

MULTIPLE SCLEROSIS AUSTRALIA

Submission to the Royal Commission into Aged Care Quality and Safety

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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:

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

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 causes, prevention, improving treatments, 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 positive 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:**
Who, as MS specialists, are 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, which addresses their changing needs.
- **International Collaboration:**
Representing the MS cause and promoting collaboration with our domestic and international partners.

SUMMARY OF RECOMMENDATIONS

- 1. The recommendations of recent aged care sector reviews need to be implemented and the current reform process needs to be progressed as a matter of urgency whilst the work of the Royal Commission into the aged care sector is undertaken.**
- 2. People are adequately supported to stay at home for as long as possible through initial and ongoing accurate assessment of functional impairments by qualified health professionals, making appropriate recommendations for their care and support and investing in additional, new home care packages.**
- 3. A comprehensive review and analysis be undertaken of the reasons for people being placed in residential aged care and the results be used to inform the design of interventions to minimise this pathway.**
- 4. State and Federal Governments must come together to develop a sustainable solution to the equitable provision of essential equipment and assistive technology to all Australians.**
- 5. Investment in dramatically-improved accessible accommodation options, funding to provide the care required through an appropriate level of NDIS packages, integration of the NDIS with the housing and health sectors, and investment in an appropriately trained and skilled disability support workforce.**
- 6. Investment in MS and other disease-specific training packages for the aged care sector workforce that address the disability needs of older Australians living with MS and other complex neurological conditions.**
- 7. If Aged Care is unable to meet the disability needs of older people, the NDIS should develop a safety net model that provides for top-up funding through the NDIS to address needs not met by Aged Care**
- 8. Eventually, the NDIS should be broadened to include all people with disability, regardless of age**
- 9. Effective interfaces with allied sectors, particularly health and palliative care, must be developed to ensure a coordinated inter and multidisciplinary approach to care.**

Introduction

MS Australia (MSA) is pleased to provide a submission to the Royal Commission into Aged Care Quality and Safety.

The focus of the comments provided in this submission are on key areas that will impact on people affected by MS. As stated above, MSA's role is to work on behalf of all state and territory based member organisations to provide a voice for people living with MS across the country.

MSA's member organisations are:

- MSWA (covering Western Australia)
- MS SA/NT (covering South Australia and the Northern Territory)
- MS QLD (covering Queensland)
- MSL (Multiple Sclerosis Limited covering Victoria, NSW, ACT and Tasmania)

Each of these state-based organisations operates independently to provide a range of services to people living with multiple sclerosis regardless of age, and, in some cases, to a broader group of people with other progressive neurological diseases. These services vary from state to state and include: phone information support and advice, on-line resources, MS clinics, specialist MS nursing, physiotherapy, allied health services, education and information workshops, seminars and webinars, psychology, financial support, supported accommodation, residential and in home respite, peer support co-ordination and employment services.

Terms of reference

The terms of reference (ToR) for the Royal Commission into Aged Care Quality and Safety are:

- a. the quality of aged care services provided to Australians, the extent to which those services meet the needs of the people accessing them, the extent of substandard care being provided, including mistreatment and all forms of abuse, the causes of any systemic failures, and any actions that should be taken in response;
- b. how best to deliver aged care services to:
 - i. people with disabilities residing in aged care facilities, including younger people; and
 - ii. the increasing number of Australians living with dementia, having regard to the importance of dementia care for the future of aged care services;
- c. the future challenges and opportunities for delivering accessible, affordable and high quality aged care services in Australia, including:
 - i. in the context of changing demographics and preferences, in particular people's desire to remain living at home as they age; and
 - ii. in remote, rural and regional Australia;
- d. what the Australian Government, aged care industry, Australian families and the wider community can do to strengthen the system of aged care services to ensure that the services provided are of high quality and safe;

- e. how to ensure that aged care services are person-centred, including through allowing people to exercise greater choice, control and independence in relation to their care, and improving engagement with families and carers on care-related matters;
- f. how best to deliver aged care services in a sustainable way, including through innovative models of care, increased use of technology, and investment in the aged care workforce and capital infrastructure;
- g. any matter reasonably incidental to a matter referred to in paragraphs (a) to (f) or that [the Commissioners] believe is reasonably relevant to the inquiry.

Inequity in the current system

We believe that people affected by progressive neurological conditions such as MS, should be able to access whichever support system best meets their needs, whether it be the National Disability Insurance Scheme (NDIS) or My Aged Care. Currently there is inequity in Government support of people living with these conditions. People under the age of 65 diagnosed with MS, and eligible for the NDIS, will access supports to meet their individual needs. People aged 65 and over must rely on the aged care system which, unlike the NDIS, is capped, means tested, requires co-payment for services and is designed to address generic ageing and frailty, not disability.

