MS RESEARCH ADVOCACY CURE
AUSTRALIA

NDIS Evidence Advisory Committee Review

NOVEMBER 2024

MS AUSTRALIA RESEARCH ADVOCACY CURE

What is MS?

Multiple Sclerosis (MS) remains one of the most common causes of neurological disability in the young adult population (aged 18–40 years) with over 2.8 million people affected worldwide. 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, financial security, mental health and relationships.

MS Australia is Australia's national multiple sclerosis (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

George Pampacos
President

Rohan Greenland
Chief Executive Officer

NDIS Evidence Advisory Committee Review

MS Australia welcomes the opportunity to provide a submission to the NDIS Evidence Advisory Committee. Over the past ten years, MS Australia has actively advocated on behalf of people living with MS for improvements to the NDIS.

This submission draws on the experiences and expertise of MS Australia's Lived Experience Expert Panel (LEEP) and our state and territory Member Organisations. The LEEP is a panel of people who either live with MS or are a carer for someone living with MS who provide MS Australia with expert advice to inform our advocacy work. Our Member Organisations are registered NDIS providers and deliver a range of supports and services to people living with MS including exercise physiology and other allied health services, support coordination, plan management, accommodation, respite, social support and in-home care. Some Member Organisations also support people living with other neurological conditions including stroke, Parkinson's disease, Huntington's disease, acquired brain injury and Motor Neurone disease.

MS Australia Recommendations

- The NDIS Evidence Advisory Committee make the following recommendations regarding **exercise physiology** as an NDIS support:
  - Exercise physiology is a safe, effective, generally high-quality and evidence-based support for people living with MS.
  - People living with MS should have access to the number of sessions per week needed to meet their individual needs, with 2-4 sessions per week being the recommended baseline.
  - Exercise physiology cannot be easily replaced by other allied health supports such as physiotherapy.
  - Participants who cannot easily access an exercise physiologist should be able to use their funding for a gym membership to access support in this setting.
  - Participants should not have this support reduced or removed without adequate evidence and consideration of the best interests of the participant.
  - Participants should have a continuum of care and not have access to this support affected by NDIS internal processes.

- The NDIS Evidence Advisory Committee make the following recommendations regarding **smart home appliances** as NDIS supports:
  - Smart home appliances are safe, effective, generally high-quality and sustainable supports for people living with MS.
  - People living with MS should have access to smart home appliances when there are no equivalent lower cost options. Strong emphasis should be placed on maintaining independence and quality of life for the participant.
  - Consideration should be given to the longer-term economic benefits of the smart home appliance versus other supports, rather than just the immediate cost.

- The introduction of an evidence base for NDIS supports should be accompanied by
  - Training for NDIS planners and decision makers in evidence-based and participant focused supports.
  - Comprehensive guidelines for NDIS planners and decision makers around supports including how to best meet the needs of participants.
  - New requirements that NDIS planners cannot remove or reduce supports from participants' plan without adequate evidence that it is no longer required or should be reduced and must provide a full explanation to the participant.
  - Participants should not be moved to NDIS managed plans without adequate evidence that this is necessary and engagement with the participant regarding the decision.
- The NDIS Evidence Advisory Committee provides clear guidance for participants, carers, providers, health professionals and disability support workers on the latest evidence for the benefits and risks of NDIS supports.

MS Australia strongly supports the use of evidence-based supports in the NDIS to improve participant outcomes and experiences. This submission will focus on **exercise physiology** and **smart home appliances**.

Exercise physiology

Exercise and MS

There is clear evidence that physical activity and exercise are a safe and effective strategy for enhancing quality of life for people living with MS[1]. Inactivity poses a significant public health risk, with people with disabilities, including those with MS, being at much greater risk of serious health problems associated with inactivity[2].

The evidence shows that exercise improves physical fitness in people with MS, with both aerobic exercise (e.g. running, swimming and cycling) and strength/resistance training (e.g. lifting weights, using weight machines or resistance bands) showing clear benefits for people with MS[3,4,5,6,7,8,9]. Physical activity (in the form of walking) and exercise (in the form of an exercise training program), when compared to no training, have been shown to improve mobility, fatigue, balance, cognition, depressive symptoms and health-related quality of life in people living with MS [10,11,12,13,14,15, 16, 17, 18,19,20,21,22,23,24,25,26].

