ME/CFS National Disability Agreement Review Submission

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1 Introduction

This submission is in answer to the Productivity Commission Issue Paper on the National Disability Agreement Review, dated July 2018.

It is estimated that Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS) affects 250,000 Australians. Of those 25% are severe or very severe and are housebound or bedbound. These severely and very severely affected sufferers require complex care and disability support services in order to maintain essential daily functioning and access to health care.

The ME/CFS and the NDIS Facebook group currently has 495 members. Many of our members fall into the severe or very severe category leaving them housebound or bedbound and unable to care for their daily living needs. Many of these people are struggling to access quality disability support from the NDIS, Aged Care Services or other Federal, State and Territory government services.

Australia is a signatory to the United Nations Convention on the Rights of Persons with Disabilities. The United Nations states in Article 19: Living independently and being included in the community:[i]

> *States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:*
>
> *a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;*
>
> *b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;*
>
> *c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.*

The Issues Paper states:

> *The bilateral agreements supporting the NDIS delineate responsibilities for services to those found eligible for the NDIS to be provided within the scheme and in mainstream services, and set out requirements for continuity of supports for those currently receiving specialist disability services who are not eligible for the NDIS. The bilateral agreements also state that, unless otherwise agreed, the responsibility of governments to provide services to people not covered by the NDIS remains.*

Whilst those who are currently on disability services are able to transition to the NDIS easily, those who are not receiving supports or are receiving supports not listed on the C List are having immense issues accessing the scheme.

Unfortunately, for many ME/CFS sufferers, they are being shut out of government services such as NDIS and Aged Care for Under 65s and are therefore denied their right to a range of in-home, residential and other community services. They are losing the personal assistance they need to support living and including in the community and to prevent isolation or segregation from the community.

In particular, this submission seeks to address the disability support needs of people with severe and very severe ME/CFS and demonstrate where these needs are not currently being met by the Commonwealth, State and Territory governments, in particular where they are left without access to a range of in-home, residential and other community support services.

2 Recommendations

We recommend that the National Disability Agreement address the following in their policy reform:

1. People with significant functional disability are falling through the cracks. There needs to be clear policy on who will fund disability supports if an applicant is found ineligible for NDIS. Policy needs to stop the referring of an applicant to another government service that does not provide that support, i.e. referring an applicant to the Health system to fund disability supports when the Health system clearly does not provide that functionality.

2. The purpose of the NDA should be to ensure that all people with a disability get the rights afforded to them under the United Nations Article 19: Living independently and being included in the community, namely that they have:

   - the opportunity to choose their place for residence and where and with whom they live;
   - access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community; and
   - access to Community services and facilities for the general population on an equal basis to persons with disabilities and are responsive to their needs.

3. The scope of the NDA should continue to cover all people with disability, especially those who are not picked up by NDIS or Aged Care schemes. It should cover all specialist disability services and/or mainstream services, and include mental health, healthcare, aged care, education, transport, housing and justice.

4. The NDA objectives, outcomes and outputs need to be achievable for all people with a disability and not just those who are deemed eligible for NDIS or Aged Care schemes, namely:

   - people with disability and their carers have an enhanced quality of life and participate as valued members of the community;
   - people with disability achieve economic participation and social inclusion;
   - people with disability enjoy choice, wellbeing and the opportunity to live as independently as possible;
   - families and carers are well supported;
   - services that provide skills and supports to people with disability to enable them to live as independently as possible;
   - services that assist people with disability to live in stable and sustainable living arrangements;
   - income support for people with disability and their carers; and
   - services that assist families and carers in their caring role.

5. The NDA objectives, outcomes and outputs should be measurable and achievable within a certain period to ensure that venerable Australians are not left without adequate services.

6. The NDA needs to set clear policy to ensure that the States continue to provide specialist disability services in addition to mainstream services.

7. The NDA needs to set policy around Local Area Coordinators (LAC) and ILC funding to ensure that those found not eligible for NDIS are given adequate information on disability services that they can access.

