



**MULTIPLE SCLEROSIS AUSTRALIA**

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# Submission to the National Disability Insurance Scheme consultation: Support for decision making

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27 August 2021

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## Introduction

MS Australia (MSA) is pleased to provide a submission to the National Disability Insurance Scheme's (NDIS) consultation on *Support for Decision Making*.

The focus of the comments provided in this submission are on key areas that will impact on people affected by multiple sclerosis (MS) and other neurological conditions for which our state organisations provide services and support. The comments have been provided by representatives of our state organisations who assist people to navigate the NDIS and directly from people living with MS. MS Australia is the national peak body and works on behalf of our state and territory-based member organisations and other key stakeholders within the broader MS Community to provide a voice for people living with MS across the country.

MS Australia's member organisations are:

- MSWA (providing services and support in Western Australia)
- MS SA/NT (providing services and support in South Australia and the Northern Territory)
- MS QLD (providing services and support in Queensland)
- MSL (Multiple Sclerosis Limited providing services and support in 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.

## Summary of recommendations

### Recommendation 1:

**Ensure Agency staff engaging with members of the MS community take a respectful, individualised approach to each participant and have a good understanding of the needs of participants with progressive, degenerative neurological conditions such as MS, in advance and throughout decision making processes**

### Recommendation 2:

**Information and decision-making resources be provided for significant others, family members, loved ones and other informal carers – including children and young people who are affected by transitions and supported decisions.**

### Recommendation 3:

**Information and decision aids in various formats be provided to explain how to negotiate the complex sector intersections between health, disability and aged care and explain who is responsible for what.**

**Recommendation 4:**

**Decision aids for those living with diseases such as MS or early onset progressive cognitive impairment be subject to a process of consumer driven design, implementation and review to decrease the risk of marginalisation and the implementation of less effective decision aids and information resources.**

**Recommendation 5:**

**Decision aids and supports for, and approaches to conversations with, Young People in Residential Aged Care, must be designed to ensure realistic choices are considered, fail safe options are offered and back up plans are in place should chosen options fail.**

## About multiple sclerosis

Multiple sclerosis (MS) is a chronic, often disabling condition involving the central nervous system (CNS) that currently affects an estimated 25,600 people in Australia. MS is a complex neuro-inflammatory, auto-immune disease-causing scars or injuries to occur with nerve impulses within the brain, spinal cord and optic nerves. Depending on where scars develop within the CNS, the disease will manifest into various symptoms. Therefore, no two people are affected in the same way.<sup>1</sup>

MS is the most common cause of non-traumatic disability in young adults. Most people are diagnosed between the ages of 20-40, but it can affect younger and older people too. Roughly three times as many women have MS as men.<sup>2</sup> There is currently no known cure for MS however there are a number of treatment options<sup>3</sup> available to help manage symptoms and slow progression of the disease.<sup>4</sup>

MS profoundly affects the quality of life of the person from the moment of diagnosis until the end of their life.<sup>5</sup> Common symptoms<sup>6</sup> that may not be readily apparent to outside observers (invisible), but are no less debilitating, include fatigue, chronic pain, mood changes such as depression, sleep disturbances, bladder and bowel problems, and abnormal speech to changes in cognition/ memory.

## Cognitive impairment and impact on decision making

Cognitive impairment has been reported in all courses, sub or phenotypes of MS, in early and in late stages of the disease.<sup>7,8</sup> This includes slowness in attention, information processing speed and memory, but also episodic verbal and visuo-spatial memory deficits, changes in emotional experience and verbal

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1 <https://www.msaustralia.org.au/what-ms>

2 Dobson, R. and Giovannoni, G. (2019), Multiple sclerosis – a review. *Eur J Neurol*, 26: 27-40. <https://doi.org/10.1111/ene.13819>

3 <https://www.msaustralia.org.au/about-ms/medications-and-treatments>

4 <https://www.msbrainhealth.org/>

5 Jongen PJ. Health-Related Quality of Life in Patients with Multiple Sclerosis: Impact of Disease-Modifying Drugs. *CNS Drugs*. 2017 Jul;31(7):585-602. doi: 10.1007/s40263-017-0444-x.

6 <https://www.msaustralia.org.au/about-ms/symptoms>

7 <https://msra.org.au/news/cognitive-impairment/> and <https://www.msaustralia.org.au/documents/symptoms-cognitive-problemspdf>

8 Brochet, B., & Ruet, A. (2019). Cognitive Impairment in Multiple Sclerosis With Regards to Disease Duration and Clinical Phenotypes. *Frontiers in neurology*, 10, 261. <https://doi.org/10.3389/fneur.2019.00261>

fluency. Around 43-70% of all people diagnosed with MS<sup>9</sup> can experience these cognitive changes, with recent research particularly focussing on alterations in decision making.