Preliminary evidence indicates that exercise may also lower falls risk and help manage MS related pain. Additional benefits include positive effects on memory, improved sleep quality and a reduced risk of developing other comorbid conditions, such as metabolic disorders and cardiovascular disease [27,28,29,3031,32]. Some studies have shown post exercise improvements in brain function, integrity and inflammation for people with MS[33,34,35,36].

Exercise is considered by some experts to be the single most effective nonpharmacological approach for improving functional outcomes and managing symptoms, including aerobic capacity, walking performance, fatigue, gait, balance and quality of life[37,38].

Exercise Physiology for people living with MS

People living with MS benefit from regular access to an exercise physiologist who can prescribe, deliver and adapt movement and exercise-based interventions to address the complexities associated with MS. MS is a degenerative condition and most people will experience increased physical impairment and a decline in functional capacity over time. They are also likely to

experience significant symptom fluctuations, impacting their level of function, exercise tolerance, mobility, range of motion, and pain levels. Therefore, exercise programs need to be adjusted and modified on the day of therapy based on the client's presentation.

Exercise physiologists who work with people with MS and other neurological conditions are trained to adapt exercise to address the specific needs of MS including managing fatigue and having appropriate rests and managing body temperature and overexertion. They can work with clients to formulate SMART goals which help with adherence and motivation through setting realistic, achievable and meaningful goals.

Our Member Organisation's clients and LEEP members have experienced a range of benefits from regular engagement with an exercise physiologist, including:

- **Improved Independence:** Greater ability to manage activities of daily living and community activities and reduced reliance on carers. People also gain empowerment through education from their exercise physiologist and strategies for self-efficacy and long-term management.
- **Enhanced Mobility and Gait:** Improved gait, better walking patterns, reduced falls risk, improvements in cardiovascular conditioning including endurance, weight management and improved safety.
- **Increased Strength and Physical Function:** Improved upper body, trunk strength and fine motor skills, enabling easier transfers and engagement in daily activities such as cooking and gardening.
- **Neurological Symptom Relief:** Reduction in pain, muscle spasticity, and improved range of motion through stretching and targeted exercises, which enhances comfort and mobility.
- **Psychological Wellbeing:** Boosted self-confidence, reduced anxiety and depression, increased motivation to stay active and feeling more positive about their progress and future goals.
- **Social Connection and Support:** A sense of community in gym settings that encourages participation and creates a supportive community environment and supports mental wellbeing.
- **Better Sleep and Energy Levels:** Improved sleep quality and increased energy with regular exercise.

The long-term benefits of regular access to exercise physiology include reduced reliance on carers and support workers, reduced hospital admissions, reduced reliance on other disability supports and offsetting other comorbidities.

Our Member Organisations report multiple clients who have been able to undertake a range of activities they were not able to previously include moving from a manual or powered wheelchair to a 4 wheel-walker, independently going grocery shopping, increasing working hours or returning to employment

The Government must ensure the NDIS provides safe, effective and high-quality supports that maximise the benefits for people with disability. The assessment for each support will include a summary of published evidence. We will also give the EAC a summary of what you tell us. The EAC will use the published evidence and the consultation summary to give advice to Government about the safety, suitability, and cost-effectiveness of various disability supports.

Below are client testimonials from our Member Organisations showing the benefits of exercise physiology for people living with MS:

Client testimonials:

'Ashley, your sessions are the only time I actually feel in control of my body. I leave feeling stronger, less stiff, and more positive.' **– Client with MS**

'I used to need help with everything. Now I can get out of bed and walk up and down stairs on my own. I've come a long way with your support.' **– Client with MS**

'When I exercise here, I don't just feel better physically. My anxiety eases and I can breathe.' **– Client with MS and severe anxiety & depression**

Below are case studies from our LEEP members of their experiences with exercise physiology:

Case Study: Deize

Deize lives with MS and sees an exercise physiologist once a fortnight. She has found working with an exercise physiologist to be one of the most empowering parts of managing her condition.