8. The introduction of NDIS has impacted considerably on those with ME/CFS who are not eligible for NDIS. This already marginalised, isolated and venerable community has been shoved from NDIS to Health to Aged Care and their needs have not been validated in the process. The NDA needs to assign responsibility for service gaps between the Federal and State governments so that cohorts such as these are not left without services.

The following sections give an understanding to the issues faced by people suffering ME/CFS when trying to access government disability and health supports.

3 What is ME/CFS

Myalgic Encephalomyelitis (ME), also known as **Chronic Fatigue Syndrome (CFS)** or **ME/CFS** is a chronic, inflammatory, primarily neurological disease that is multisystemic, i.e. affecting the central nervous system (CNS), immune system, cardiovascular system, endocrinological system and musculoskeletal system. It has been classified as a neurological disease by the World Health Organisation (WHO) since 1969 (ICD- code: 10 G93.3[ii]).

The diagnostic criteria for ME/CFS can be found in Section 9 of this submission.

Post-exertional Malaise (PEM) is a cardinal feature of ME/CFS. It is a pathological inability to produce sufficient energy on demand with prominent symptoms primarily in the neuroimmune regions.[iii]

The level of exertion involved in triggering PEM will vary depending on the severity of the individual. The more severe the ME/CFS, the less exertion it takes to trigger PEM. In severe cases, the exertion that triggers PEM may be as simple as taking a shower or walking. In very severe cases it can be as simple as having a conversation or brushing teeth.

Persistent or repeated exertion may lead to a deterioration of health and greater functional decline. Acute exercise can negatively impact neurophysiological processes in ME/CFS contributing to an exacerbation in symptoms including fatigue, headaches, muscle aches, cognitive deficits, insomnia, and swollen lymph nodes.

ME/CFS is often a relapsing-remitting disease with new symptoms occurring either in discrete relapses (or “crashes”) or accruing over time.[iv] The *National Organization for Rare Disorders* (NORD) states: "Symptoms and their severity can fluctuate over the course of the illness, even from hour to hour."[v] The US National Institutes of Health notes that sensitivity to noise, light and chemicals may force patients to withdraw from society.[vi]

Symptom Severity and Impact

For a diagnosis of ME, symptom severity must result in a significant reduction of a patient’s premorbid activity level[vii].

- **Mild** (meet criteria, significantly reduced activity level),
- **Moderate** (an approximate 50% reduction in pre-illness activity level),
- **Severe** (mostly housebound), or
- **Very Severe** (mostly bedridden and needs help with basic functions). Those who are very severely affected are too ill to attend regular medical appointments.

Approximately 25% of people with ME/CFS fall in the Severe and Very Severe categories and have severely impacted functional capacity. Those at the severe end in terms of symptoms, can remain housebound or bedbound for months or years.

Being severe and housebound means leaving the house is either impossible, or cause major triggering of PEM symptoms, that the person can only go out less than once a week on average.

Being very severe and bedbound means the individual must spend all, or nearly all their time lying in bed. This may or may not include being able to leave bed for toileting, bathing, and some other minor activities.

It is also important to note that there can be a marked fluctuation of symptom severity and hierarchy from day to day or hour to hour.

ME/CFS can cause profound disability in those affected, and affects many aspects of life. In the young, for example social and school life can be severely impacted. In those of working age, many are unable to maintain employment due to their illness. Social and family life is often drastically restricted which causes strain on relations. As a result, many lose contact with pre-illness friends and non-supportive family members.

A person with ME/CFS may be able to do an activity one day, but not be able to repeat it the next day. If they do repeat it the next day, it may take considerable time to recover. An example would be a shower:

