RESEARCH
ADVOCACY
CURE

2023-24 PRE-BUDGET SUBMISSION

JANUARY 2023

2023-24 Pre-Budget Submission

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President

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EXECUTIVE SUMMARY

Recommends:

RESEARCH

- **$8 million over five years** to fund a National MS Biobank to support Australian studies towards early detection and prevention of MS,
- **Funding for the establishment of a Neurological Mission** within the Medical Research Future Fund
- **$550,000** for the Australian Institute of Health and Welfare to establish the current neurological data gaps and opportunities, including:
  - » **$400,000** for the for a scoping study leading to the development of a minimum data set for neurological and neuromuscular conditions in Australia.
  - » **$150,000** for a data report on neurological conditions in Australia would report the latest available data

MS NURSES

- **$5 million** to employ an additional 50 MS Nurses for the 8,000 people with MS currently without access in Australia.

DISABILITY

- **Increased funding to upskill the National Disability Insurance Agency including:**
  - » improved disability education and training and the establishment of a resource library of disability materials.
  - » establishing a NDIA neurological advisory group
  - » increasing the number of NDIA staff who have lived experience
- **Increased funding to improve early access and support including:**
  - » Improved and simplified guidelines, pre-planning, assessment and planning resources, materials and best practice examples
  - » Increasing the number and training of Local Area Coordinators
  - » Improved early intervention access pathway
- **Increased funding for age-appropriate specialist disability accommodation for young people with disability living in residential aged care**
- **Funding a national review of disability programs** funded outside of the NDIS with an emphasis on streaming programs and improving access.
- **Funding a single, nationally consistent assistive technology program** to support people with disability who are not eligible for the NDIS
- **An immediate increase in the rates of the Disability Support Pension and New Start Allowance** and a more person-centred focus on the delivery of income payments to people with disability

AGED CARE

- **Increasing aged care funding to support older people living with disability** including:
  - » Appropriate funding under the new in-home aged care program
  - » Increased funding under the AN-ACC for residential aged care

INTRODUCTION

MS Australia is pleased to lodge this pre-budget submission to the Australian Government for the 2023 - 2024 Budget. This submission focusses on key areas that will have a direct impact on people affected by multiple sclerosis (MS).

MS Australia seeks commitments from the Australian Government through the 2022-23 Federal Budget to:

- Prevent and ultimately defeat MS in Australia through a significant investment in research funding for better treatments, prevention and ultimately, a cure for MS
- Improve access to MS Nurses
- Improve support for people with MS living with disability
- Improve support for people ageing with MS

MS AUSTRALIA

MS Australia is Australia's national MS not-for-profit organisation that empowers researchers to identify ways to treat, prevent and cure MS, seeks sustained and systemic policy change via advocacy, and acts as the national champion for Australia's community of people affected by MS.

MS Australia represents and collaborates with its state and territory MS Member Organisations, people with MS, their carers, families and friends and various national and international bodies to:

- Fund, coordinate, educate and advocate for MS research as part of the worldwide effort to solve MS
- Provide the latest evidence-based information and resources
- Help meet the needs of people affected by MS

MS is the most commonly acquired neurological disease in younger adults around the world with over 2.8 million people affected. More than 33,300 Australians live with MS and over 7.6 million Australians know someone or have a loved one with this potentially debilitating disease.

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. For some, MS is characterised by periods of relapse and remission, while for others it has a progressive pattern of disability. MS robs people of quality of life, primarily driven by the impact of MS on pain, independent living, mental health and relationships.

MS INCREASE

Research to be released by MS Australia in February 2023[1] will reveal that there has been a significant increase in the number of people living with MS in Australia over the last four years. There were 33,335 people living with MS in Australia in 2021, an increase of 7,728 people (from 25,607 people) since 2017. Notably, this increase is accelerating (more than doubled) from MS Australia's previous estimate from 2010 to 2017 where there was an increase of 4,324.

