

MULTIPLE SCLEROSIS AUSTRALIA

Comments on the draft Programme Manual for the new Commonwealth Continuity of Support (CoS) Programme

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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 comments on the draft Programme Manual for the new Commonwealth Continuity of Support (CoS) Programme.

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.

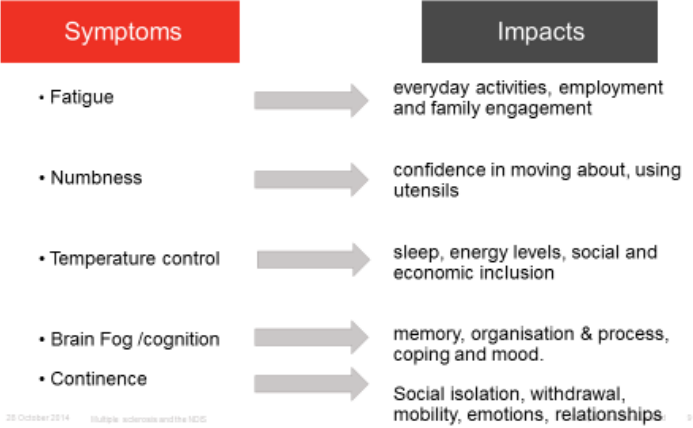
An Economic Impact study of MS conducted by A. Palmer in 2011 stated that, “the typical course of MS is initially relapsing-remitting, with symptoms partially or completely disappearing during remissions. However, after about 10 years, the majority of people enter a secondary progressive phase and disability 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

The episodic nature and invisible symptoms of MS

Diagnosis-specific, specialist advice services and support 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. The invisible and often relapsing/remitting nature of these symptoms has some synergy with the way mental health symptoms are also described. Common MS symptoms and their impacts are set out in the graphic below.

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

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



The importance of a continuum of support

There is significant value adding for the person, their family and community when they have a good understanding of the disease/condition, the related symptoms and the 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 able 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.

Accessing an articulated pathway or continuum of support, early on following diagnosis, 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.

General comments on the CoS Programme

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.

Whilst the CoS Programme has been designed to support people over 65 with disability who are recipients of State disability services, MSA remains concerned about the disability needs of those people who do not qualify for the NDIS, and who are not recipients of State schemes.

Also, the CoS Programme will continue those State disability services that many in the MS community regard as inadequate to begin with. This overall concern underpins many of the specific concerns detailed below.

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, there 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.

These concerns are illustrated in the two case studies 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.

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.

There does not appear to be an overall commitment in the CoS Programme to avoid residential aged care placement.

Specific concerns in the CoS Programme Manual**CoS Programme Objectives (p3)**

The CoS programme's objectives to achieve similar outcomes to State programs, does not address the concern that in some cases current outcomes are not adequate. If the stated aim to "enhance the independence and wellbeing of clients" is to be achieved, this program will not meet these by continuing existing inadequate supports. The monitoring and review mechanisms outlined in the introduction to the Manual will be key to ensuring enhancements are identified and built in.

Services that are timely and flexible (p3)

To ensure services are flexible, timely and respond to local needs, funding levels within packages need to take into account the higher costs of services delivered out of office hours.

People ageing with disability, especially degenerative conditions like MS, who may be wheelchair dependent, need services spread across the week.

Also, people over 65yrs unable to enter the NDIS and where the Aged Care system is not of value or of their choice – should be able to achieve outcomes that enhance their wellbeing and independence through the provision of a variety of supports and services that meet their needs. The choice of all CoS supports should be available and not limited to their currently accessed services.

People who are not eligible (p5)

The CoS Programme will not include people on waiting lists for State disability supports and no new entrants to the CoS Programme after NDIS roll out in a region. People over 65 are on the waiting list for State disability services for a reason – they have already been assessed for services and support that the Aged Care system cannot meet now or in the future.