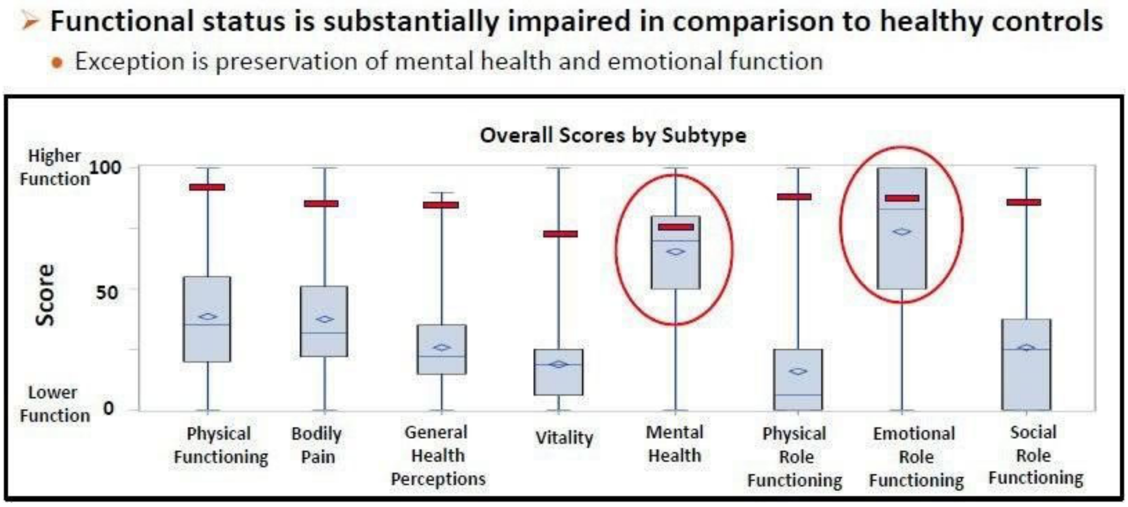
- A person with Severe ME/CFS may have a shower, however they may need to rest for considerable time afterwards and may not be able to undertake another activity such as leaving the house for a medical appointment. They may not have the energy to have another shower for two to three days.

- A person with Very Severe ME/CFS may need to be sponge bathed, and even that level of activity would need to be carefully managed as sensory input may cause post-exertional malaise.

4 Why people with Severe and Very Severe ME/CFS need Disability Services

ME/CFS results in significant impairment in those who experience it, especially those with Severe and Very Severe ME/CFS.

A recent study found that people with ME/CFS have poorer quality of life than people with other serious, disabling conditions such as diabetes, cancer, angina, heart attack, rheumatoid arthritis or lung disease[viii]. Dr Elizabeth Unger (Chief of the Chronic Viral Diseases Branch of the Centers for Disease Control (CDC)) presented data from the CDC's multisite study of ME/CFS[ix], indicating that people with ME/CFS have lower overall functioning compared to healthy controls (the exceptions being mental health and emotional functioning), which were within normal limits:



➢ **Functional status is substantially impaired in comparison to healthy controls**

- Exception is preservation of mental health and emotional function

(Source: Dr Unger's presentation, CDC Grand Rounds, Feb 2016).

The Disability-Adjusted Live Year (DALY) Weights for Chronic Fatigue Syndrome (Estimated using EQ-5D+ regression model)[x] are:

- Mild handicap 0.137
- Moderate handicap 0.449
- Severe or profound handicap 0.760

In comparison, the DALY weights for MS are:

- Relapsing-remitting phase 0.330
- Progressive phase 0.670
- Progressive from onset 0.670

MS is included on List B of approved conditions for NDIS, because the condition can cause significant functional impairment, but not in every case. Further assessment is required to determine the impairment for each individual.

ME/CFS is more disabling than MS when at its most severe as evidenced in the DALY scores, yet it has not been included in List B, making access to the NDIS significantly more challenging for sufferers.

People with severe to very severe ME/CFS require assistance in the following areas:

1. **Personal Care.** Depending on the severity of symptoms people with ME/CFS may need assistance with personal hygiene, washing, showering, bathing, dressing, feeding and toileting.

2. **Assistance with Shopping and Food preparation.** Where a person with ME/CFS is able to leave the house, they may need assistance with getting to and from shops and with the shopping process. If the person is unable to leave the house to do the shopping then they may need someone to do their shopping for them.

   People with ME/CFS may need assistance with food preparation as they often have trouble with cutting up vegetables, or being able to be upright and expending energy for the time required to prepare meals.

3. **Home Care.** People with ME/CFS need assistance with cleaning the house or looking after the garden as people they are not physically able to do these activities. The act of doing such domestic duties can bring on PEM and deterioration of their overall condition.

