



Submission to the Joint Standing Committee on the National Disability Insurance Scheme: Inquiry into general issues around the implementation and performance of the NDIS

We would like to thank the Committee for holding this inquiry and giving us the opportunity to make a submission on behalf of Australians living with migraine.

Migraine Australia is a new patient advocacy body representing the 4.9 million Australians who live with migraine. We are the only migraine specific body working to support Australians living with migraine.

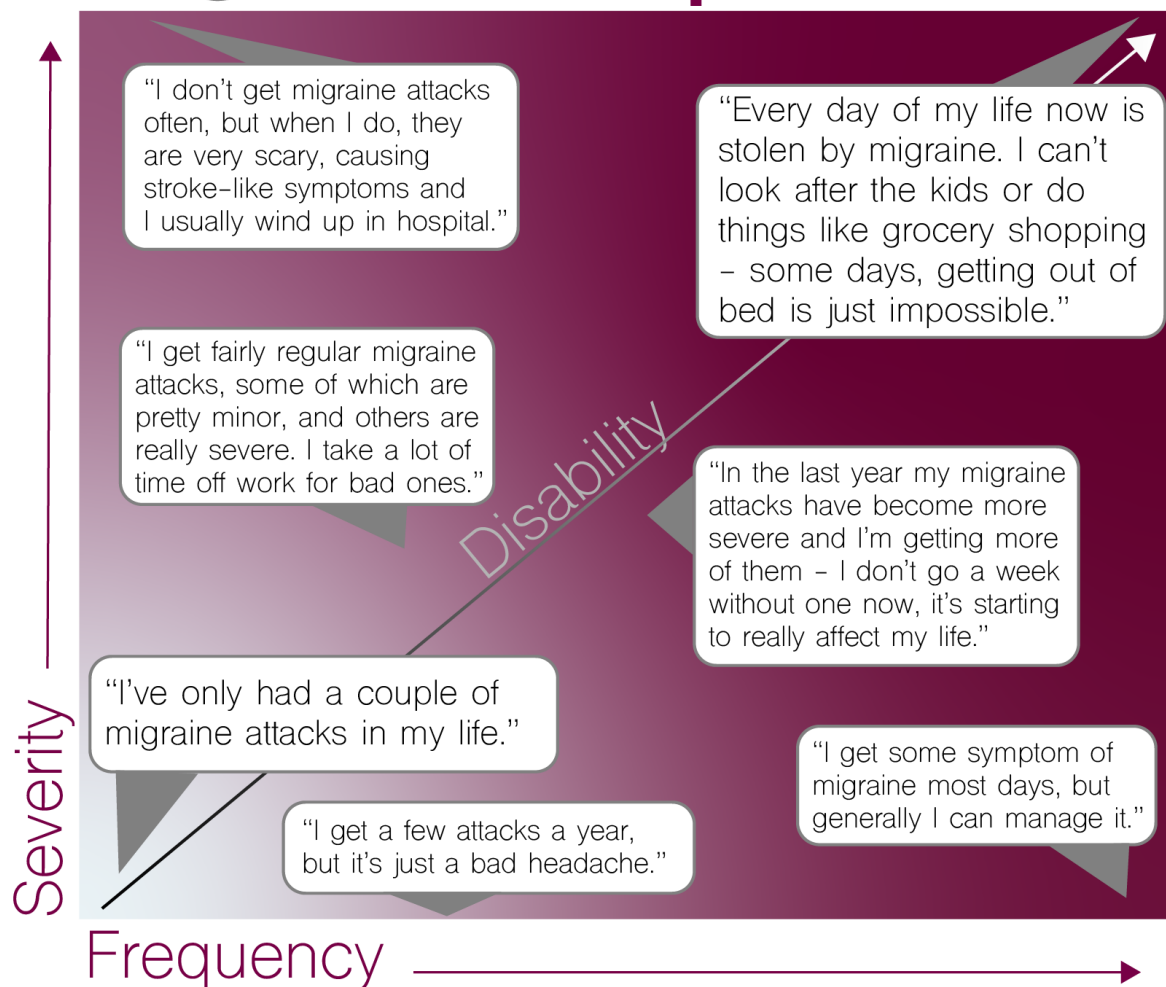
About migraine

Migraine is a complex, neurovascular, genetic condition that requires a 'trigger' to bring on a migraine attack. Attacks commonly involve any combination of sensitivity to light, sound and/or smell; nausea and vomiting; and/or headache. A third of migraine patients also get 'aura', a period before the acute phase that involves a number of neurological symptoms from loss of vision, to loss of feeling and/or motor function, to loss of consciousness and even coma.

It is between the attacks where migraine becomes most invisible, and most debilitating. The anxiety people with migraine live with, particularly the constant fear of food or environmental triggers making them ill, is often more disabling than the attacks themselves. According to the American Migraine Foundation, 60% of people living with migraine also have clinical anxiety, and 25% have depression. More than half of people with Chronic Migraine (more than 8 migraine affected days per month) have depression. For those who have their mental health well managed, there is still the burden of having to always adjust and control your environment, having to catch up for work not done during attacks, and/or the stress of needing to conceal and cover for your condition because of the pervasive stigma that 'migraine is just a headache'.

Like Autism, migraine is a spectrum disorder with a variety of presentations and differing levels of individual capacity to participate in the wider community. People with migraine move up and down the spectrum during their lives. Some normal adjustment points related to hormonal changes, and changes in diet or lifestyle, can make attacks better or worse. For many, the decline from a condition they barely thought about to severe and frequent migraine attacks can be rapid. And, as only about 20% of people with migraine have proper medical care for their condition, there is a significant adjustment and learning curve at each change point, similar to the impact of a new diagnosis.

Migraine is a Spectrum



Everyone who lives with migraine has their own unique experience. Some are completely debilitated and require care; some are rarely bothered by it; most are somewhere inbetween. And all will move up and down the spectrum throughout their lives.