Taking the 2021 Australian Census population estimates into account (and noting slowed population growth from the previous reporting period due to COVID-19 and the halt in overseas migration to Australia), there were 131.12 people living with MS per 100,000 people in Australia in 2021. This is an increase from 103.7 per 100,000 people in 2017 and aligns with the increase in prevalence in local areas of Australia and globally.

ECONOMIC IMPACT OF MS

An increase in the number of Australians living with MS corresponds with an increase in the total costs for people with MS in Australia. The annual costs of MS per person in Australia in 2021 were $73,457 an increase of $5,075 from 2017. Annual per person costs increase with increasing disability levels from $32,829 for people with MS with no disability to $123,333 for people with severe disability. Total costs for all people with MS in Australia have increased from $1.751 billion in 2017 to $2.449 billion in 2021.

This submission provides funding options that will improve the lives of people living with MS and reduce the economic impact of MS on the Australian health, disability, social services and aged care systems including:

- Research to prevent people from developing MS, improving early diagnosis and to develop effective treatments and interventions to slow or prevent disease progression
- Increasing access to MS Nurses and the associated improved health benefits
- Improved support to access early and appropriate NDIS supports and services that delay disease progression and support continued engagement in the community and workforce
- Improved access to aged care services that meet the needs of older people with disability and improve community and social participation

MS RESEARCH

Supercharge MS research through significant investment in better treatments, prevention, information and ultimately a cure for MS

MS BIOBANK

Great progress has been made in MS over the past 25 years. In this timeframe we have delivered many specific MS therapies where there were none available previously. MS occurs because the immune system mistakenly attacks the brain and spinal cord, and MS therapies suppress the immune attack.

Despite the incredible progress made, MS remains a serious burden on people's quality of life and on the economy. The great unmet need in MS is to prevent, halt and reverse neurological damage and disability. Experts believe a large proportion of MS could be preventable. Even being able to halt MS at an earlier stage has enormous potential to significantly reduce the burden of this disease.

Working with Australian researchers, MS Australia has initiatives in place to tackle the reversal of neurological damage and disability. Our urgent unmet need now is to prevent or detect MS earlier and to stop irreversible damage to the brain and spinal cord before it begins.

Using an MS Biobank to Stop MS Earlier

At present, MS can often be delayed or significantly halted from the time it is first seen in the clinic. This is usually soon after the onset of clinical symptoms, such as vision problems, loss of feeling, pain or weakness of the limbs.

Given the powerful therapies now available, earlier detection of MS would give us the power to shut down the attack on the brain much earlier. This could help preserve precious brain tissue, halt or delay disease, and potentially reclaim many years of function for people with MS.

Earlier detection of MS requires the development of reliable markers of early disease, an effort that is reliant upon MS biobanks.

The 'pre-MS' period

We have known for many years that the disease process in MS likely begins many years before the onset of typical clinical symptoms at around age 30-40.

But over the last decade, large studies have shown a trend of declining health in the years before MS diagnosis. A newer concept of an 'MS prodrome' has emerged, with early signs and symptoms that occur years before typical MS clinical symptoms appear[2].

Better understanding and better detection of this 'pre-MS' phase could profoundly improve our ability to recognise and diagnose MS earlier; allowing us to prevent MS or halt/delay symptoms and disability.

Finding biomarkers of 'pre-MS'

Given the genetic susceptibility to MS, insights into the 'pre-MS' period have come from studies of healthy close relatives of people with MS. Brain imaging of these relatives (including many twins) showed that 14 per cent had brain abnormalities fitting MS criteria; and many of these went on to develop MS later. This suggests there are early changes in the brain before MS clinical symptoms appear[3]. However, regular brain imaging may prove impractical and too costly for screening large numbers of healthy people.

We do not have a blood test to detect early MS, however, international MS biobanks have identified promising candidates. One of these is a breakdown product of damaged nerves that can be detected in the blood. Levels of this 'neurofilament light chain' are raised in the blood from around 6 years before MS onset[4] . Further work is required to understand the potential of this, and several other candidates, as blood markers for the "pre-MS" phase. MS biobanks are critical to this work.

