



<https://myositis.org.au/>

Myositis is a medical term that describes inflammation of muscle tissue. The most common defined forms of Myositis are:

- **Dermatomyositis;**
- **Polymyositis;**
- **Inclusion Body Myositis;** and
- **Juvenile Myositis.**

The seriousness of these diseases lies in the fact that the body's inflammatory response is turned against us causing our autoimmune system to attack and destroy our own muscle tissue. Once gone the muscle cannot be regenerated (**permanent impairment/disability**) and over time this can result in a progressive and cumulative loss of muscle that leads to further weakness and disability.

The Myositis Association – Australia Incorporated (Myositis Association Australia) was formed around 20 years ago. The Association is a not-for-profit charitable organisation. We have approximately 350 members nationwide. We are all adult members, although it is a disease that can affect babies and juveniles as well. The most prevalent form of myositis that we represent is Inclusion Body Myositis (IBM) and whilst there are other forms of myositis that are quite disabling, Inclusion Body Myositis is a slowly progressive severe muscle disease that usually affects people over the age of 50. It is a neuromuscular disease and the loss of muscle function is not unlike motor neurone disease. Ultimately it leads to disability with a high equipment need. Power wheelchairs, modified vehicles and hoists will be required. Help will be needed with transfers, showering, toileting, feeding, etc.

Below is a link to a short video on our website about Myositis in general.

<https://myositis.org.au/what-is-myositis-2/>

Access and Eligibility Policy questions.

1: what will people who apply for the NDIS need to know about the independent assessments process?

We find ourselves in a circular position with this question. In order to be eligible we need a doctor's or specialist report or letter showing that we have a condition or disease that has led to permanent impairment/disability, that outlines the treatments tried and the steps taken to live the best lives we can plus loss of function. This is all before undergoing the independent assessments that focus on loss of function.

Our current membership is reporting back to us that they are struggling with getting the doctors to do the reports and the wording right to get over the 1st hurdle. Particularly if they are low income and dependent on the public health system.

How is this information best provided?

Information booklet or sheets that cater to rare diseases and progressive/degenerative diseases.

2: what should the NDIS consider in removing the access lists?

There needs to be recognition and acknowledgement that there are rare diseases such as myositis that lead to progressive disability.

3: how can we clarify evidence requirements from health professionals about a person's disability & whether or not it is, or is likely to be, permanent & life long?

These professionals are often time poor and are unable to research how the letter should be structured. We ask that some sort of template be easily available to medical specialists, in order for them to complete accurately.

4: how should we make the distinction between disability & chronic, acute or palliative health conditions clearer?

We need case managers/coordinators that understand chronic health conditions linked with co-morbidities and rare diseases such as myositis in bringing all the fragments together for a clearer picture. We ask that you stop making the distinction.

5: what are the traits & skills you most want in an assessor?

An essential trait is empathy. Tertiary trained, experienced, well supervised, supported, medical, allied health and disability workers.

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6: what makes this process the most accessible it can be? For example, it is by holding the assessment in your home.

For the majority of myositis sufferers, home is most accessible. The disease does not typically affect brain function. However, we do have some members with trauma and the slow progression creates a huge psychological plus physical burden. So offering phone or online chat or a non-threatening venue as an option would be a good idea.

7: how can we ensure independent assessments are delivered in a way that considers & promotes cultural safety & inclusion?

The assessors should be trained and have an understanding of cultural sensitivities.

8: what are the limited circumstances which may lead to a person not needing to complete an independent assessment?

Survivors of trauma and those with anxiety issues should be allowed to refer back to previous functionality reports or have their plan fund an OT report by someone they are comfortable with.

Quality Assurance:

9: How can we monitor the quality of independent assessments being delivered & ensure the process is meeting participant expectations?

360 degree feedback, consumer panels and audits.

Communications & Accessibility of Information

10: how should we provide the assessment results to the person applying for the NDIS?

Easy to understand with options available to participants to receive online or via the post.