We acknowledge that for many, including many who live with migraine, the idea of 'a headache' being a disability can be quite confronting. There is a concerted effort from

migraine patient bodies around the world to have migraine recognised as a disability and a spectrum disorder that is lived with all the time, and not just a headache. The WHO Global Burden of Disease Study found migraine to be the sixth most disabling condition in the world, and the number one cause of disability for people under 50.

There are few reliable statistics on migraine in Australia, but under freedom of information, the Department of Human Services (as it was then known) advised there are 14,176 Australians on Disability Support Pension (DSP) in part or whole because of migraine. This is 2% of the entire DSP case load, and less than 1% of the number of Australians living with migraine. However, many people who would be eligible for DSP never apply because they believe the Government does not consider migraine a disability.

There are four sub-types of migraine that are particularly disabling:

- **Migraine with brainstem aura**, also called brainstem migraine and previously basilar type migraine, is a rare and serious sub-type that causes difficulty with vision, speech, and loss of consciousness. In rare serious attacks patients can slip into a coma or require significant medical intervention, including time in ICU. Because of the loss of consciousness that can strike at any moment, brainstem patients are often told not to drive, swim or take a bath, and may require around the clock care.
- **Hemiplegic migraine** is a serious sub-type which presents with stroke like symptoms. Weakness and numbness down one side is common; facial droop, difficulty speaking, and in rarer cases paralysis generally warrant a trip to emergency to rule out a stroke. Paralysis or motor weakness can last for days, weeks and even months. Some require rehabilitation to recover from attacks, and may require regular ongoing care and therapy. Rare cases can include symptoms more commonly associated with Brainstem presentations, including coma.
- **Vestibular migraine** is a serious subtype that presents with persistent dizziness and vertigo, but rarely headache. Severe motion sickness and vomiting is common. This subtype may make people house bound, and in some cases bed bound, as well as prone to injury from regularly falling down. Many require ongoing care, home modifications, walking or balance aids, and regular physical therapy.
- **Abdominal migraine** is a rare and serious subtype of migraine that presents with acute abdominal pain, with diarrhoea, nausea and vomiting, but no headache. The related