Carers (p7)

Carers may need access to supports beyond the time they have undertaken the carer role, e.g. bereavement counselling following the death of the individual they have been caring for.

Client contributions (p8)

The Manual states that there are no changes in client contributions under the CoS Programme, but any participant who changes to the Aged Care system (page 33) may be financially disadvantaged - people should be able to access financial advice before making the decision to transition to aged care.

Block-funded activities (p10)

The block-funded activities sub-programme arrangements set out on page 10 indicate that the CoS Programme seems to be recreating the former state block funding system but on a national scale, just at the time when many disability service organisations are gearing up for the “fee for service” environment of the NDIS. These organisations will need to retain a level of block funding infrastructure and resources to operate these services. It is unclear how the maintenance of parallel systems will be funded.

Transition arrangements (p23)

There are people who currently have no access to review of their current and changing needs now or for the next two years. Ageing, Disability and Home Care (ADHC) in NSW have refused

to review Community Support Programs (CSPs) for over 65s. It is not clear what will happen to this group in the interim.

Review of client supports (p27)

The annual review arrangements set out on page 27 may need further clarification. If the funding level is set and the person has a longstanding disability, an annual review seems unnecessary. Many people with a disability as a result of a chronic illness are frustrated and annoyed by repeatedly having to explain and review their diagnosis. If this is an opportunity for the client to check the suitability of the provider, some more details of how the process is envisaged may be necessary.

Aids and equipment (p28 and p42)

Arrangements for the provision of aids or equipment remain the responsibility of the States, however it is unclear how the current level of unmet demand for aids and equipment under State programs will be met and how restrictions, such as Commonwealth programs currently being restricted from using the NSW Enable equipment program, will be addressed.

Return of unused funding (p28)

As stated on page 28 (para 2.2.6) of the Manual, “unused funding will be returned to the Department... recipients may not carry forward or ‘bank’ unused funding”, though this is inconsistent with the statements on page 29 (para 2.2.9) that say, “consider planning for unexpected events, including funding and support arrangements that may be required should these arise (e.g. illness of a carer)”.

Requirement for a business case (p35)

The availability of extra supports requires a business case to be assessed by a CoS Advisor; the extra burden is on the person or carer during the time of crisis to develop this business case.

Significant changes (p36-37)

If the significant changes occur as described on page 36, the Manual states that “older people with disability will be assisted to access the care that best meets their needs”. The Manual is not clear on who will provide this assistance if the client does not have case management under the CoS program, nor who is responsible for recognising that a crisis is occurring as a result of significant changes.

The “significant changes in supports - Exceptional circumstances” funding set out on page 37, is only for people living in supported accommodation; this limits accessibility for people with MS in times of relapse.

Exiting the programme (p39)

There is concern that some people are already on a higher level of care than what is offered on an Aged Care package and that if their current circumstances change (through relapse or progression of their MS) the only alternative is to transition or exit the program, as described on page 39, "where a client's needs have changed and additional support options are not available clients will be supported to exit the programme on a permanent basis".

Residential Aged Care (RAC) facilities are seen as offering the highest level of care and the end-point to meeting someone's high support needs. This lacks any understanding of a disability such as MS that can require extensive one-on-one support to manage symptoms. People exiting high level support packages in the community for nursing homes will often be worse off in terms of having their care needs met.

The process of assessing outcomes under the Aged Care System compared to the CoS Programme must be periodically reviewed to ensure outcomes are properly measured and the assessment process is accurate.

Ongoing reliance on State systems (p48) and the need for CoS Programme evaluation

State Governments will continue to have responsibility for complaints and restrictive practice arrangements (p48) and aids and equipment (p28). This ongoing reliance on state-based systems and the overall assumption that there is an equivalence between the various existing state and territory disability support systems, may prove problematic. It will be necessary to evaluate the Programme's effectiveness to ensure a “postcode lottery” has not been embedded into the Programme.
