Myalgic Encephalomyelitis
Chronic Fatigue Syndrome
and Lyme Association of WA

ME/CFS and Lyme Association of WA, Inc.
The Centre for Neurological Support
The Niche, 11 Aberdare Road
Nedlands WA 6009
www.mecfswa.org.au

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National Disability Advocacy Program
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Review of the National Disability Advocacy Program (NDAP)

Thank you for the opportunity to provide a submission. Since 1997, our organisation has been assisting individuals in Western Australia (WA) who are suffering from Myalgic Encephalomyelitis and/or Chronic Fatigue Syndrome, commonly abbreviated as ME/CFS.(1) Recently we have expanded to also assist people who are diagnosed with a Lyme-like illness.

Our patient community is often neglected in disability advocacy and funding, with many not meeting assistance criteria as well as perhaps needing far more individualised assistance than what is generally available to them. This submission answers selected questions being asked in the NDAP discussion paper.

We have also included some quotes provided by members of the local WA patient community, which we hope will lift their voices and concerns to a national level. There is no doubt that disability advocacy is of the utmost importance, and we hope that all of the submissions received as part of this NDAP review will pave the way forward for all.

> “I am extremely thankful for the advocacy that I have received - without it things would have been much worse.” - WA patient

> “I am disappointed that myalgic encephalomyelitis and chronic fatigue syndrome, along with chronic illness related to borrelia bacteria such as Lyme disease or a Lyme-like illness, are not considered truly disabling. For many patients these are more disabling than multiple sclerosis and other conditions that receive funding and assistance.” - WA patient

There are many patients out there asking questions and so are we, such as:

Will ME/CFS patients within Western Australia and nation-wide be included in NDAP and NDIS funding and access, or will people with ME/CFS be left to advocate for themselves?

ME/CFS is:

- **primarily a physical impairment;**
- **permanent for some people and for others takes up a significant numbers of years of their life;**
- **results in reduced mobility; and**
- **patients have a need for ongoing support.**

"The target group for advocacy support provided by NDAP agencies, as required under section 8 of the DSA, consists of people with disability that:

a) ‘is attributable to an intellectual, psychiatric, sensory or physical impairment or a combination of such impairments;
b) is permanent or likely to be permanent; and
c) results in:
  i) a substantially reduced capacity of the person for communication, learning or mobility; and
  ii) the need for ongoing support services."

Source: Department of Social Services (2)

Myalgic Encephalomyelitis (M.E.) is characterised by post-exertional neuroimmune exhaustion with long recovery periods, neurological impairments, immune and gastrointestinal impairments, and energy production/transportation impairments. Symptoms are debilitating, and may include difficulty processing information, short term memory loss, pain, sleep disturbance, muscle weakness, flu-like symptoms, susceptibility to infections, cardiovascular-, respiratory-, or thermostatic issues, and sensitivities to food, odours and chemicals.(3)

Myalgic Encephalomyelitis refers to a specific pathophysiology, and is classified by the World Health Organisation as a postviral syndrome under ICD-10 G93.3.(4)

Chronic Fatigue Syndrome (CFS) symptoms are much like M.E., but unlike M.E., this diagnosis doesn’t say anything about the underlying pathophysiology causing the illness.(5) Much research is still required to uncover all the underlying pathophysiologies that can cause CFS, but the good news is that some potential causes and contributors are being found.

The discovery of Lyme-like illness in Australia has proven to be a very significant finding for the ME/CFS community, as it has opened up an important new avenue for investigation.

> “ We've documented, as have others, that the level of functional impairment in people who suffer from CFS is comparable to multiple sclerosis, AIDS, end-stage renal failure, chronic obstructive pulmonary disease. The disability is equivalent to that of some well-known, very severe medical conditions. ”
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> *Dr. William Reeves - former Chief of the Chronic Viral Diseases Branch at CDC, speaking at a 2006 CDC press conference about CFS.*

Prevalence of CFS in Australia

There isn’t any consensus on the prevalence of CFS as there is no diagnostic test for CFS, and criteria for diagnosing CFS clinically vary. Estimates include:

- RACP Guidelines on CFS (2002) estimates “The prevalence of CFS in the community is 0.2%-0.7%.”(6)
- A meta-analysis on prevalence of ME/CFS by Johnston S et al (2013) found a prevalence of about 0.76% for clinical assessment.(7)
- International Consensus Guidelines for Myalgic Encephalomyelitis (2012) report a worldwide prevalence of M.E. of ~0.4% to 1.0%.(8)

With a population in Australia of about 24,000,000(9), we can estimate that the prevalence of ME/CFS in Australia is somewhere between 0.2% (48,000) and 1.0% (240,000).

NDAP discussion paper

The NDAP discussion paper raises many important questions that need to be answered, and we are pleased to see a variety of organisations putting in a submission. Our submission will address the following questions that are relevant to us:

> 2) Improving access to advocacy supports
> 2.1) How do we improve access for people with disability in rural, regional and remote locations?
> 3) Improving the advocacy evidence base and coordination on systemic issues
> 3.1) What mechanisms could be used to ensure information on systemic issues gets to the right people and organisations?
> 3.2) How can we help disability advocacy organisations work with a wide range of other organisations with similar aims?
> 4) The interface with the NDIS
> 5) Understanding and improving access to justice

2) Improving access to advocacy supports

Many patients rely on their partners or families to care and advocate for them, while others are not so lucky and need to care and advocate for themselves.

Cognitive impairment and memory problems, as well as lack of energy to handle multiple things at a time can all severely impact on a person's abilities to seek out advocacy services and assistance.

As funding for Home and Community Care (HACC) is now primarily for those who are older, many adults and younger people with ME/CFS are missing out on important assistance.