Decision making is an everyday function for us all. An inability to make decisions can result in challenges and severe consequences, effecting all areas of our lives, especially if these decisions directly impact on treatment, lifestyle and access to supports.

Additionally, decision making can be especially affected by fatigue, which is one of the most common symptoms of MS. Despite advances in treatment options, fatigue affects almost 80% of people with MS (PwMS). Fatigue can be defined as “*a subjective lack of physical or mental energy that is perceived by the individual or caregiver to interfere with usual and desired activities*”<sup>10,11</sup> The MS International Federation (MSIF) distinguishes between two types of fatigue in PwMS, namely: physical or motor fatigue (i.e. slurred speech, unable to perform daily tasks) and cognitive fatigue (i.e. deterioration of cognitive function such as, reduced reaction time response, alertness during the day, difficulty in thinking, concentration, memory, recall, word finding).<sup>12,13,14</sup>

Other factors such as sleep dysfunction, adverse medication effects, pain, depression and physical deconditioning can also impact on fatigue symptoms and cognitive functioning.<sup>15</sup>

## What is necessary for effective decision making?

For a decision process to occur, the person with MS<sup>16</sup> has to:

- Be aware of the nature of the decision
- Have the necessary mental and imagination abilities to weigh up probabilities
- Demonstrate the ability to understand the probability of risk, and the short and long term consequences
- Have the capacity to weigh up decisions using a number of emotional components<sup>17</sup>

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<sup>9</sup> Mireille Neuhaus, Pasquale Calabrese, Jean-Marie Annoni, "Decision-Making in Multiple Sclerosis Patients: A Systematic Review", Multiple Sclerosis International, vol. 2018, Article ID 7835952, 9 pages, 2018.  
<https://doi.org/10.1155/2018/7835952>

<sup>10</sup> Multiple Sclerosis Council for Clinical Practice Guidelines. Fatigue and Multiple Sclerosis: Evidence-Based Management Strategies for Fatigue in Multiple Sclerosis. Washington DC: Paralyzed Veterans of America (1998).

<sup>11</sup> Khan, F et al, Management of Fatigue in persons with multiple sclerosis, Front. Neurol., 15 September 2014  
[|https://doi.org/10.3389/fneur.2014.00177](https://doi.org/10.3389/fneur.2014.00177)

<sup>12</sup> <http://www.msif.org/wp-content/uploads/2021/02/MS-FATIGUE-BOOKLET-DIGITAL.pdf>

<sup>13</sup> Multiple Sclerosis International Federation (MSIF). Fatigue and MS, in MS in Focus. London: Multiple Sclerosis International Federation (2011).

<sup>14</sup> <https://www.msif.org/about-ms/symptoms-of-ms/fatigue/>

<sup>15</sup> Silveira, C., Guedes, R., Maia, D., Curral, R., & Coelho, R. (2019). Neuropsychiatric Symptoms of Multiple Sclerosis: State of the Art. Psychiatry investigation, 16(12), 877–888. <https://doi.org/10.30773/pi.2019.0106>

<sup>16</sup> Mireille Neuhaus, Pasquale Calabrese, Jean-Marie Annoni, "Decision-Making in Multiple Sclerosis Patients: A Systematic Review", Multiple Sclerosis International, vol. 2018, Article ID 7835952, 9 pages, 2018.  
<https://doi.org/10.1155/2018/7835952>

<sup>17</sup> A. R. Damasio, Descartes Error: Emotion, Reason, and the Human Brain, Grosset Putmann, New York, NY, USA, 1994.

- Utilise a number of executive functions i.e. categorisation, monitoring, prospective thinking and learning ability and the use of feedback
- Utilising many areas of the brain at once.

The paradox with that of most intellectual disability is that people living with MS who experience cognitive decline or deficits, have *had* the ability to make unassisted decisions in the past, and sometimes can still have the ability if not affected by varying symptoms. The traditional focus of disability supports and research into supported decision making in this regard has however been predominantly on populations with intellectual disability and acquired brain injury<sup>18</sup> rather than those living with declining cognition such as progressive cognitive impairment and neurological disorders.