This inequity is causing many people to be pushed into financial hardship or residential aged care earlier than they wish.

Access to disability services for people with MS aged over 65 is being restricted as they are required to fit into a “frail aged” service paradigm. This is a major problem for many people with disabilities including MS. It is ageist and potentially discriminatory and tends to deny access to funding to access a range of necessary services, based on need.

Inadequate assessment and support for people with MS has led to problems with the level of aged care programme and/or plan funding and longer wait periods as problems in the original assessment and support emerge. This leads to people having longer wait times, an increased financial burden, stress and inappropriate levels of care, placing further stress on their current function and capacity for family, friends and health care providers to support their functional needs.

To ensure people 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 funding for supports 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 and flexibility 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 currently 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 a chronic, progressive neurological condition.

How many people with MS are affected?

We estimate that approximately 23% (almost 6,000 individuals) of the total MS population with MS in Australia are aged over 65.

The need to maintain reform momentum

On 16 September 2018, the Prime Minister announced a Royal Commission into the aged care sector. The Department of Health's website says, "The Royal Commission will primarily look at the quality of care provided both in residential and at home aged care services, to senior Australians. It will also include young Australians with disabilities living in residential aged care settings."

In recent years there have been many reviews of the aged care sector and major reforms have commenced. For example, in 2017, the Government embarked on the More Choices for a Longer Life budget measure and in 2018 announced the Single Quality Framework and a new Aged Care Quality and Safety Commission.

MS Australia is keen to see the momentum of reform maintained whilst the work of the Royal Commission continues, and then to see the recommendations of the Royal Commission addressed and implemented as a matter of urgency.

Recommendation:

The recommendations of recent aged care sector reviews need to be implemented and the current reform process needs to be progressed as a matter of urgency whilst the work of the Royal Commission into the aged care sector is undertaken.

Support to stay at home for as long as possible (ToR c. i.)

We are keen to ensure that people are adequately funded and supported to stay in their homes for as long as possible and only be recommended for residential care when every other possible avenue of care and support has been exhausted. This will, for example, require an intervention in Aged Care Assessment Team processes to ensure a person's functional impairment is accurately assessed and appropriate recommendations can be made for their care and support. We do not want people with MS to run the risk of being admitted to residential or aged care facilities earlier than is absolutely necessary.

This also necessitates investment in additional home care packages to alleviate long waiting lists. MS Australia supports the Council On The Ageing (COTA) recommendation for 30,000 additional packages to ensure older Australians never have to wait longer than three months.

What to consider when making an assessment

Eligibility for home care packages is assessed by Aged Care Assessment Teams/Services; there is a need to mandate the appropriate, adequate and expert assessment of a person's disability needs, by suitably qualified health professionals, including the

application of an understanding of fluctuating and progressive neurological conditions such as MS, and other special needs that a person with MS may have¹. Here are some examples:

- Aids and equipment
- Flexible respite options (for the person with MS and their carer(s))
- Appropriate therapy/health service supports with a level of hours of support adequate to ensure a person can remain at home
- Medical cooling subsidy/initiatives (90% of people with MS are heat intolerant and run their air conditioners 15 times more than average households)
- Continence needs (any state subsidies are lost when a person enters aged care, whereas the NDIS fully funds continence requirements).

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.

Recommendation:

People are adequately supported to stay at home for as long as possible through initial and ongoing accurate assessment of functional impairments by qualified health professionals, making appropriate recommendations for their care and support and investing in additional, new home care packages.

Why do people with MS end up in residential aged care?

In many cases entry into residential aged care, regardless of age, could be considered a failure of the aged care, health and disability care systems. An analysis of the reasons that people with MS end up in residential aged care is important to inform interventions that will prevent what many consider to be an inevitable progression into RAC.

The circumstances leading to admission to RAC are likely to include:

- Lack of funding to access quality and availability of services;
- Inadequate advanced planning, that is, planning for future eventualities that the client has not considered or does not have knowledge of;
- Lack of understanding of family circumstances by decision-makers e.g. life-long care provided by a partner/family member rather than a formal care arrangement using external services. The burden of care on the family member becomes too much and he/she cannot cope. This is often brought about by the physical progression of MS, but the biggest burden is brought about by cognitive decline.
- Clinical needs which are unable to be safely met in the community, including: dysphagia and the risk of choking and/or the need for percutaneous endoscopic

¹ For example, an understanding that some people have little or no insight into their condition and will insist they are fine and do not need support, when objective clinical evidence shows the opposite to be true.

gastrostomy (PEG) feeding (a procedure in which a flexible feeding tube is placed through the abdominal wall and into the stomach), incontinence and seizures.