condition cyclical vomiting syndrome is where the vomiting simply will not stop and usually requires hospitalisation. Abdominal migraine is more common in children, often transforming to headache migraine subtypes in puberty, but can persist into adulthood. Abdominal migraine differs from most other types as it is simply impossible to work through it, or persist in whatever task you were doing when the attack hits, regardless of how severe the attack is: you simply must go to the bathroom, often for considerable lengths of time.

These four sub-types of migraine should always be considered significantly disabling, regardless of the frequency of attack, because in addition to the actual attack, there is often significant physical impairment, a long recovery time, and a significant fear of attack. These factors necessitate some level of withdrawal from a full and contributing life, or physical limitation that prevents ordinary activities. Additionally, it is possible to have more than one of these subtypes at the same time: two of the founding members of Migraine Australia have both brainstem and hemiplegic migraine.

Migraine and the NDIS

Despite the obvious physical limitations and genetic nature of the disorder, the NDIA does not consider any type of migraine to be permanent, let alone a disability.

While a small proportion of the overall number of people living with migraine, many people living with the above migraine subtypes and chronic migraine who were debilitated enough to require care have applied to the NDIS. Most that we have been in contact with have had their applications denied.

While some managed to qualify on some of the criteria with admission that they did live with significant disability, the primary reasons for denial have been not meeting:

- Section 24(1)(b) of the NDIS Act, which requires that you must have an impairment which is permanent, or likely to be permanent; and,
- Section 24(1)(e) of the NDIS Act, which requires that you must be likely to require support under the NDIS for your lifetime.

Migraine is a genetic condition: it cannot be considered anything other than permanent.

And, while we would like for everyone living with migraine to be able to manage their condition to a point where they will not endure frequent attacks, this is still a lifelong challenge. As noted above, people with migraine move up and down the spectrum during their life, but they will always be on the migraine spectrum the way someone with Autism is also always on the spectrum.

Migraine Australia disability survey

To reinforce the anecdotal reports, we conducted a survey of 203 members in our Facebook Support Groups. While not a representative sample of everyone living with migraine, it gives a good indication of the scale of the problem. The survey found:

- 43% were unable to work or study because of migraine
- Only 24% work full time
- 25% report having lost their job as a direct consequence of the severity of their migraine, with more reporting being bullied, threatened or demoted at work because of their migraine.
- 20% applied for Newstart assistance, and more than a third of those had medical exemptions from mutual obligation activities.
- 22% had applied for Disability Support Pension, but only half were successful.

The reasons given for rejection of DSP application were often that migraine was not a disability, or was not a permanent disability. A number of respondents appealed the rejection:

“My first application was denied. I appealed and went through a reasonably lengthy process. I attended a tribunal hearing at which time the judge(?) was quick to advise Centrelink that I was definitely entitled to DSP based purely on my migraine.”

“I was initially assessed as not meeting criteria as daily migraine alone was not considered severe enough. It was only when comorbid conditions were fully considered that my appeal was successful.”

A number of respondents also indicated they had been told by Centrelink staff not to apply for DSP, or felt that staff didn't take migraine seriously:

“Even though I have been on Newstart for some time I have not applied for the disability allowance as staff at the Centrelink office actively dissuaded me...”

“Any time I’ve applied for any Centrelink payment and asked if I suffer any medical issue I note migraine and it’s never taken seriously.”

One odd anomaly appeared through the results: three respondents were denied DSP because migraine is not permanent, but were then denied medical exemption and forced to participate in mutual obligation activities for Newstart because their migraine was a permanent condition. This issue has been raised with the Minister.