**Therefore there cannot be a one size fits all approach.**

MS is an unpredictable disease characterised by uncertainty. Those diagnosed with this disease, their families and carers, have to find ways to tolerate this variability through various coping strategies. People with MS must manage the day-to-day effects of the disease on their lives. Having an ability to exercise choice and being the “CEO” of their own lives is fundamental in adapting positively to the diagnosis of MS.<sup>19</sup>

## Key considerations in engaging with someone with MS

Some key considerations in engaging with someone with MS to improve individual capacity and support decision making are:

- For decision supporters to make initial efforts to **understand MS prior** to any type of engagement. MS Australia has previously partnered with the Disability Advocacy Network of Australia (DANA) and the NDIA in producing several internal training resources to explain MS, including a short fact sheet and video. A regular theme and feedback from participants with MS is a plea not to deplete the person’s energy and time in initially trying to bring the decision supporter up to speed in understanding the disease, as this takes up valuable time and energy, leaving less resources available to tackle the actual decision making or purpose of the meeting.
- **Respectful engagement** is required when engaging with someone with MS, including being sensitive to the participant’s capacity to make decisions in the past and an understanding of how the veil of fatigue, cognition, pain and other factors are diminishing this ability.
- **Sensitivity to logistic considerations** can make a huge difference to the person living with MS and the meeting outcome.
- The following considerations could assist:
  - Follow up all phone calls with a written email/letter as a record of a conversation
  - Ask the participant when a convenient time might be to have a meeting. Be flexible with the time it takes to go through a particular document. Sometimes a person with MS might

<sup>18</sup> Bigby, Christine, Jacinta Douglas, Terry Carney, Shih-Ning Then, IlanWiesel, and Elizabeth Smith. 2017. “Delivering decision making support to people with cognitive disability — What has been learned from pilot programs in Australia from 2010 to 2015.” Australian Journal of Social Issues 52 (3):222-240. doi: <https://doi.org/10.1002/ajs4.19>.

<sup>19</sup> Landmeyer, N. C., Dzionsko, I., Brockhoff, L., Wiendl, H., Domes, G., Bölte, J., Krämer, J., Meuth, S. G., & Johnen, A. (2020). The Agony of Choice? Preserved Affective Decision Making in Early Multiple Sclerosis. *Frontiers in neurology*, 11, 914. <https://doi.org/10.3389/fneur.2020.00914>

- require multiple sessions in shorter broken up sections than one long meeting time. Consider travelling time and the impact on fatigue this alone can have prior to a meeting. Where possible, offer to see the person with MS at their home or a location close to their home.
- Ask the participant if they would like to bring along or invite (including if online or by phone) a support person. Sometimes this can be an informal or formal support person. They can take notes and remind the participant of issues to be raised or questions they might have noted down prior to the meeting.
  - Provide as much information as possible to the participant with MS prior to the meeting, to allow pre-meeting preparation. Sometimes referring to notes can greatly assist a person.
  - Be mindful that for a lot of people with MS, a barrier to effective cognition is anxiety and stress – PwMS have provided us with feedback that they are finding conversations and interactions with government representatives and online systems very stressful. For example, recent announcements and issues raised around the introduction of Independent Assessments to the NDIS has damaged the brand of NDIA, causing distrust, confusion, alarm and concern within the disability community.
  - Make sure that appointments have reminders and check-ins to ensure a person is still able to attend a previously arranged appointment.
  - If a face-to-face appointment is planned, ensure that the venue has accessible parking (for those living with physical symptoms or fatigue), close to a disabled toilet (for those living with bladder and bowl symptoms) and is air conditioned (due to sensitivity to temperature, especially heat).
  - Make sure directions to an appointment are clear and communicated in a number of ways.
  - During the interview, frequently ask the participant to restate their understanding of the conversation and allow opportunity for questions. Also provide the participant with opportunities for a break, if needed.
  - Informal supports such as carers, spouses, family members, friends and other contacts can add valuable insights to the conversation, with the participant present. By asking direct questions to ascertain day to day responsibilities, it will become evident what level of support a participant actually needs, for example, by identifying who does what at home.
  - After an engagement or contact with a participant, it is helpful to follow a conversation up with a written email or letter to confirm what was discussed and what was the agreed outcome.

**Recommendation 1:**

**Ensure Agency staff engaging with members of the MS community take a respectful, individualised approach to each participant and have a good understanding of the needs of participants with progressive, degenerative neurological conditions such as MS, in advance and throughout decision making processes**

## **Concerns around people with disability being more involved in making decisions for themselves**

Progressive cognitive impairment indicates the inevitable transition towards reliance on others to assist in decision making. Supported decision making has been identified as an alternative to substitute decision making, but it should not be applied in a rigid or doctrinal way. A person living with an

intermittent or progressive cognitive impairment might still require a bridge between autonomy and supported decision making – and of course substitute decision making.<sup>20</sup> They might require a stepped approach or a spectrum of supported decision-making supports. The practical and conceptual application of this might create some challenges for all involved. These transitions can be very stressful and could be associated with depression, anxiety, conflict and risk. Periods of transition implies change of roles and responsibilities in key relationships. Progressive cognitive impairment should therefore be talked about and tackled in a holistic and systemic way. It is important to remember that a substitute decision-maker should not be engaged as if they are the participant.