- Need for two person transfer by hoist and insufficient funding to provide this.
- Absence of family or friends able to provide out of hours support
- Lack of understanding by family/carers of what care is needed, or where to go for help and guidance
- Refusal of assistance and supports leading to pressure related issues and other co-morbidities; e.g. poor hygiene and or nutritional status and safety concerns
- Admission to hospital with medical episodes, including pressure areas, and an absence of funding and/or supports to facilitate safe discharge
- Health professionals (GPs and neurologists) unlikely to provide assistance/guidance on what care or services are needed
- Lack of access to short term respite/relief accommodation options for both person and carer e.g. when home modifications are taking place
- Lack of transitional housing/accommodation leads to person being placed in RAC – individuals often deteriorate more quickly in this setting.

Recommendation

A comprehensive review and analysis be undertaken of the reasons for people being placed in residential aged care and the results be used to inform the design of interventions to minimise this pathway.

Ensure equal access to assistive technology² (ToR f.)

The current system

The National Disability Insurance Scheme (NDIS) provides funding to support people with disabilities, their families and carers. Rollout of the scheme commenced in 2013. In the aged care sector, My Aged Care is the main entry pathway to the aged care system, providing a central access point to aged care funding. Home care funding for older people living independently in their own home has been consolidated into two main programs: the Commonwealth Home Support Programme (CHSP) and Home Care Packages (HCP) Programme. Under this new funding structure, it is unclear where the responsibility lies for addressing the assistive technology needs of older people with a disability, people acquiring a disability because of a degenerative condition or the ageing process and/or people experiencing frailty.

Funding and access to assistive technology for people over 65 in Australia is inequitable and confusing. Programs for people over 65 are spread across multiple departments at both the Commonwealth and State level. There is limited coverage under some private health insurance and condition-specific not-for-profits. Despite the spread of funding streams, many people are sacrificing their limited income to self-purchase or are simply falling through the gaps. The lack of clarity about what will happen to the Commonwealth Government's Continuity of Support Program after July 1st 2019 makes access to assistive technology all the more precarious.

² Assistive technology: any item, piece of equipment or product that is used to increase, maintain, or improve the functional capabilities of people living with a disability.

Case study: 62 year old Lyn has a 70 year old husband Bob who has been living with MS for the past 30 years.

Because of the rules in place with NDIS, Bob can only access My Aged Care, which doesn't provide the same amount of assistance as he would receive under the NDIS. Presently Bob has been waiting 15 months for any action/assistance on his approved aged care level 4 application. In that 15 months they have spent in excess of \$10,000 directly attributable to meeting Bob's needs. With an NDIS package these costs would have been covered; with no requirement for co-payment.

Disability affects more than the person with the disease, it also has a huge impact on the life of the carer as well as family. In this case if Lyn was the one with MS, she would get an NDIS package and their life and wallet would be a whole lot better off!

Short term solutions

Federal and State Disability Ministers should be asked to:

1. Confirm funding arrangements after 1 January 2019 and provide clear information to the sector about where older Australians with a disability will go to receive their assistive technology services.
2. Confirm that they will honour their legislative obligations to provide support and services to all Australians living with a disability, by confirming they will continue to subsidise the purchase or hiring of assistive technology through state-funded assistive technology programs (such as SWEP in Victoria), until such time as an equitable program is developed for older Australians with a disability.
3. Ensure sufficient funding for assistive technology requirements is available to older Australians.

Recommendation

State and Federal Governments must come together to develop a sustainable solution to the equitable provision of essential equipment and assistive technology to all Australians.

Prevent young people entering residential aged care (ToR b. i.)

More than 6,000 Australians aged under 65 live in aged care facilities³. Of those, around 2,000 have joined the NDIS but so far only 2% of these participants have received housing support in their plans.

MS Australia is pleased that this Royal Commission will seek to address the issue of young people living in residential aged care.

New admissions of young people into residential care are not acceptable in 2019 and beyond; unless specifically required on clinical grounds.

³ Summer Foundation Young People in Nursing Homes Fact Sheet www.summerfoundation.org.au

Immediate adjustments are needed to:

- Remove barriers to provide young people currently in RAC with NDIS packages, including Supported Independent Living options with Specialist Disability Accommodation allowances that enable young people to leave residential care.
- Ensure the NDIS is integrated with the housing and health sectors so that accommodation options are more readily available, equipment and other disability support needs are met as well as meeting ongoing health needs such as nursing and clinical supports.
- Invest in an appropriately trained workforce to ensure young people with disabilities receive the support they need
- Invest in specialist accessible housing and accommodation developments to dramatically increase supply
- Commit state disability systems to deliver their full suite of services to young people who remain in aged care while they wait for the NDIS to reach them

Case study: Sammy, now 30 was diagnosed with primary progressive MS at aged 23

Why is residential care wrong for me?