Similar to the sentiment around DSP, only 15 respondents had applied to the NDIS, with others who would be eligible believing migraine is not a qualifying condition, or having been actively discouraged from applying.

“I didn't apply for the NDIS as I was told I was not disabled enough with my chronic migraine disorder or disability even though I cannot get out of bed on a daily basis, cannot look after my children, cannot clean my house, and cannot cook...”

“GP considers it a waste of time applying as applications are not approved. Too much trouble when it appears to be an automatic knock back.”

All of those 15 NDIS applicants had supporting information from multiple treating doctors and specialists. Only three applicants were assessed as eligible for NDIS support. Every one of those three had to appeal an initial rejection, or had to emphasise other conditions enabling them to qualify for the NDIS.

The mental health impact and other concerns

As migraine is a variable condition the NDIS should provide the answer to the variable needs for care and support. To have all of us denied support because the NDIA believes our genetic, incurable condition is not permanent, is difficult to process.

As the committee is no doubt aware, this issue is a greater problem for those who have lost state disability supports, and fallen through the ‘NDIS gap’. We have significant concern for the wellbeing of several people in our community in demonstrable need of care, who have been without any support for some time now. For some, their lives are routinely put at risk.

Others have had their condition significantly worsen because of the lack of support. Some have moved to another State to get the support they need to survive.

New medications have become available in the last two years that can significantly assist in the management of migraine. While these new medications will not eradicate migraine related impairment and disability, they would go a long way to reduce the demand of people living with migraine on disability supports. However, they have not been listed on the PBS, with a clear signal from the Pharmaceutical Benefits Advisory Committee that they do not believe managing migraine is worthy of tax payer money. The first of these new medications, Aimovig, has been withdrawn from the PBS process by Novartis because of the attitude of the PBAC. While the PBAC is beyond the remit of this committee, it is important to understand the context that this adds insult to the injury of wholesale NDIS rejection, and the 'NDIS gap' issue. We cannot get the drugs to manage our condition, we cannot get the necessary care and support to manage our condition, we are simply left out in the cold. These factors combined are causing many in our community to become depressed, and even suicidal.

Recommendations

These recommendations are reflective of where we are as a community. While we want a management plan, comparable to that covered by the NDIS for our sister disorder epilepsy, currently such a plan does not exist. And, as a very new organisation, Migraine Australia does not have the funding or resources to create it. Thus, the following recommendations are what we need to set the groundwork, and stop people from being abandoned without support in the interim.

1. **Develop a definition of migraine to be used throughout the Government which acknowledges it is a permanent, genetic, and serious neurological spectrum disorder.** As patients, we should be forced to constantly explain what migraine is, and protest that it is not 'just a headache', nor in anyway temporary. We shouldn't have to pray for luck that the individual assessor that we get understands migraine. There should be one common understanding throughout the system.
2. **Add migraine to the 'List B' conditions.** To remove any debate or dispute about what migraine is, and whether it is a disability, it would be helpful to have it on the list.

While the particularly disabling subtypes noted above are the most likely to apply, we do not recommend listing the subtypes as we will then descend into further debates about definition and diagnosis.

3. Add migraine to the 'List D' conditions.

Migraine can be very debilitating in children, and can severely affect their development and socialisation from a young age. We often hear stories of children with migraine missing up to half of the school year. Early intervention and support is crucial to help them, their family, and their school, adjust to what is necessary to manage their migraine.

4. Review all rejected migraine applicants.

As noted, most people with migraine who have applied for support from the NDIS have been rejected because of the argument that migraine is not permanent. We would like all migraine cases that have been rejected on those grounds to be reviewed.

When we complete the Migraine Management and Action Plan, which we expect will take about a year, we would appreciate that being covered by the NDIS as similar management plans are for other disabilities.

Thank you again for this opportunity. We are happy to answer any questions the committee may have, and attend a hearing to give further evidence.

Sincerely,

Raphaella Crosby

On behalf of Migraine Australia