Exercise physiology has provided Deize with tailored movement plans that help maintain strength, balance, and mobility. Rather than generic workouts, these are based on how MS affects her body day-to-day, especially considering fatigue, spasticity, or weakness. They have helped her balance activity with rest while designing sessions that boost energy over time rather than drain it.

Deize's exercise physiologist has educated here about how MS interacts with the musculoskeletal and nervous system. This has helped her to understand both her limits and her potential. She has also learned strategies to cool down properly to prevent heat-related symptoms, pace herself without guilt and modify exercises when relapses occur.

Exercise has given Deize a sense of control over her body again. She has seen a range of benefits from exercise physiology including:

- Better walking stability, less stiffness in her muscles, improved mobility and increased endurance for daily tasks. She has gained more confidence and is less afraid of falling. Even small gains—like standing longer or walking further without needing to rest—have made a big difference in her daily life.
- Better Energy and Fatigue Management - before, she felt 'wiped out' even after light activity. Her exercise physiologist helped her pace herself and build up her endurance in a way that didn't trigger her fatigue. Now, she can get through the day with more energy and fewer crashes.
- Mental and Emotional Benefits – She has reduced stress and anxiety and feels more positive as she has a routine and can see progress. Exercise physiology has been a huge part of how she manages her MS mentally as well as physically. She is less anxious about the future because she knows she has the tools to maintain her function and slow down progression.

Case Study: Mary

Laura lives with MS and works in a high-pressure job for a global company that requires regular travel. Laura meets with an exercise physiologist weekly at her local gym which supports her to maintain a regular exercise routine tailored to meet her specific MS needs.

Laura's exercise physiologist can adapt her exercise program to address her specific MS needs including longer rests between sets, getting enough high intensity exercise minutes, managing body temperature and overexertion.

In the past, Laura had difficulty travelling for work including managing her luggage, the extra walking required and fatigue. After working with her exercise physiologist to increase her resilience and strength she is now better equipped to manage travel and her work trips have become easier. As a result of these improvements, Laura can continue in full-time employment, earning money and contributing to the economy.

Access to an exercise physiologist has also allowed her to build physical strength and resilience and increase muscle mass to buffer myself against future relapses.

Case Study: Julie

Julie lives with MS and experiences severe muscle spasticity in her legs and back, resulting in everyday pain. She also has poor grip strength in her left hand and is at risk of falls due to drop foot. Julie sees an exercise physiologist once a fortnight who helps her with exercises and manual manipulation to try and alleviate some of the pain associated with muscle spasticity and improve her hand strength and drop foot.

Access to this support has allowed Julie to maintain her independence and mobility. She has also experienced less scuffing and reduced falls, and improvement in her grip strength. This has significantly improved her quality of life and ability to remain engaged in family life and be an active member of her community.

Julie would like to access her exercise physiologist on a more regular basis, especially when her symptoms are worse, but cannot as he is fully booked out.

Frequency of exercise physiology sessions

For people living with MS, the frequency of exercise physiology sessions will vary according to each individual's physical capacity, independence, fatigue, symptom fluctuation, lifestyle and environment. Typical recommendations for MS clients range from 2–4 sessions per week, aligning with Exercise & Sports Science Australia's (ESSA) position statement on the benefits of exercise to treat multiple sclerosis[39]:

> *'To achieve optimal benefits from exercise, people with MS who have mild to moderate disability need to engage in at least 30 minutes of moderate intensity aerobic exercise twice per week and strengthening exercises of major muscles affected by MS twice per week. Additional balance-training exercises are recommended for those people with MS with poor balance and have a history of frequent falls'[40].*

Our Member Organisations report that most clients (over 50%) access exercise physiology services two or more times per week, with many wishing to attend more frequently but restricted by NDIS funding limits. Clients benefit from a combination of individual and group programs, including specialised classes for neurological conditions and chronic disease management.