### The importance of an individualised approach

It is important to have an individualised approach to engage participants, ascertaining their will and preferences through a range of communication tools (including non-verbal). There should always be a presumption that the participant’s ability to make decisions even if they are unable to express themselves in normal ways. Any assessments of their communication needs should be sensitively done, with consideration of their need for support, time and individual context. Any decision making framework should address the potential stigma attached to supported decision making interventions.

### Understanding the views of families and loved ones

It is important to try to understand and ascertain the views of not only the person living with MS, but also that of their family and loved ones. Supported interventions should be tailored to both the participant and their *relational-decision making unit*<sup>21</sup>. Their collective experience regarding decision making should be respected. Decision making does not only relate to the person or individual in a moment in time, but rather linked to a range of relationships and roles, requiring the insights from other significant supports, family and loved ones. They might have established relationships and a deep knowledge of the person and situation as it evolves. And this can sometimes be inconsistent or different to that of the participant, as they might have a different view of the problem and potential solution. It is important that a decision-making framework does not alienate the person living with MS from his/her informal supports and attempt to keep the informal support network intact.

#### **Recommendation 2:**

**Information and decision-making resources be provided for significant others, family members, loved ones and other informal carers – including children and young people who are affected by transitions and supported decisions.**

<sup>20</sup> Sinclair C, Gersbach K, Hogan M, Blake M, Bucks R, Auret K, Clayton J, Stewart C, Field S, Radoslovich H, Agar M, Martini A, Gresham M, Williams K, Kurrle S. "A Real Bucket of Worms": Views of People Living with Dementia and Family Members on Supported Decision-Making. *J Bioeth Inq.* 2019 Dec;16(4):587-608. doi: 10.1007/s11673-019-09945-x. Epub 2019 Dec 12. PMID: 31832863; PMCID: PMC6937221.

<sup>21</sup> Sinclair C, Gersbach K, Hogan M, Blake M, Bucks R, Auret K, Clayton J, Stewart C, Field S, Radoslovich H, Agar M, Martini A, Gresham M, Williams K, Kurrle S. "A Real Bucket of Worms": Views of People Living with Dementia and Family Members on Supported Decision-Making. *J Bioeth Inq.* 2019 Dec;16(4):587-608. doi: 10.1007/s11673-019-09945-x. Epub 2019 Dec 12. PMID: 31832863; PMCID: PMC6937221.



### The impact of cognitive decline

The impact of cognitive decline as a result of MS is a psychological burden on both the participant and their significant loved ones. Throughout the course of MS, the fluctuations and episodic nature of symptoms and complications can take its toll. The addition of cognitive decline and the need for supported decision making should consider this psychological impact and the potential need for support in this regard.

### Increased risk of abuse and neglect

Although the involvement of close family members and significant others are encouraged, the reality is that people living with cognitive decline are often more vulnerable and at risk of abuse and neglect. Not only could a transition or a supported decision making point cause conflict, it might also illuminate existing and problematic relationships that might impact negatively on the participants wellbeing and safety. It is therefore important for agency staff and formal supported decision makers to be trained to identify and flag potential abuse.

### Realistic support and service options must be available

Practitioners, and agency representatives should not engage with a person living with cognitive decline until they have meaningful and real support and service options available. There are often barriers to accessibility and suitability of service offerings, particularly in rural and remote locations or those living with a complexity of need that is not mainstream. It is unethical to engage with participants and their families and potentially raise their hopes if supports are not going to safely match their individual needs.

### Importance of providing MS specialised support

MS is a complex disease and often requires a complex and specialised response. Participants often recognise the importance of having a greater understanding of the disease and therefore require someone from a specialist MS background to provide support. This should not be seen as a conflict of interest but rather an attempt to engage someone who brings a specialised and expert understanding and approach to the conversation and this approach is usually the choice of the participant. Not all individual advocacy organisations intimately understand MS and a generalised approach should therefore be avoided.

