nursing to manage her wound dressings. To access this service she had to forgo one of her personal care services.

This was not sustainable so Margaret resorted to using her private health insurance to access respite in the form of a private hospital admission so she could 'bank' some hours, it also enabled her to get her pressure areas attended to properly.

This gave Margaret a reprieve for a while but regrettably, early in 2015 she had to move to an aged care facility because her Package just was not sufficient to allow her to remain living independently at home.

(b) **What type of information will consumers and providers require in moving to the new arrangements?**

Diagnosis-specific, specialist advice services are essential to addressing and understanding the episodic nature of MS and the invisible symptoms associated with MS such as extreme fatigue, problems with balance, blurred vision, body temperature dramatically switching from burning hot to freezing cold, to name but a few examples, which may or may not progress as a person ages. These invisibility of these symptoms has some synergy with the way the invisibility of mental health symptoms are also described. Common MS symptoms and their impacts are set out in the graphic below.



Inter play of symptoms & their functional impact on day to day life -

Symptoms	Impacts
• Fatigue	everyday activities, employment and family engagement
• Numbness	confidence in moving about, using utensils
• Temperature control	sleep, energy levels, social and economic inclusion
• Brain Fog /cognition	memory, organisation & process, coping and mood.
• Continence	Social isolation, withdrawal, mobility, emotions, relationships

We are confident that people affected by multiple sclerosis, and the neurological sector more broadly, benefit greatly from early specialist support tailored to the individual situation that promotes a well-articulated pathway and continuous model of care, regardless of age.

There is significant value adding for the person, their family and community when they have a good understanding of the disease/condition and the related condition, and significant functional impairment that may result in the future as it progresses. Improving the capability of people to be aware of what the service sectors offer and to be to navigate across service sectors and within their community is vital and will reduce the need for intensive crisis-centred information, advice, support and complex case management.

Key fact:

- **Of the more than 23,000 people in Australia with MS, 15,800 (66.7%) needed assistance with at least one of the ten everyday activities considered in the 2009 Survey of Disability, Ageing and Carers. Notably 46% of people with MS needed assistance with mobility tasks.**[2]

Accessing an articulated pathway early on will allow people to determine what exists within their own network of support and in many situations, provide the individual with the confidence to explore and link with services that best suit their needs and situation.

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[2] Australian Bureau of Statistics (ABS). Profiles of Disability, 2009. Cat. No. 4429.0. Canberra: Australian Bureau of Statistics.

(c) **What additional information and support will the assessment workforce require in the lead up to February 2017?**

Given that eligibility for home care will continue to be assessed by Aged Care Assessment Teams, there is a need to mandate the appropriate, adequate and expert assessment of a person's disability needs, including the application of an understanding of progressive neurological conditions such as MS, its relapsing-remitting nature in some cases, and other special needs that a person with MS may have; here are some examples that were mentioned earlier:

- Aids and equipment and assistive technology
- Flexible respite options (for the person with MS and their carer(s))
- Appropriate therapy/health service supports with a level of hours of support to ensure a person can remain at home
- Medical cooling (90% of people with MS are heat intolerant and run their air conditioners 15 times more than average households)

There is also a need to ensure an integrated approach to assessing the needs of the individual including the impact and implications for family. Often when ongoing support through, for example, an MS clinic, can be provided, the burden of care can be minimised and the family feel more able to sustain the home environment. Support for the primary carer and family to return to their own personal pursuits and roles is also critical.

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