Client testimonial from our Member Organisations:

'I wish I could come more often. Two sessions a week make a huge difference to my mobility, but I know if I had three or four, I'd be able to walk longer without pain. – **Client with MS**

Barriers to access

People living with MS are finding it increasingly difficult to access adequate levels of exercise physiology due to inadequate NDIS planning processes and a lack of understanding of the value of supports, including:

- **Insufficient plans:** When participants with MS receive their first NDIS plan, they often do not receive an adequate number of hours of exercise physiology. There is also a misunderstanding among NDIS planners who believe that access to any allied health support is adequate and do not understand the distinct role of each health professional.
- **Removing or reducing supports**: Since the introduction of the NDIS supports list, an increasing number of people with MS have had exercise physiology reduced or removed from their plans. This happens without warning and participants are given no explanation by their NDIS planner. These decisions are not made based on evidence and are not in the best interests of participants. Additionally, clients end up with unspent funds that planners will not allow them to spend on other supports.
- **Plan renewals, approvals and reviews**: Long delays in these NDIS processes result in an interruption in continuity of supports and have a significant impact on participants (see more detail below).
- **Price limits:** the freezing of NDIS pricing for exercise physiology means it has not kept pace with the real costs of services especially in regional, rural and remote locations. Additionally, it is more costly to access health professionals who provide specialised neurological supports and have advanced training.
- **NDIS Plan managed:** Some people with MS have reported being moved to an NDIS managed plan without explanation and as a result losing control over their choice of exercise physiologist.

These barriers also have a flow on impact for our Member Organisations who must spend many additional hours supporting clients to gain access to the level of supports that they need. It also places an additional burden on other allied health professionals such as physiotherapists who must take on additional clients and spend time writing reports to support a review of the participant's plan. In many cases there are no alternatives to exercise physiology as other allied health in the region do not have capacity to take on these clients.

Case Study: Brigitte

Brigitte lives with MS and until recently had a self-managed NDIS plan. Through this she has been able to choose a range of flexible supports including an exercise physiologist who is not a registered NDIS provider.

The NDIS moved Brigitte to a NDIS managed plan without notice or explanation. As a result, Brigitte can no longer use her plan to access her regular exercise physiologist who has a comprehensive understanding of her MS needs and who she has built rapport and trust with over many years.

Brigitte lives in a regional area where there is limited access to exercise physiologists and as a result has been unable to find an appropriate one. The resulting impact on Brigitte is that her functional ability has dramatically declined, limiting her independence and ability to undertaken daily tasks.

Brigitte is actively engaged in health and disability advocacy and her work in this space is severely limited due to the impact of not having access to an exercise physiologist. This includes not being able to attend MS Australia's national conference as a representative of the LEEP.

Many people also struggle to access an exercise physiologist due to the limited number available and the large number of clients they already serve. Access is especially difficult in regional, rural and remote areas. There should be more flexibility in accessing exercise physiology, including options that combine telehealth programs with gym memberships and personal trainers.

Case Study: Kate

Kate lives with MS and attends one group session with an exercise physiologist and one individual session per week. Her aim is to increase to two group sessions per week, but this is currently challenging due to work and life commitments.

Kate lives in a regional town and has struggled to access a MS-specific exercise physiologist. Prior to her finding her current exercise physiologist she saw an exercise physiologist via telehealth and did her program at her local gym, where she was supervised by a personal trainer. She was not able to claim her gym membership or personal training sessions against her NDIS budget and had to pay out of pocket for these expenses.

Access to tailored exercise physiology has strengthened specific areas of her body where her MS has had past impacts or is more likely to cause issues in the future. It has also given her a regular exercise routine and the support to adjust it so she can continue to be physically active even if she's having a bad day/week/month with her symptoms. She has also learnt the impact that exercise can have on fatigue and how she can use it and adjust it to help her navigate the ups and downs of day-to-day living with MS

Kate reports that she is fitter and stronger than she has been in a long time, maybe even more so than when she was diagnosed! Exercise physiology has allowed her to feel a sense of achievement when she progresses to more complex exercises and heavier weights. She has also made great social connections at the gym which adds a sense of fun to the hard work as well.

