MULTIPLE SCLEROSIS AUSTRALIA

Submission on the New Aged Care Short-Term Restorative Care Programme Policy Consultation Paper

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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 New Aged Care Short-Tem Restorative Care Programme Policy Consultation 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 had 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.

Our submission is framed around the ten main sections in the consultation paper on which feedback has been invited.

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

1. Policy context

MSA welcomes the overarching statement in the consultation paper that “wellness, reablement and restorative approaches are emerging as powerful ways to help older people improve their function, independence and quality of life”.

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.

We are concerned that the flexible care subsidy of $190 per person per day will provide adequate funding and recommend that a review of this funding level be built into an evaluation process for this programme.

2. The STRC Programme

MSA welcomes the stated program objective of “helping older people regain their independence after a setback” and that the programme is provided so older people “can remain living in, or return to, their homes”. As previously stated, 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.

MSA welcomes the stated goal of the STRC Programme, “to reverse and/or slow functional decline in older people with the aim of improving wellbeing”.

The case study below is included as an example of a set of circumstances that MSA envisages the STRC Programme would address.

Case study:

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.

3. How the STRC Programme differs from other types of care

MSA welcomes the stated intent of the STRC Programme, “to deliver early intervention care options to older people following a setback that has resulted in a change of care needs”. MSA has a history of advocating strongly for early intervention mechanisms and the enormous benefits they bring to individuals, families and carers and the value these interventions bring to the viability and sustainability of service support systems.

MSA also welcomes the statements that the Programme will “enable flexibility as to whether the care is best delivered in the home or in a residential setting or a combination of both”. Flexibility will a key element to the success of this programme.

4. Approval of care recipients to receive short-term restorative care under the STRC Programme

Given that eligibility for the Programme will 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:

- 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 within restorative care.

5. Eligibility to receive short-term restorative care under the STRC Programme

MSA supports Option 2, to ensure the Programme is available to as many people as possible.

6. Length of time care recipients are eligible to receive short-term restorative care under the STRC Programme

We are concerned that the time period of up to 8 weeks (56 days) for provision of Programme for each recipient will be enough, and recommend that a review of this time period be built into an evaluation process for this programme.

7. How STRC Programme places are allocated

MSA supports Option 2, to ensure the quality framework can be stringently applied, audited and outcomes publically and transparently reported.

8. The care and services required to be provided as part of the STRC Programme

MSA welcomes the stated approach to “allow flexibility in STRC Programme delivery”. MSA also welcomes the statement that , “providers (will be) encouraged to develop and offer a range of consumer focused and innovative models of short-term restorative care to assist older people to regain their independence and continue to function in their home.” This aligns with our statements made earlier regarding keeping people with MS supported at home.

MSA is keen to ensure that the “consumer focused and innovative models” referred to in 8.3, and the “care plan” referred to in 8.5, include the addressing of specific disability needs.

MSA welcomes the approach that “providers will be expected to work closely with other service providers and health professionals to ensure a holistic multi-disciplinary approach “. This approach aligns well with previous MSA statements and advocacy regarding a holistic multi-disciplinary approach to meeting the care and support needs of people living with MS.

9. Arrangements relating to subsidy, payment and fees for the STRC Programme

These arrangements set out in this section of the consultation paper seem reasonable. We reiterate our concern that the flexible care subsidy of $190 per person per day will provide adequate funding and recommend that a review of this funding level be built into an evaluation process for this programme.

10. Responsibilities and accountabilities of approved providers

The arrangements set out in this section of the consultation paper seem reasonable. It will be important that service providers be required to publically report on complaints received and how they were resolved or escalated, and that this process be regularly audited; similarly for the Aged Care Complaints Commissioner.

Thank you once again for the opportunity to comment on the New Aged Care Short-Tem Restorative Care Programme Policy Consultation Paper.

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