   The emphasis of this assistance should be to conserve the energy of the person receiving the services, rather than assisting them to take on a more active role. This will allow the person with ME/CFS to make gains in their physical health.

4. **Allied Health.** Whilst there is currently no cure, nor any effective treatments for ME/CFS people living with the condition may benefit from the services of Occupational Therapists, Physiotherapists and Psychologists in helping them manage their condition. Whilst these services may be helpful, accessing them is difficult for those who are severely unwell (see Section 6.1)

5. **Mobility and Assistance equipment and home modifications.** Depending on the severity of the person's condition, they may benefit from equipment such as hospital beds, hoists, lift chairs, wheelchairs, scooters. There may also be the need for low risk equipment and consumables, i.e. feeding tables, incontinence products etc.

   There may also be a need for home modifications for wheelchair access or bathrooms for assisted access.

6. **Community participation.** Where a person with ME/CFS is able to leave the house, assistance with community participation may be required to enable social interaction and improve wellbeing outcomes.

7. **Mobility and Transport.** Where a person with ME/CFS is able to leave the house, assistance with mobility and transport may be required. This may involve complex

transfers by ambulance for medical appointments for those who are bedbound to ensure that they can receive quality medical care.

Many also require assistance with transport as they are unable to drive or catch public transport. This may involve taxi services or carer provided transport.

5 Applying for NDIS with ME/CFS

In a survey of 88 people in the ME/CFS & the NDIS Facebook group the following was observed:

- 53.5% (47) had not applied for the NDIS because there were either too ill or found the application process too hard and too stressful.
- 17% (15) had given up during the application process after rejection because they were too ill or found the review process too hard and too stressful.
- 4.5% (4) were in the process of appealing an internal review and a further 4.5% (4) were appealing at AAT
- 6.8% (6) were preparing their access request and a further 4.5% (4) had submitted their access request and was awaiting a response.
- 4.5% (4) had received a plan, with a further 3.4% (3) being accepted under existing supports listed in the C List Funding program
- 1.1% (1) was in an area where roll out had not yet occurred. Most of the people with ME/CFS who have apply for NDIS have been rejected.

The general consensus from members was that ME/CFS claims are almost always rejected, regardless of impairment. There was also a sense that the NDIA draws out the application process, through legal processes like AAT, in the hope that the applicants will give up on the process.

The reasons that these members had been rejected have been varied:

- ME/CFS is considered medical and not a disability
- Not completed recommended treatment – CBT/GET
- Not considered permanent
- Not considered substantially functionally impaired

5.1 ME/CFS is considered medical and not a disability

In many cases, the staff at the NDIS have ignored specialist reports and declared that ME/CFS is a medical condition and that it is best treated within the health system. Unfortunately, as outlined in Section 4 of this submission, people with ME/CFS need long term assistance with daily living. Such assistance is not provided by the health system.

Since 1969, the World Health Organisation has classified ME/CFS as a neurological condition. It falls into the same family of conditions such as MS and Parkinsons both of which are covered under the B List of the NDIS.

To date, calls to add ME/CFS to the B List have been rejected on the basis that some people recover from ME/CFS, and therefore ME/CFS is not a permanent condition. However, this is contradicted by scientific evidence, which shows that recover rates are low. In addition, we know that many who appear to have recovered, may actually be in remission, as ME/CFS can take a relapsing-remitting course (as it does for some with MS).

There are also known issues with recovery rates in ME/CFS, as the studies that have been done have included people with “Chronic Fatigue” as well as those with “Chronic Fatigue Syndrome”. Chronic Fatigue is a symptom can be caused by depression, post viral illnesses, cancer and other conditions. Once those conditions are treated, the Chronic Fatigue symptom disappears. With Chronic Fatigue Syndrome, sufferers have the symptom of Chronic Fatigue. There is no know treatment that is effective for Chronic Fatigue Syndrome and therefore the symptom Chronic Fatigue remains.