Impacts of removing exercise physiology

Exercise Physiologists who support people with MS and other neurological conditions have years of experience and training to meet the specific needs of this group. This cannot be easily replaced by another professional, fitness instructor or trainer.

Removing or reducing access to exercise physiology for people living with MS has significant and lasting impacts. Undertaking exercise without the oversight of a properly qualified professional

means there will be no one to assess, monitor and adapt a person's exercise program to suit their changing MS symptoms, prevent injury, monitor adverse reactions and biometrics and manage co-morbidities. The immediate impacts include:

- Significant decline in physical function, leading to increased dependency on support workers, carers and family members.
- Worsening of neurological symptoms such as increased spasticity and pain, which could lead to further complications and hospitalisations.
- Loss of cardiovascular fitness and potential weight gain, increasing risk factors for chronic disease.
- Decreased mental health and wellbeing due to loss of social interaction and psychological support provided through exercise sessions.
- Increased difficulty in participating in community activities, reducing overall quality of life.

Longer term, the impacts of removing exercise physiology include an increased burden on the health system and the economy, difficulty in maintaining employment, increased health issues and co-morbidities and increased depression and other mental health conditions. Over time participants will have a greater need for disability supports putting a greater burden on the NDIS. In turn, there will be a greater burden on carers leading to carer burnout, difficulty maintaining employment, breakdowns of the family unit and increase depression and anxiety.

MS Australia recommends that the NDIS Evidence Advisory Committee make the following recommendations regarding exercise physiology as a NDIS support:

- Exercise physiology is a safe, effective, generally high-quality and evidence-based support for people living with MS.
- People living with MS should have access to the number of sessions per week needed to meet their individual needs, with 2-4 sessions per week being the recommended baseline.
- Exercise physiology cannot be easily replaced by other allied health supports such as physiotherapy.
- Participants who cannot easily access an exercise physiologist should be able to use their funding for a gym membership to access support in this setting.
- Participants should not have this support reduced or removed without adequate evidence and consideration of the best interests of the participant.
- Participants should have a continuum of care and not have access to this support affected by NDIS internal processes.

Smart Home Appliances

Smart Home Appliances for people with MS

Our Member Organisations report that their clinical experience has shown there are a range of benefits for people with MS using smart home appliances, especially participants with impaired mobility and/or who experience muscle weakness, pain, fatigue and other disabling symptoms. Use of each item varies for participants, but all are in frequent use. e.g. kitchen appliances for meal preparation may be used daily, whilst robotic vacuum cleaners may be used weekly or multiple times per week.

Our Member Organisations always work with clients to determine if there are other suitable low-cost assistive technology or other alternatives before requesting funding for smart home

appliances.

We are aware that the NDIS Evidence Advisory Committee are comparing smart home appliances to other supports that may achieve the same goals including paid formal supports, standards household appliances, low tech assistive technology, community services and informal supports. Outlined below are the benefits of access to smart home appliances for people living with MS and the reasons why alternative supports may not always be more appropriate:

- **Independence:** Access to these appliances facilitates independence for participants, reduces their reliance on carers and other family members, improves mental wellbeing and allows them to feel active and engaged in their day-to-day life. Participation in these daily activities is meaningful for people with MS and can tie into their sense of identity and key roles in their lives. Participants are also able to remain in their own homes for longer, without the need to move to specialist disability accommodation.

- **Quality of Life:** These appliances ensure people with MS remain as independent as possible despite disease progression and maintain a high quality of life. The ability to continue undertaking general household tasks can also lead to people remaining engaged with hobbies or other tasks they value. This allows participants to further engage with other activities of daily living and meaningful tasks and better meet their NDIS goals.

- **Flexibility:** Many people with MS experience fatigue and fluctuating symptoms, meaning their ability to undertake tasks within the home may vary from day to day. Access to smart home appliances ensures they can undertake these tasks regardless of their symptoms and do not need to rely on a carer, family member or support worker being available at short notice.

- **Economic benefit:** The cost of a smart home appliance is substantially cheaper over time than paying for a support worker, cleaner, gardener or other disability worker to provide supports.