Members Stories

Gordon (Inclusion Body Myositis) resides Queensland

NDIS Application Process

1. Early January 2019 - Initial Application for access to the NDIS was carried out over the phone
2. NDIS forwarded request, dated 15 January 2019, for further information and evidence of my impairment from treating doctor or specialist and the impact of my impairment on my life to support the application
3. Completed NDIS Access Request – Supporting Evidence Form with supporting documentation attached was forwarded on 25 January 2019 in the form of Letters from treating General Practitioner, treating Specialist and copies of WEB documentation regarding sIBM
4. Letter from NDIS dated 4 February 2019 was received advising Access request received
5. **Two** Letters both dated 1 March 2019 were received advising the outcome of my request to access the NDIS did not meet the access requirements set out in the National Disability Insurance Scheme Act 2013 more specifically:

Disability requirements – Both Letters

Section 24 (1) (c) – which requires that you must have an impairment or impairments that result in substantially reduced functional capacity for one or more of the following activities:

Communication
Social interaction
Learning
Mobility
Self-care
Self- management

Early Intervention requirements – one letter

Section (1) (b) – which requires that the provision of early intervention supports must be likely to benefit by reducing future needs for support in relation to your disability.

6. 15 March 2019, Meet with Social Worker Muscular Dystrophy Queensland and with her support and assistance completed an Application for a review of a reviewable decision.
7. 22 March 2019, Letter from NDIS advising Request for review of a reviewable decision received by Internal Review Team
8. 5 to 9 August 2019, Tried to send numerous emails to the NDIS Internal Review Team regarding status due to months of delay but was unsuccessful due to Internal NDIS email issues. Called and discussed with the Call Centre staff and was advised to start the process again, however I had to advise that as I was now over 65 that I would be considered unsuccessful due to age.
9. 9 August 2019, Finally managed to get through by email to NDIS and received notification that my request for status of my review application was received.
10. 17 August 2019, advised that NDIS Internal Review team had received my request for status of Review application

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11. 29 August 2019, Letter from Delegate of Chief Executive Officer NDIA advising that the earlier decision made on 1 March 2019 had been set aside and that as of 29 August 2019 I was a participant of the NDIS and can access support. It was found that I did meet all requirements to become a participant of the NDIS.
12. 30 August 2019, Letter from National Access Team advising of NDIS Number and preparation material for getting ready for planning.
13. 3 September received a Planning meeting appointment with Local Area Coordinator (LAC) for 13 September 2019.
14. 20 September 2019, Letter advising NDIS Plan approved and Plan attached.

Independent Assessments Comments

From my interpretation of the Consultation Papers and investigation of some of the associated links, it appears that the reasons for making the change as outlined within Current Challenges in the Consultation Papers could potentially be a benefit to participants, however I am concerned that the new process could have other impacts on potential or existing participants.

The independent Assessment policy I feel doesn't change much in regard to the existing policy with regard to acceptance and funding apart from maybe speeding up the initial access process. There could still be the same number of reviews due to unacceptance of NDIS entry decisions or the funding provided.

The current being a person in NDIA interprets the documentation you send in from Health professional, etc and makes a decision on whether they feel you are acceptable for NDIS and you then meet with an LAC and submit requests and a person in NDIA make a decision on what proposed draft funding is allocated and you then go through the planning and funding process.

In the new policy an Independent Assessor provides their opinion to a Delegate in the NDIA based on assessment tools provided by the NDIA and the Delegate then makes a decision on whether they feel you are acceptable for NDIS and makes a decision based on the opinion on a draft funding to be allocated and you then go through the same planning and funding process.

With both the old and new policies, all applicants are required to provide information on their age, residence and evidence of disability. This includes advice from their treating health professional as to whether their impairment or impairments are, or are likely to be, permanent.

Under the new policy the documents state:

- Results of the independent assessment will be provided to the access delegate and will inform decisions about the applicant's eligibility to access the NDIS.
- We will use the results of a person's independent assessment to determine whether they have substantially reduced functional capacity to undertake any of the six activity domains in the NDIS Act. This will include consideration of environmental factors, the presentation of their condition (i.e. episodic) and whether they were having a typical day for them.
- An independent assessment will allow us to determine where a person's functional capacity lies on a continuum in relation to the wider Australian population. This helps us understand if a person's support needs are best provided by the NDIS or other mainstream systems of support, such as the health system.
- The information from the independent assessment will also be used to inform decisions about the need and eligibility for some specific supports such as Specialist Disability Accommodation.

As the access and funding is dependent on the opinion of the Independent assessors, it would be beneficial to know who will be assessing which disability group and what experience they have, etc or can any of them be utilised for any application assessment?

The documentation states the health care professionals will be from a range of areas including:

- occupational therapists
- physiotherapists
- speech pathologists
- clinical and registered psychologists
- rehabilitation counsellors
- social workers.

In my opinion we currently have enough problems with Doctors and Specialists understanding our situation and requirements, I would not like the bottom four assessing me and the others would need to not be newly out of University with little or no experience. As I have found even with Occupational Therapists, they all have different expertise and experience and this is a major factor for assessments for functionality, capability and requirements with assistive technology and home improvements.