5.2 Not completed recommended treatment – CBT/GET

The recommended treatment in Australia for ME/CFS is Graded Exercise Therapy (GET) and Cognitive Behavioural Therapy (CBT). This recommendation was made based on discredited research conducted in the UK in 2011.

These recommendations are now outdated. Around the world, recommendations for GET and CBT are being removed from clinical guidelines, in keeping with biomedical research which has emphasised the metabolic and energy production issues found in ME/CFS.

For example, the US Centers for Disease Control and Prevention (CDC) has removed all recommendations for GET and CBT from their website and has indicated that *“While vigorous aerobic exercise can be beneficial for many chronic illnesses, patients with ME/CFS do not tolerate such exercise routines. Standard exercise recommendations for healthy people can be harmful for patients with ME/CFS”.* Similarly, the UK is in the process of reviewing the NICE guidelines due to the potential for harm that GET can cause those suffering from ME/CFS..

Unfortunately, in Australia, we are still insisting that people applying for NDIS or the Disability Support pension undergo these potentially harmful treatments.

Patient surveys routinely find a significant majority who report experiencing harm from GET. In surveys by the Norwegian, British and Dutch ME Association, between 63% and 74% of more than 3000 patients reported harm. These data confirm the conclusions of a number of studies that patient health was negatively affected by CBT and GET, including one that found that in 82% of patients with severe ME their symptoms were made worse by GET.

It should be noted that, whilst these studies do not find that all patients report harm, there is consistently a significant majority who do. There is currently no means of determining which patients will be harmed by GET treatment, thus blanket recommendations for GET represent a high risk of harm to people with ME/CFS.

Consequently, we should stop using CBT and GET as (compulsory) treatments for ME/ CFS to prevent further unnecessary suffering inflicted on patients by physicians, which is the worst of all harms, yet totally preventable.

It has also been acknowledged by one of Australia's ME/CFS specialists that has a clinic that uses GET and CBT treatments that they are "somewhat helpful" but he also concedes the treatment "doesn't help everybody".[xi]

The NDIS guidelines on treatments state that a recommended treatment should be based on proven evidence and have a high success rate. If GET and CBT are "somewhat helpful', have such low success rates, and not based on proven evidence then these do not prove these conditions. The potential for harm should also preclude GET and CBT from being a required treatment in order to receive government disability support.

5.3 Not considered permanent

Rule 5.4 of the NDIS legislation establishes that an impairment "is, or is likely to be, permanent only if there are no known, available and appropriate evidence-based clinical, medical or other treatments that would be likely to remedy the impairment.[xii]

In Mulligan v NDIA[xiii], the AAT affirmed Rule 5.4 "provides that an impairment is, or is likely to be, permanent only if there are no known available and appropriate evidence-based clinical, medical or other treatments that would be likely to remedy it".

There is a universal view throughout practitioner, researchers and institutions alike that there is no known cure for ME/CFS nor CFS[xiv]. This view is echoed by the Better Health Channel (November 2017[xv]): "Scientists are starting to understand the biological causes of ME/CFS, although they have not yet found a prevention or cure. Genes appear to be a factor in many cases."

Baraniuk (2017)[xvi] affirmed the view on cure, stating: "Longitudinal studies indicate that 17% to 64% of patients improve with treatment; however, less than 10% meet criteria for full recovery, and up to 20% of patients may worsen over time".

The term 'recovery' means the "return to premorbid functioning"[xvii], hence is the equivalent of "cure". Vink (2017)[xviii] affirms this view, stating:

> *... if an ordinary person was asked the meaning of recovery, the answer would be that all problems have gone and that health has returned to how it was before the illness. This was worded by Kennedy in the following manner: recovery "is the elimination of...symptoms and a return to premorbid levels of functioning" (Vink M. , 2017b, p. 4)*

Recovery, like cure, means a "return to health" or "rehabilitation in ME/CFS and CFS - it does not mean mere improvement.