- **Carers**: Access to these appliances reduces the workload for carers leading to reduced carer burden and an ability to remain in employment and contributing to the economy.

- **Access to informal and paid support:** Many people do not have regular, ongoing access to informal support from family and friends, or the support may not be adequate and/or appropriate. Additionally, there is a lack of suitably qualified and skilled disability support workers across Australia, especially in regional, rural and remote locations.

- **Suitability:** Low tech and standard household appliances do not meet the same function as smart home appliances and cannot provide the full range of support needed, especially for people experiencing MS symptoms such as fatigue, dizziness, pain, spasticity and spasms, reduced strength, sensory or visual issues and balance and walking issues.

- **Safety**: Access to these appliances ensures people with MS are undertaking daily tasks in a safe environment, especially if they experience symptoms such as dizziness, pain, spasticity and spasms and sensory or visual issues.

MS Australia recommends that the NDIS Evidence Advisory Committee make the following recommendations regarding smart home appliances as NDIS supports:

- Smart home appliances are safe, effective, generally high-quality and sustainable supports for people living with MS.

- People living with MS should have access to smart home appliances when there are no equivalent lower cost options. Strong emphasis should be placed on maintaining independence and quality of life for the participant.

- Consideration should be given to the longer-term economic benefits of the smart home

appliance versus other supports, rather than just the immediate cost.

NDIS Planning & Decision Making

MS Australia supports the establishment of the NDIS Evidence Advisory Committee and ensuring that NDIS supports are informed by the best available evidence about the benefits, quality, safety and cost-effectiveness of supports. However, MS Australia is concerned that the biggest barrier to accessing appropriate supports for people living with MS are the NDIAs planning and decision-making processes.

Currently, many decisions regarding NDIS supports are made on the basis of reducing immediate costs rather than what is appropriate for the individual or the long-term costs. Any economic evaluation of potential interventions and supports for people living with disability should consider all relevant costs and benefits including health, economic and societal[41]. NDIS supports should be focused on participant and carer wellbeing, independence, quality of life and broader societal impacts.

For people living with MS, there is already a significant economic cost to living with MS including costs borne by the government and community. The *Health Economic Impact of Multiple Sclerosis in Australia* report found that the total average costs per person living with MS in 2021 was $74,000 per year [42]. This is significantly increased for people with severe disability ($123,333 per year) compared to those with mild disability ($59,957 per year) or no disability ($32,829 per year). Consequently, supports that reduce and delay disability will have a huge impact on the cost of MS.

There is also little understanding by NDIA staff of the impact of reducing or removing supports from participants with no warning or explanation. Additionally, there is limited flexibility in the provision of supports including alternatives for people living in regional, rural and remote areas.

MS Australia believes that a crucial part of establishing an evidence base for supports is ensuring that NDIA staff are appropriately trained and supported by clear guidelines and procedures.

MS Australia recommends that the introduction of an evidence base for NDIS supports should be accompanied by

- Training for NDIS planners and decision makers in evidence-based and participant focused supports.
- Comprehensive guidelines for NDIS planners and decision makers around supports including how to best meet the needs of participants.
- New requirements that NDIS planners cannot remove or reduce supports from participants' plan without adequate evidence that it is no longer required or should be reduced and must provide a full explanation to the participant.
- Participants should not be moved to NDIS managed plans without adequate evidence that this is necessary and engagement with the participant regarding the decision.

Future Change to NDIS Supports

Finally, MS Australia would like the Committee to note that supports for people with disability are changing at a rapid pace, especially with changes in technology and artificial intelligence. It is important that supports are regularly reviewed to ensure that they are keeping pace with this change and are also meeting the needs of people with disability without exposing them to harm.

Participants, carers, providers, health professionals and disability support workers should have access to information on the latest evidence on the benefits and risks of supports. This is especially important with the use of smart appliances and other technology that may access personal details

and information.

MS Australia recommends the NDIS Evidence Advisory Committee provide clear guidance for participants, carers, providers, health professionals and disability support workers NDIS on the latest evidence on the benefits and risks of NDIS supports

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