Sammy says, “When I was first diagnosed, I was overcome by a lot of fear and anxiety. My biggest fear was that I would become reliant on other people to help me live my life. One of the biggest challenges for all young people, whether they have a chronic illness or not, is establishing an individual sense of identity. This challenge increases when coupled with the struggle of adapting to a new way of life, as well as battling the emotions that surround the illness.

It took some time to realise that I can have an illness and still be independent. I have tried various treatment programs and created a blog where I release my anxieties. Several aspects of my life are more difficult now but through the love and support of my family, I have been able to work out new strategies to adjust life activities accordingly.

I understand that not everybody with MS has access to a support network but it is our responsibility to ensure that MS doesn’t mean resignation. Residential care is quite dangerous in this regard. When you are constantly in situations where others need to take care of you, it drives home this message that you lose your independence upon diagnosis.

Of course the assistance of others is a real need for many with the condition but programs that encourage independence are more effective. Practically, this makes more sense as there are many with MS that can contribute to society in a variety of meaningful ways. By placing young people in residential care, we are giving up on them and wasting a valuable resource. We are also losing funds that could be applied to more long-term projects that encourage an independent lifestyle.”

Recommendation

Investment in dramatically-improved accessible accommodation options, funding to provide the care required through an appropriate level of NDIS packages, integration

of the NDIS with the housing and health sectors, and investment in an appropriately trained and skilled disability support workforce.

The Australian Government’s Younger People in Residential Aged Care - Action Plan

Most recently, in March 2019, the Australian Government has announced a “Younger People in Residential Aged Care - Action Plan”. This Plan has three goals:

1. Supporting those already living in aged care aged under 45 to find alternative, age appropriate housing and supports by 2022, if this is their goal;
2. Supporting those already living in aged care aged under 65 to find alternative, age appropriate housing and supports by 2025, if this is their goal; and
3. Halving the number of younger people aged under 65 years entering aged care by 2025.

MS Australia welcomes this announcement, supports these three goals and also supports the aim in the Plan to, “Continue to work beyond 2025 to minimise to the fullest extent possible the number of younger people aged under 65 years entering and living in aged care.”

Under the heading “Understanding younger people who enter aged care”, the Plan states that the “Australian Government will conduct an analysis of the characteristics of younger people in aged care to understand their needs and what works. This work will also improve data and reporting.”

It will be important for this analysis to include the *reasons* for younger people entering aged care, as we believe this is symptomatic of system failure, and detailed analysis may assist with developing solutions.

Lack of aged care sector workforce knowledge (ToR f.)

MS Australia is concerned that there is a lack of aged care sector workforce knowledge regarding MS, and other neurological conditions, recognising, treating and addressing symptoms and providing for the disability needs of older Australians more broadly. A solution is for the sector to invest in training packages for the aged care sector workforce. This training could take the form of short on-line modules that lead to professional development accreditation, and could draw on, or be modelled on, the MS “snapshot” and video, recently developed in consultation with MSA by the National Disability Insurance Agency (NDIA) for internal use by NDIA staff.

Recommendation:

Investment in MS and other disease-specific training packages for the aged care sector workforce that address the disability needs of older Australians living with MS and other complex neurological conditions.

Interface with other sectors

Everyone living with a progressive neurological or neuromuscular condition should have access to the right care, in the right place at the right time.

We want to create articulated pathways of care and support, with an emphasis on consumer-directed care, recognising that families and carers can only do so much. The majority of organisations have clinical guidelines and training packages available for health professionals working in aged care to have the necessary understanding of how to work with people with progressive neurological and neuromuscular conditions. The introduction of policies to bring about mandated integration between the aged care, health care and disability care systems will ensure people with a disability have their needs met, regardless of which system they access. This approach will also bring about efficiencies in the NDIS, through the streamlining of services and support.

Recommendations:

- (i) If Aged Care is unable to meet the disability needs of older people, the NDIS should develop a safety net model that provides for top-up funding through the NDIS to address needs not met by Aged Care;**
- (ii) Eventually, the NDIS should be broadened to include all people with disability, regardless of age;**
- (iii) Effective interfaces with allied sectors, particularly health and palliative care, must be developed to ensure a coordinated inter and multidisciplinary approach to care.**

KEY FACTS:

- Multiple sclerosis (MS) is a neurological condition affecting the central nervous system (brain and spinal cord) that affects more than 25,600 people throughout Australia
- It is the most common chronic neurological condition diagnosed in young adults.
- MS is most commonly diagnosed between the ages of 20 and 40
- 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 means a progressive decline over time. For all, it is life changing.
- Symptoms vary between people and can come and go; they can include severe pain, walking difficulties, debilitating fatigue, partial blindness and thinking and memory problems.
- There is no known cause or cure.