The RACP (2002)[xix] guidelines deal with the issues of recovery from the symptoms of CFS. The symptoms of CFS caused the impairments (as demonstrated in 7.2.1 above) – ergo recovery is recovery from the impairments arising from the symptoms of CFS. With respect to permanence, the RACP assert the following global position with respect to CFS:

> *By contrast, full recovery in patients with established CFS is less common ... In an Australian study conducted in a specialist setting, 65 of 103 patients (63%) who had had*

> *symptoms for about five years reported abatement of symptoms and improvement in functional capacity over the next three years, but complete recovery was uncommon (6%) ... At the more severe end of the clinical spectrum, although improvement over time can occur, the prognosis for recovery is poor. Patients who have had CFS for more than 10 years are more disabled than those with shorter-duration illness, and have significantly more severe symptoms (particularly cognitive impairment) and more frequent symptoms of fibromyalgia...*
>
> *The notion of "permanent" disability is problematic, as most people with CFS improve gradually, and some eventually recover. In people who have been severely disabled and unable to work for more than five years, the probability of substantial improvement within 10 years is less than 10%– 20%. This may be regarded as "permanent disability" for medicolegal purposes. (Loblay, et al., 2002, pp. S 41-S42, S47)*

Improvement in functional capacity does not mean that impairment has ceased. The key take-away point of the RACP is that just 6% recovered. That means 94% of those in the study did not recover. Indeed, the RACP made it even clearer with respect to the 25% of patients in the severe end of the spectrum – "prognosis for recovery is poor". Substantial improvement occurs in just 10% to 20% of patients before 10 years – but again, that still means the patient has impairment.

5.4 Not considered substantially functionally impaired

In many cases, people with ME/CFS who have applied for NDIS have been rejected because they do not meet the substantial functional impairment criteria. The application of this criteria seems to be subjective and dependent on the assessor who is accessing the claim. People in the ME/CFS group have reportedly been told that a four wheeled walker is a common item, and if they use a walking stick, say on a good day, that they do not meet these criteria.

ME/CFS is a fluctuating condition. In rule 5.5 of Becoming a Participant Rules, it states that an impairment may be permanent notwithstanding that the severity of its impact on the functional impact of the person may fluctuate or potentially improve.

The NDIA also states in 8.3.1 of it's operational guidelines, that when considering whether a fluctuating or episodic impairment results in substantially reduced functional capacity to undertake relevant activities, the NDIA will consider the impact on the person's ability to function in the periods between acute episodes. What the NDIA is not considering is that the fluctuations between good days and bad days is a lessening of symptoms and not the absence of symptoms on a good day.

Several ME/CFS symptoms including fatigue, cognitive dysfunction, pain, sleep disturbance, post-exertional malaise, and secondary depression or anxiety may contribute to significant impairment or disability.

Patients with ME/CFS have been found to be more functionally impaired than those with other disabling illnesses, including type 2 diabetes mellitus, congestive heart failure, hypertension, depression, multiple sclerosis, and end-stage renal disease. Symptoms can be severe enough to preclude patients from completing everyday tasks, and 25-29 percent of patients report being house- or bedbound by their symptoms. Many patients feel unable to meet their family responsibilities and report having to significantly reduce their social activities. [xx]

This data, however, only include only patients who were counted in clinics or research studies, and may underrepresent the extent of the problem by excluding those who are undiagnosed or unable to access health care.

Rule 5.8(a) identifies that a substantial reduction in capacity results if the “person is unable to participate effectively in the activity, or perform tasks or actions required to undertake or participate effectively in the relevant activity due to their impairment, without assistive technology, equipment (other than commonly used items such as glasses) or home modifications” (National Disability Insurance Scheme, 2014c, p. 5).

In Sheldon and National Disability Insurance Agency, [2018] AATA 2560 (30 July 2018)[xxi], the applicant was found to have substantially reduced functional capacity due to his reliance on a stand assist recliner to sit in his home and a four wheeled walker or wheelchair to move outside his home environment. Both these items were found to note be “commonly used items”.

6 Issues faced by people with ME/CFS accessing NDIS, Aged Care and other Health and Disability Services

6.1 Housebound and Bedbound patients access to GPs and Specialists for reports

Obtaining the necessary medical reports to make a NDIS claim or access Aged Care for Under 65s can be difficult for people who are housebound or bedbound with ME/CFS.