Stopping MS Before It Starts

A recent study has provided the strongest evidence yet that infection with the Epstein-Barr virus (EBV, the causative agent of glandular fever) is essential for the development of MS[5] . EBV infection increased the risk of developing MS by 32-fold in a large US military cohort measured over many years. Signs of nerve damage in the blood only ever appeared after EBV infection.

We are closer than ever to preventing EBV infection, with two new-generation EBV vaccines currently in international clinical trials. In future, biobanking will be essential to monitor any rollout of EBV vaccines, and their impact on rates of glandular fever and MS.

A biobank would also allow us to monitor the other important environmental risk factors for MS, including low vitamin D and sunlight exposure, smoking and obesity, and the effect of public health initiatives towards preventing MS.

The National MS Biobank

A national research platform is needed to develop markers to detect MS earlier, and to identify people at high risk of developing MS so we can prevent it. For this work we need very detailed insights into people's MS, or their risk factors for MS. This will include blood and other biological sample markers and genetics. Together with clinical data and brain imaging, this rich data source will allow us to screen and group people according to risk or stage of MS.

Such a resource is essential if we are to find patterns to detect MS earlier, and ultimately a large proportion of new cases of MS could potentially be prevented.

NEUROLOGICAL MISSION

Neurological conditions should be considered a major national priority for medical research. Nearly 1.6 million Australians live with a progressive neurological or neuromuscular condition in Australia with an annual cost to the Australian economy of over $36 billion. The establishment of a MRFF Neurological Mission would bring together key researchers, health professionals, stakeholders, industry partners and patients to tackle the health challenges related to neurological conditions.

Currently, MRFF activities are based on areas of national priority identified by the Australian Medical Research Advisory Board (AMRAB) and widespread consultation. The AMRAB is required to take into account ‘the burden of disease on the Australian community’ in determining the MRFF Priorities. In 2021 the Australian National Audit Office (ANAO)_ undertook a review of the Department of Health’s Management of Financial Assistance under the MRFF[6]. The ANAO found that diseases with a high disability burden, such as asthma, musculoskeletal diseases and neurological and psychiatric disorders, have been overlooked or had received limited coverage with primary care meriting greater priority in funding allocations.

MS Australia calls on the Department of Health and the AMRAB to allocate funding for the establishment of a MRFF Neurological Mission.

NEUROLOGICAL DATA

High quality data on neurological and neuromuscular conditions is essential to building a strong evidence base and assisting in planning and prioritising health programs and funding, evaluating the effectiveness of intervention programs and initiatives and identifying unmet and emerging needs.

Currently, the Australian Institute of Health and Welfare (AIHW) National Centre for Monitoring Chronic Conditions (NCMCC) undertakes national surveillance and monitoring of chronic conditions in Australia. The AIHW NCMCC includes the measurement of risk factors, prevalence, hospitalisations, comorbidities, burden of disease, mortality and expenditure for conditions such as cardiovascular disease, diabetes, kidney disease, musculoskeletal conditions and respiratory conditions. The AIHW does undertake some monitoring of neurological conditions, including stroke, brain cancer and dementia as part of other programs of work. The AIHW also currently monitors some aspects of neurological conditions as a condition group including mortality and burden of disease. The AIHW is well-positioned to focus efforts and coordinate these data for comprehensive monitoring of all neurological conditions either individually or as a group in Australia.

The Neurological Alliance Australia (NAA), of which MS Australia is a founding member, met with the AIHW in November 2022 to discuss to discuss the current national neurological data gaps and opportunities for monitoring neurological conditions, with a view to improving health outcomes for people living with neurological conditions and inform evidence-based policy. The AIHW advised that there are two essential projects that must be undertaken to establish the current neurological data gaps and opportunities:

- A scoping study that comprises a short report reviewing and assessing Australian data sources for neurological conditions, including identifying gaps and opportunities for data improvements pertaining to the topics of interest; and
- A data report on neurological conditions in Australia that would report the latest available data.