## **Helping people with disability to make decisions for themselves**

Leading up to and after diagnosis, people with MS will find themselves negotiating the complexities of the Australian health and disability care sectors. As a chronic health condition, people with MS will require access to a range of health-related services throughout the course of their lives. As most people diagnosed with MS experience a relapsing form of the disease, they will have intermitted periods of decline and recovery. But sometimes, even with the best disease modifying and symptomatic therapies, some people with MS will require access to necessary supports to live an ordinary life. The onus should not be on the person with MS to navigate the paucity and complexity of responsibilities between various service sectors. Like any other person born with a disability, people with MS and those living with chronic disease that impacts on their ability to perform every day tasks, should not be subjected to discrimination, marginalisation or confusion as a result of this siloed approach to sector integration.



**Recommendation 3:**

**Information and decision aids in various formats be provided to explain how to negotiate the complex sector intersections between health, disability and aged care and explain who is responsible for what.**

Respect and understanding

The NDIS considers MS as a “demyelinating disease of the central nervous systems, a permanent condition for which functional capacity are variable and further assessment of functional capacity if generally required before meeting the access criteria to become a participant”.<sup>22</sup> The person living with MS will usually only approach the NDIA as a source of last resort. It indicates the toll that MS has taken on their bodies and their everyday life. To face up to these areas of dysfunction and decline is very demoralising and depressing. People with MS therefore require every consideration and respect from those within the Agency to make their journey as easy as possible.

From the very first contact with NDIA, someone with MS will benefit from having access to shared decision making, decision aids and evidence-based participant information. In light of the plethora of uncertainties already associated with MS, people with MS require access to a range of tools and resources to support their informed decision about their eligibility, what evidence would work best to illuminate their needs, how to understand the various processes associated with embarking on a NDIA journey and specifically to this cohort, how to navigate the intersection between health, disability and aged care. MS organisations are perfectly placed to guide the production of this information.

The importance of consumer driven design

Decision aids for those living with diseases such as MS or early onset progressive cognitive impairment should be subject to a process of consumer driven design, implementation and review to decrease the risk of marginalisation and the implementation of less effective decision aids and information resources. One of the factors requiring consideration is the concept of disability or living with a disability. Many people living with stable, reduced or increased functional impairments as a result of MS and other co-morbidities would find the concept of being labelled “disabled” foreign and not applicable to their situation. It is important to use terminology that does not alienate this cohort from accessing necessary supports through the Scheme. Similarly, and equally important, is the need for continuing capacity building within the agency to increase awareness of MS. MS Australia would welcome any opportunity to assist the Agency with this.

**Recommendation 4:**

**Decision aids for those living with diseases such as MS or early onset progressive cognitive impairment be subject to a process of consumer driven design, implementation and review to decrease the risk of marginalisation and the implementation of less effective decision aids and information resources.**

<sup>22</sup> <https://www.ndis.gov.au/about-us/operational-guidelines/access-ndis-operational-guideline/list-b-permanent-conditions-which-functional-capacity-are-variable-and-further-assessment-functional-capacity-generally-required>

## Supported decision making for young people in residential aged care

The Australian Government's Young People in Residential Aged Care (YPIRAC) targets and strategy have already made some inroads in preventing people living with MS under the age of 65 years entering residential care - the decreasing numbers are welcome.

People who are already living in residential aged care settings because of their high care needs require their own unique set of resources to make informed supported decisions. Supported decision making in this milieu is predicated on the assumption that the resident and their family and carers have choice – which is not always the case. There is also a presumption or misplaced understanding that the resident and their information decision supporters have a developed understanding of their choice and options. We fear that residents and their informal supports might be at risk of being set up to fail if their holistic support needs (housing and care needs) are not adequately met. Additionally, some residents might choose to remain in the aged care home for a number of reasons. In those cases, residents should be supported – along with aged care staff and management – in how best to access NDIA supports to improve their quality of life.

### **Recommendation 5:**

**Decision aids and supports for, and approaches to conversations with, Young People in Residential Aged Care, must be designed to ensure realistic choices are considered, fail safe options are offered and back up plans are in place should chosen options fail.**

## **Conclusion**

MS Australia welcomes the opportunity to provide a submission to the National Disability Insurance Scheme's (NDIS) consultation on *Support for Decision Making*.

Unfortunately, the NDIS is not available to all – especially for those outside the eligibility of the Scheme. At least 50% of people over 65 years identify as having a disability and up to 80% of people over the age of 65 years have at least one or more long-term health condition. It would be remiss of MS Australia not to note this issue again in this submission and to ask the Scheme to consider broadening the access criteria for all people with disabilities in Australia in any future changes to the NDIS legislation.