> "I have had Silver Chain clean my house each week since 2007. This has been the one thing that has helped my health and my family. I am still receiving home help but am no longer able to be reviewed by Silver Chain or HACC. If I required extra help they would not be able to do anything for me at present." - WA patient

It is important that people with a disability or illness who are in school or university also have access to independent advocacy support not connected with where they are enrolled.

> "As my condition worsened during my university studies, I decided to seek out help from the on campus disability services provided to students. The staff had no knowledge of my condition and did not know how to help me. Even though CFS is a recognised condition in Australia, there are no services provided to students seeking to better themselves in higher education. Unless you are in a wheelchair, disability services does not seem to know what to do with you. Unfortunately, I have been forced to withdraw from my course since then, as the physical exertion required to come into campus just one day a week became too much, and I had no help in managing my workload." - WA patient

2.1) How do we improve access for people with disability in rural, regional and remote locations?

People with a disability in rural and remote areas would benefit from funded appointments and sessions with advocacy, legal, and medical services by phone or internet. Patients can be too disabled to travel to the city for appointments, or not have the funds to do so, and can therefore be disadvantaged and delay or cancel seeking out any help.

> "It would be nice if people like me with disabilities and ME/CFS could receive Medicare funded in-home medical appointments, as well as Skype or phone appointments with doctors. It is very difficult to see my doctors sometimes and people with disabilities should be able to see their own doctor from the comfort of their home, at no cost. It is even more important that it be Medicare reimbursed, as many people with disabilities are unemployed and on welfare payments." - WA patient

3) Improving the advocacy evidence base and coordination on systemic issues

3.1) What mechanisms could be used to ensure information on systemic issues gets to the right people and organisations?

Our organisation would like to see ME/CFS, and separately Lyme-like illness, both included in statistics and data points collected by NDAP agencies and also the NDIS.

At present there is no formal communication or datasets from a national level being relayed to state based ME/CFS organisations. State organisations like ours are finding out issues and statistics from in-house surveys and communications within the patient community.

This disconnect means that advocacy agencies are not being provided adequate information on how they can best help the individuals they are there to assist. Likewise, patients have limited knowledge of who and where to seek assistance and advocacy from.

3.2) How can we help disability advocacy organisations work with a wide range of other organisations with similar aims?

Regular forums and focus sessions could be run by NDAP and other agencies, where state advocacy agencies and patient support organisations like ours could all sit down to discuss issues.

Patients and their carers could also be invited. Issues could be identified from the ground up, and ensure a larger demographic of people are included when trying to identify any shortfalls.

4) The interface with the NDIS

> "I have been knocked back by NDIS because of the type and amount of assistance I am receiving. They said if I had been diagnosed with multiple sclerosis I would have been accepted." - WA patient
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> "There are sufferers around me who cannot even sit upright in bed, and I doubt that NDIS would consider them as being eligible for any help. There is so much stigma and non-inclusion with these illnesses and lack of government funding, and I find it really unfair how the system has left us behind just like it did with AIDS sufferers once upon a time in history." - WA patient

5) Understanding and improving access to justice

Legal advocacy is urgently required for people with ME/CFS to assist them toward dealing with Centrelink and the Appeals Tribunal. Our organisation receives - as well as sights - many requests for help with dealing with Centrelink and dealing with the process following being declined for the Disability Support Pension (DSP).

Assistance in navigating the Centrelink system, including meeting the requirements for benefits such as Sickness Allowance and the DSP are urgent, with the DSP being a very complex process due to the restrictive nature of the criteria and the need for appropriately targeted medical reports.

As Centrelink frequently rejects the medical evidence provided by a patient's general practitioner in their DSP application, the patient is then put in the position of needing an advocate or advocacy agency to assist them with an appeal.

When a person is applying for DSP, they are generally not in a good financial situation or have used up their savings. This means they are unable to afford to seek costly legal advice.

> "I receive no in-home help or assistance, and am put under psychological stress from the government in having to prove that I am disabled enough for welfare. Where am I supposed to go to receive help for welfare appeals and legal assistance, when most people out there (other than my doctor and other patients) do not know anything about my medical situation and how disabling it is?" - WA patient

About this submission

This submission was written by volunteers who suffer with these illnesses themselves.
The Association wishes to thank all those who assisted.

Quotes have been used with permission, and were provided by both members as well as patients located in Western Australia who have all been diagnosed with ME/CFS, and some with Lyme-like illness. Names have been redacted to respect their privacy.

Enquiries regarding this submission or any assistance that can be provided in response to any of the items raised within this submission can be emailed to info@mecfswa.org.au

References

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[1] In Australia, many practitioners do not differentiate between Myalgic Encephalomyelitis and Chronic Fatigue Syndrome. This is why in Australia the combined name of ME/CFS is currently used.

[2] https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/national-disability-advocacy-program-ndap

[3] Myalgic Encephalomyelitis International Consensus Primer for Medical Practitioners.
http://mecfswa.org.au/UserDir/Documents/ME_International_Consensus_Primer_2012.pdf

[4] http://apps.who.int/classifications/icd10/browse/2016/en#/G90-G99

[5] http://www.nightingale.ca/index.php?target=whatis

[6] Chronic Fatigue Syndrome Guidelines from the Royal Australasian College of Physicians
https://www.mja.com.au/journal/2002/176/9/chronic-fatigue-syndrome

[7] The prevalence of chronic fatigue syndrome/ myalgic encephalomyelitis: a meta-analysis.
http://www.ncbi.nlm.nih.gov/pubmed/23576883

[8] http://mecfswa.org.au/UserDir/Documents/ME_International_Consensus_Primer_2012.pdf

[9] http://www.abs.gov.au/AUSSTATS/abs@.nsf/Web+Pages/Population+Clock?opendocument