The outcome of these projects can then help to guide the future monitoring of neurological conditions by the AIHW. The AIHW have recently undertaken a similar project with the creation of the National Centre for Monitoring Dementia (NCMD) which was established to undertake a range of data improvement activities. This included scoping data gaps and opportunities, a comprehensive data report and the implementing an ongoing monitoring and reporting program for dementia in Australia.

Recommends:

- **$8 million over five years** to fund a National MS Biobank to support Australian studies towards early detection and prevention of MS,
- **Funding for the establishment of a Neurological Mission** within the Medical Research Future Fund
- **$550,000** for the Australian Institute of Health and Welfare to establish the current neurological data gaps and opportunities, including:
  - **$400,000** for the for a scoping study leading to the development of a minimum data set for neurological and neuromuscular conditions in Australia.
  - **$150,000** for a data report on neurological conditions in Australia would report the latest available data

MS NURSES

Improving the healthcare of people with MS through increased access to MS Nurses

Multiple Sclerosis (MS) Specialist Nurses or MS Nurses are an integral part of the multidisciplinary healthcare team of specialist healthcare professionals providing support, education, advice, and care for people with MS. Access to MS Nurse care brings health benefits for people with MS. These include lower disability level, slower self-reported disease progression, less severe symptoms, lower levels of depression and anxiety, and a higher quality of life.

The *MS Nurse Care in Australia* Report[7] by MS Australia, in collaboration with the Menzies Institute for Medical Research and MS Nurses Australasia found that one-third of Australians living with MS (equivalent to 8,000 people) do not have access to life-changing MS nurse care and have consistently worse health outcomes. MS Nurse care reduces the need for other, more costly health professionals, such as GPs and neurologists and prevents emergency department presentations and potentially, hospital admissions. It is a highly cost-effective model of care.

If every Australian with MS had access to MS Nurse care as part of their ongoing MS management plan this would result in substantial cost savings for MS healthcare in Australia. It would significantly delay disease progression and contribute to an increased quality of life. There are further savings from a reduced reliance on National Disability Insurance Scheme (NDIS) supports and other health, disability and aged care programs and supports.

The increasing numbers of Australians living with MS will significantly impact on the Australian health system. An immediate increase in MS Nurses is crucial if this growing need is to be met.

MS AUSTRALIA

Recommends:

- **$5 million** to employ an additional 50 MS Nurses for the 8,000 people with MS currently without access in Australia. This could reduce the cost of their overall MS care by $64.3 million annually assuming cost savings of 10 per cent.

DISABILITY

Improved support for people living with MS through a better, fairer NDIS

Over the past seven years, MS Australia has actively advocated on behalf of people living with MS for improvements to the National Disability Insurance Scheme (NDIS). MS Australia recognises that the NDIS provides crucial supports and has improved the lives of many people with disability, including those living with MS. However, we believe there are still outstanding issues that need to be addressed to ensure that people have timely access to the supports and services they need, and the Scheme has a focus on participant choice and control. Increased funding to support improvement to the Scheme are crucial and timely, especially given the NDIS Review that is currently underway.

National Disability Insurance Agency

MS Australia is concerned that National Disability Insurance Agency (NDIA) staff are not appropriately trained and resourced to effectively engage with and support people with disability. There is a lack of understanding by NDIA staff about people living with progressive, degenerative, neurological and neuromuscular conditions such as MS. Additionally staff do not have a good understanding of disability including how to communicate with and support people with disability; understand consent, decision making and choice; and how to facilitate person centred planning.

Funding for improved training and education should include disease specific education, such as neurological conditions, and broad disability awareness and understanding. This should be supported by the establishment of a resource library of disability materials for use by NDIA staff. MS Australia has already developed the MS 'Snapshot,' an e-learning, disability training package for NDIA staff, which could be incorporated into this library. Improved education and training will lead to improved access, planning and communication for NDIS participants.