Your own Allied Health professionals, Doctors and Specialists opinions on recommended requirements will only be taken into consideration during the planning, goal and funding allocation process after the draft plan and budget is provided and may or may not alter how the already provided funding is altered or utilised.

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TRACY (Inclusion Body Myositis) resides South Australia

Why I am concerned about NDIS assessments: I find the idea of NDIS doing independent assessments a great concern, as these will be done by personnel who have no idea about “every” condition that they are looking at. My current assessments for my condition are conducted by therapists and specialists that have been dealing with me for some period of time and have researched my rare condition and have an understanding of how it progresses and what supports I require. These people also see my progress over the months and years and are best fit to judge if I have made any improvements or how fast I am deteriorating.

To be seen by an independent assessor for approx. 20 minutes, is not going to give that person any idea of what the condition of the participant is, or how it affects them. Are these independent assessors going to have access to our specialised reports, and if they do, will they have time to read and digest the information in them, to best assess the participant?

Will these independent assessors be the only ones to assess our individual needs and circumstances – will they have the knowledge to apply to what we do need and what our circumstances are? How will this affect our funding. If we don’t get enough funding, it is a massive undertaking, both mentally and physically, and time consuming, to get reviews done to fix inaccuracies in our support.

The government needs to properly consult with disability participants and their families so that this change will benefit everyone, not just the government.

What guarantee can the government give that we will not be worse off due to these independent assessments, as they are not conversant with all our conditions.

From what I have seen of the NDIS in the short time (since last year), that I have been with them, it is a very slippery slope. I was initially rejected as they said that I did not fit criteria. This “assessment” was done by personnel that had no idea of my rare condition (and it took 5 months for them to say no). It was not until I got Muscular Dystrophy SA involved, did I get access to NDIS. And I feel that I have been battling with them ever since, in order to get the supports that I need. If I have this much trouble with NDIS personnel, what is it going to be like when I have to deal with independent assessors that have no idea of my rare condition and have too short a time to assess me correctly. Not to mention all the mental stress and anguish that I have had, and am still going through, with them!

If the government is doing this as a cost cutting exercise, then they may find themselves in a lot worse off situation in the future, with a disability sector that is well under funded and supported. And that may well cost them votes.

Cassandra (Dermatomyositis) resides Victoria

I am a current participant in the NDIS (2020-2021). I have lived with my own serious diseases & disabilities for 40 years. I have been a Member of the Myositis Association of Australia for one year.

Parent & Carer of a Current Disabled Child NDIS Consumer:

I was the mother & sole-carer of a disabled child (2004-2019).

I managed my child's government funding for Early Intervention Autism (2009-2011).

I managed my child's Disability Support Package under the former Department of Health & Human Services 'Disability Support Register' (2011-2018).

I chose plan management when my child transferred to the NDIS (2018-).

Daughter & Carer of a Disabled Elder who is Ineligible for the NDIS:

I was the sole carer of my elderly mother through cancer treatment & dementia (2014-2019).

I obtained a Council Each package & tackled My Aged Care via an ACASS.

Mum was on a two year wait-list for a Home Support Package Level 3 & in July 2019 she was unilaterally placed in a nursing home interstate by my sibling before any commonwealth home support funding started.

Former Health, Welfare & Housing Worker:

I was employed in the private, public and community health sectors for approximately 25 years.

Former Media & Communications Professional: I was a newspaper journalist & public relations executive in the 1980s & 1990s in NSW, Vic, & South Australia.

Current Community Advocate:

I am a survivor of severe family abuse & violence. I am a trained Safe Steps Survivor Advocate.

I provide consumer feedback to a major public hospital about its response to domestic abuse via a Family Violence Reference Group (2018-).

I appeared before a federal parliamentary enquiry & contributed to multiple government focus groups.

I have given public & private presentations, some of which are accessible on organisational websites.

I participated in numerous tv, radio & newspaper interviews about my experiences of domestic abuse & system abuse.

I have a YOUTube video about being a survivor of family violence who used to work with victims & perpetrators of domestic abuse in the private & public health systems.

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My Opinion About the NDIS Independent Assessments:

I am one of the 8 per cent of Australians who live with a rare disease. I fear Australians with rare diseases will experience more suffering & discrimination, shorter lives & profound poverty if we are forced to participate in the proposed NDIS Independent Assessments.