MS Australia acknowledges the recent changes to the NDIA Board and the inclusion of more people with disability to oversee the work of the NDIA. This can be further improved by increasing the number of NDIA staff with lived experience of disability. People with lived experience of disability can bring a unique perspective the NDIA and are better equipped to engage with people with disability and ensure they get the best outcome from the NDIS. It also increases confidence in the organisation and ensures the NDIA better reflects the cohort it represents

Nearly 1.6 million Australians live with a progressive neurological or neuromuscular condition in Australia with an annual cost to the Australian economy of over $36 billion. The Neurological Alliance of Australia (NAA), of which MS Australia is a member, estimates that around 15 per cent of NDIS participants have a progressive neurological or neuromuscular condition. MS Australia believes that creating a neurological voice within the advisory and consultative structure of the NDIA will ensure fairer representation for those living with progressive neurological or neuromuscular conditions and improve the understanding of the NDIA in relation to these conditions. This could be achieved through funding the establishment of a NDIA Neurological Advisory Group.

Early access and support

For many people accessing the NDIS is complex, time consuming and overwhelming. People with disability and their families need support to access the Scheme and navigate the various stages of assessment, planning and service access. Many people navigating the NDIS have no previous experience interacting with the disability system, limited understanding of the disability providers and services in their area and are unsure of what supports and services they need. There is currently a gap in the available NDIS resources on access, assessment and planning including:

- A lack of appropriate pre-planning support resources including resources that are easy to use and reflect the current reality of accessing the NDIS
- Limited information on the level and type of detail required in access request, supporting evidence and other NDIS forms
- Limited examples of goals and corresponding services and supports to help guide planning and initial engagement
- Limited resources and training for health professionals in how to support patients accessing and navigating the NDIS

Funding improved access, assessment and pre-planning resources will significantly reduce the stress of accessing and navigating the NDIS and ensure participants get a plan that meets their needs. It will also reduce access and plan reviews and appeals. Greater support for medical professionals will increase their confidence in making referrals and supporting patients through their NDIS journey.

The NDIS advises participants that Local Area Coordinators (LAC) will help them to understand and access the NDIS and create, implement and change their plan. However, this is not the reality for many people accessing the NDIS. In many regions LACs are not able to provide these services because they either do not have the appropriate skills and training or cover too large an area to provide individual support. There is also no required minimum training for LACs and many have limited understanding of how to support people accessing and navigating the NDIS. Funding to increase the number of LACs and improve training will ensure that participants receive timely support and are able to receive the plan that best meets their needs.

Access to support coordination is another crucial factor in accessing NDIS supports, especially for people living with MS who may experience brain fog, memory and fatigue issues that make it difficult to manage their plan. Access to ongoing support coordination ensures they can access the services and supports they need and manage interactions with providers. The current guidance on support coordination is unclear, leading to inconsistencies across planning and no clear reasoning on which participants are approved for support coordination. It is essential to fund improved guidelines on eligibility for and access to support coordination, with an emphasis on listening to participants.

MS is an incurable, progressive condition and most people are on a trajectory to meet the Schemes full access criteria within their lifetime. Most people are diagnosed with MS between the ages of 20-40 and the early stages of MS are an ideal time for access to early invention supports that allow them to continue working, being an active member of their community and slow the progression of their MS. Currently, the NDIS early intervention pathway for adults is unclear and not well understood by planners and assessors. Many people do not know that they can access it, how it can support them, what supports are available and what evidence is needed to meet the criteria. Investing in a clear, streamlined early access pathway for adults with disability will slow the progression of their disability, allow them to continue in employment and community engagement, reduce carer burden and have long term economic benefits to the NDIS.

Younger people in residential aged care

Many young people with disability live in aged care because there is nowhere else for them to live. MS Australia welcomed the release by the Australian Government of the Younger People in Residential Aged Care Strategy 2020-25 and the commitment that by the end of 2025 no younger person (under the age of 65) is living in residential aged care unless there are exceptional circumstances. While there has been a substantial drop in the number of younger people entering and living in residential aged care, the latest data[8] shows that the two targets set for 2022 have not been met:

- **Target 1 - No people under the age of 65 entering residential aged care by 2022:** During April to June 2022, 99 people under the age of 65 were admitted into permanent residential aged care in Australia.
- **Target 2 - No people under the age of 45 living in residential aged care by 2022:** At 30 June 2022, there were 68 people aged under 45 living in residential aged care in Australia.

Given that these targets have not been met and there are still 2,934 people aged under 65 living in residential aged care in Australia, more funding and resources need to be dedicated to supporting young people with disability to access the accommodation that best suits their needs and person goals. A renewed focus on supporting young people with disability to leave residential aged care and funding an increase in the availability of age-appropriate specialist disability accommodation is essential.

MS
AUSTRALIA

Recommends:

- **Increased funding to upskill the National Disability Insurance Agency including:**
  - improved disability education and training and the establishment of a resource library of disability materials.
  - establishing a NDIA neurological advisory group
  - increasing the number of NDIA staff who have lived experience
- **Increased funding to improve early access and support including:**
  - Improved and simplified guidelines, pre-planning, assessment and planning resources, materials and best practice examples
  - Increasing the number and training of Local Area Coordinators
  - Improved early intervention access pathway
- **Increased funding for age-appropriate specialist disability accommodation for young people with disability living in residential aged care**

IMPROVED SUPPORT FOR PEOPLE WITH A DISABILITY WHO ARE NOT ELIGIBLE FOR THE NDIS

Currently there are 4.4. million Australians who have a disability[9] and as of 30 September 2022 there are 554,917 NDIS participants with approved plans[10] (12.6 per cent of the disability population). As a result, the overwhelming majority of Australians with disability are reliant on programs outside of the NDIS to access supports and services.

Unfortunately, since the introduction of the NDIS many state and territory governments have reduced or removed funding for disability programs with the claim that people can access these supports through the NDIS. As a result, many people living with disability are struggling to access the support and services they need and must either self-fund or go without. This creates significant economic stress, carer burden, poor mental health and significantly increase the burden of disease and disability.

Funding a national review of disability programs funded outside of the NDIS would providing an opportunity to explore gaps in service review the disability services funded outside the NDIS and how they can be streamlined and improved. For example, as outlined above the introduction of a national assistive technology scheme can significantly streamline and improve access to assistive technology for people with disability. MS Australia recommends a review of disability programs funded outside of the NDIS with an emphasis on streaming programs and improving access.

Assistive Technology

Assistive technology and home modifications play a critical role in the lives of people living with MS by facilitating independence and participation in everyday activities. Currently, many people living with MS struggle to get access to the assistive technology they need. Those who are not eligible for the NDIS must access assistive technology through state and territory-based aids and equipment programs. Many of these schemes are underfunded or have reduced funding over time as the assumption is that people will receive these services under the NDIS. Many people may have to a pay large financial contributions towards the cost of items and have long wait lists and a limited number of aids and equipment from which they can choose.

A study of assistive technology undertaken by Monash University[11] found there are currently 87 Government funders, administering 108 assistive technology and home modifications schemes outside the NDIS. There is a distinct lack of equity and consistency across the 108 schemes and people with similar needs receive different amounts of support depending on their age, geographic location and when and where their disability was acquired. The eligibility criteria across many of the schemes are historic in nature and are not fully aligned with assistive technology provision guidelines or good practice standards. Many schemes do not provide wraparound services to ensure appropriate customisation, training, set up and maintenance.

The Assistive Technology for All (ATFA) Alliance, of which MS Australia is a member, proposes the establishment of a national assistive technology program for people who are not eligible for the NDIS. Access to a national scheme would maximise the safety, independence, inclusion and participation of people with disability, reduce the burden on families and carers, drive nationally consistent outcomes, reduce administrative burden on governments and minimise downstream costs by reducing demand in other areas such as acute health, community services and aged care. This also aligns with Australia's obligations under the Article 20 of the *United Nations Convention on the Rights of Persons with Disabilities*[12].