The quantity & quality of my life literally depends on me receiving ongoing NDIS funding to live semi-independently in a rented home. Without the NDIS, Centrelink & my dog (who is supported by a pet charity) I would probably suicide. I would end my life in a deliberately planned way if the NDIS funding ended because I could not bear to be forced into a nursing home.

Nursing homes are unsuitable for people in their 50s. For those of us on life-long chemotherapy & immunotherapy, they are pandemic death traps. Also, as a survivor of severe domestic abuse & family violence I cannot tolerate being controlled by individuals within systems that deny my autonomy. I will never ever again be invisible, voiceless & shamed into silence. My relatively young age, rare disease, & complex trauma necessitate I live alone on the edge of the community away from disrespectful employees of systems which manage human beings as if we were commodities.

I am terrified by the possibility an NDIS assessor could disregard my insights & the expert opinions of my health & welfare team; then write a factually & interpretively wrong report rescinding my funding, leaving me with absolutely no right of appeal. No single individual, no sole system silo should be able to control me and my circumstances to this degree. It is eerily like the power still held by Family Court Report Writers in the Federal Circuit Court & the Family Court where parents can lose sole & shared care of their children based on a single report.

The complex & progressive characteristics of rare diseases such as the neuro-muscular inflammatory myopathies require multi-disciplinary specialist assessments & flexible approaches to assessment, care & support. We must be granted equitable access to the NDIS & be guaranteed that assessments are undertaken in a collaborative manner where trained & supervised rare disease consumer advocates are present with the consumer & carer (if there is one). Often, we are too ill & our carers too worn-out to provide effective self-advocacy in the face of systemic ignorance, bias & bullying.

I found the NDIS staff I encountered from 2019 to 2020 seemingly worked without any medical, welfare nor disability qualifications & therefore did not understand the medical & allied health reports supplied. Indeed, one worker selected an incorrect 'drop box' category diagnosing me with rheumatoid arthritis (I do not have this) & rejected my application with no reference to any discernible clinical guidelines or disease specific impairment tables.

The Myositis Association of Australia & Rare Voices Australia could step into this service gap by promoting the expertise of Murdoch University and the Australian National University research teams to commercialise their services for NDIS, Aged Care & Centrelink consultancy & assessments.

Unfortunately, I did not have such a resource. It took two applications & 18 months of strenuous advocacy by me, my General Practitioner of 17 years, two specialist doctors & four Occupational Therapists for the NDIS to accept the correct diagnosis. Ironically, I was assigned by the NDIS to an Early Intervention stream, but by the time the actual plan started in May 2020 (nearly two years since diagnosis & 5 years since my acute deterioration) I was being described by doctors as on an “aggressive, treatment resistant” incurable disease & disability course.

As far as I know, the proposed NDIS assessment instruments are not empirically validated. These so-called generic ‘assessments’ are nothing more than unproven blunt instruments of coercion & control. They are totally inappropriate to capture the subtlety & complexity of rare diseases such as the neuro-muscular inflammatory myopathies which present on a spectrum understood only by a few experts in Australia and around the globe.

If the best doctors that money, education & persistence could buy in a capital city took five years to diagnose my rare disease, then what hope do I have in the hands of an under-trained poorly supervised NDIA worker whose very employment contract compromises the title ‘Independent Assessor’. What will happen long-term if such a worker informs herself about the impairments of our cohort & approves more than her share of packages than the government algorithm allows? Will the NDIS assessment process become another Centrelink-like robo-debt scandal which resulted in consumers self-harming, suiciding & driven to other desperate acts.

I’ve lived just long enough to see Australia’s 1970s universal medical care & education systems progressively eroded by a Neo-Liberal mindset that divides citizens into two classes of people - the lifters & leaners. The NDIS assessment policy clearly views its consumers as leaners who will be allowed to speak in assessments but not heard in terms of appealing wrong decisions about funding & levels of support. The assessments proposed by the NDIS were previously used by the Commonwealth Employment Services in the 1980s (conducted by Commonwealth Medical Officers) to reduce the dole queues during economic depressions & recessions. Since then, these types of assessments have been implemented by Centrelink for the past 15 years (Job Capacity Assessments, Disability Support Pension Medical Assessments). A related example of the impact of such punitive targeted policies to coerce & control vulnerable clients is the Department of Education, Skills & Employment ‘Job Active’ program (An ABC Radio National Damien Carrick 2020 ‘Law Report’). This has driven single, unemployed, marginally housed parents & children into dire poverty & homelessness. That’s what I fear will happen to future myositis people & those of us who are just below the radar of NDIS & Centrelink surveillance.