Disability Support Pension and New Start Allowance

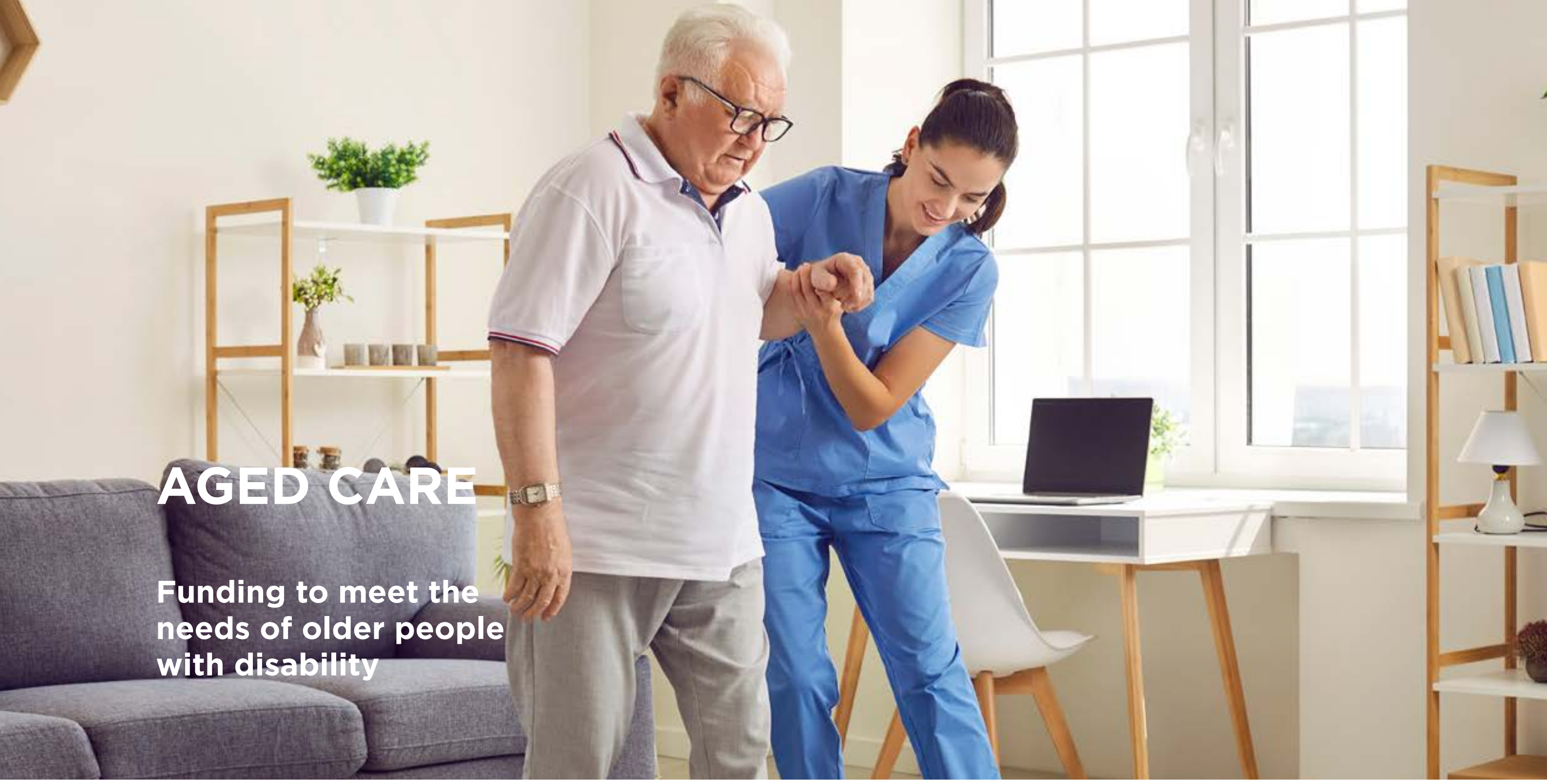
Research undertaken by UNSW and ACCOSS[13] found that people with disability face an elevated risk of poverty and it is estimated that the rate of poverty among adults with disability is 17 per cent (compared with 13.2 per cent across the whole population) and that people with disability make up 38 per cent of all people in poverty. In households whose reference person receives the Disability Support Pension, 36 per cent live below the poverty line.

The AIHW found that 38 per cent of people with disability and 51 per cent of people with severe or profound disability have a low level of personal income, compared to 27 per cent without disability. Government pensions or allowances are the main source of income for 56 per cent of people with disability and up to 76 per cent for people with severe or profound disability. The most common payment type is the Disability Support Pension (DSP) followed by New Start Allowance.

It is clear that the rates of both the DSP and the New Start Allowance are not adequate to meet the costs of those living with disability and need to be raised immediately. Feedback received by MS Australia from people living with MS is clear that these government payments are not adequate to meet the full costs of people living with MS. It places substantial economic burden on people living with MS and their carers and directly influences their health and wellbeing and the rate their disease progresses at. They are also difficult to access and maintain and do not provide adequate support and flexibility for those seeking employment. There is a strong focus on compliance rather than supporting individuals to meet their needs.

MS AUSTRALIA ***Recommends:***

- **Funding a national review of disability programs** funded outside of the NDIS with an emphasis on streaming programs and improving access.
- **Funding a single, nationally consistent assistive technology program** to support people with disability who are not eligible for the NDIS
- **An immediate increase in the rates of the Disability Support Pension and New Start Allowance** and a more person-centred focus on the delivery of income payments to people with disability



AGED CARE

Funding to meet the needs of older people with disability

Australians living with MS aged 65 and over when the NDIS was introduced and those who develop a disability and/or first access services after turning 65 are ineligible for the NDIS and must pursue their disability needs through the aged care system. However, the current aged care system does not cater to the needs of older Australians living with fluctuating or episodic disability or chronic health conditions.

The Royal Commission into Aged Care Quality and Safety (Royal Commission) found that older people with disability receiving aged care do not have access to services and supports at the same level as those provided to people through the NDIS. The Royal Commission recommended the new aged care system include equity for people living with a disability (recommendation 72):

> *By 1 July 2024, every person receiving aged care who is living with disability, regardless of when acquired, should receive through the aged care program daily living supports and outcomes (including assistive technologies, aids and equipment) equivalent to those that would be available under the National Disability Insurance Scheme to a person under the age of 65 years with the same or substantially similar conditions1 Older people with a disability must be able A New Program for In-Home Aged Care to access the supports and services they need and to maintain their independence*[14]*.*

Aged care services do not meet the disability specific needs of people living with MS, including providing appropriate assistive technology and supported independent living. Currently the average spend on assistive technology and home modifications per person per year for NDIS participants is $2,500, compared with just $51 per person per year for aged care recipients[15] . The funding cap on home care packages leaves many people receiving only basic services such as cleaning, personal care and meals. There is limited funding left for essential services including access to allied health and therapeutic services and supports for social and community participation. Residential aged care is focused on care for frail, older people and is not a suitable environment for people living with MS who are still active in their community.

Currently, older people living with MS must either self-fund the shortfall in aged care services or go without, causing a significantly increased rate of disease progression and disability leading to increased hospitalisation and greater long-term burden on the health and disability systems. A lack of appropriate supports to remain independent and living at home can lead to early and unnecessary entry to residential aged care.

The new in-home aged care program and existing residential aged care program must both be adequately funded to provide the full range of services and supports that older people with disability need.

Recommends:

- **Increasing aged care funding to support older people living with disability** including:
    - Appropriate funding under the new in-home aged care program
    - Increased funding under the AN-ACC for residential aged care

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