Most people who are housebound or bedbound with ME/CFS have difficulty attending medical appointments. Some may be able to attend appointments if sufficient supports are provided (appropriate transport such as, somewhere to lie down while waiting, etc), but for most are unable to under almost any circumstances. Many medical or specialist clinics also do not offer the option of telephone or telehealth consultations.

For housebound or bedbound people with ME/CFS it is very hard to get continuity with GPs and specialists in order to get the reports required to access disability services such as NDIS and Aged Care. Most specialists will only write reports if they have seen their patient in the past year, and will not write a report unless they have seen the patient in person. This means that the people most in need of support from the NDIS or Aged Care are unable to collect the necessary documentation to access it.

Most General Practitioners or specialists have little idea of which of their patients are housebound or bedbound (or nearly so) because this is not a problem that doctors consider. Intake paperwork does not ask if a patient is housebound or bedbound.

If a chronically ill or disabled patient stops attending the surgery, there is no follow up to check whether that person needs home visits or telephone consultations. There is no Medicare incentive for tracking this knowledge. To the system, the homebound/bedridden patient remains simply invisible.

For the very severe, attending medical appointments may also need special travel accommodations, such as stretcher transfers to a hospital in order to access GP and specialist treatments. If the person lives in a rural setting, seeing a specialist in this setting is nearly impossible as most specialists are based in capital cities.

When the disability and healthcare needs of any population are not met there are impacts to the individuals involved as well as impacts on society in general. Some impacts to housebound and bedbound people whose healthcare needs are not met include:

- Reduction in overall health - an increase in morbidity and mortality.
- Inability to recover from minor setbacks - injuries or illnesses which are untreated or under-treated may become a new contributing disability rather than a temporary event.
- Capacity to do things at home is diminished – when all energy is spent accessing healthcare, there is a significant loss in capacity to reach out to people, to work, to study, to participate in family life.

- Social isolation becomes more severe as a result of increasing isolation - all of life becomes "smaller". This also causes mental health to decline even if there is no underlying mental illness.

- Those with episodic conditions find that they become constant because there is no access to the healthcare needed to reach the upswing of the cycle.

At the economic level, in the long term these things will inevitably cause increased medical costs, increased mental healthcare costs, and increased disability support costs. Having a family member who is housebound or bedbound also often means that at least one other family member is excluded from the paid workforce as they need to take a caring role.

6.2 Cognitive issues in understanding NDIS and Aged processes

Many people with ME/CFS have difficulty processing and retaining information. This often means that the individuals are unable to navigate the complexity of the application process alone and do not have advocacy/support to do so. Even with support, there are repeated examples across the country of people commencing applications but withdrawing due to what they experienced as a highly stressful and at times traumatising process.

There are many people with ME/CFS who have no knowledge or understanding of the scheme. They have turned to the ME/CFS & the NDIS Facebook group in desperation to understand what is required to navigate access the scheme.

This is particularly the case for those who live on their own and are isolated from the community. There is no funding for assertive outreach in order to engage and inform these hard-to-reach, yet most likely to meet NDIA eligibility criteria.

Many from this group of potential participants will need to hear the message about the NDIS several times before they absorb it and are prepared to engage with the NDIS.

More often than not, when a person with ME/CFS is denied access to the NDIS, they are not informed that they may also be eligible for the Aged Care for Under 65 package or informed how to access the Aged Care scheme.

6.3 People who were eligible for state disability services are not eligible for NDIS

The NDIS is not designed to cater for all disabilities, and instead focusses on those with substantial functional impairment and disability. The State disability services were available for a wider range of disability levels.

The States have needed to hand most of their disability funding to the NDIS but there is a gap left where people with less severe disabilities are left without services. This is especially true for people was not already receiving State disability services at the time of roll over into NDIS.

If the person was already accessing State disability services and those services are listed on the C List for NDIS, then they are automatically transitioned into the NDIS scheme. However, people who previously did not have State services are being left with no disability support services at all.

This is a considerable flaw in the disability system and needs to be addressed by NDA policies.

6.4 Long wait times for Aged Care Services

In most cases there is a 12-18 month wait for Aged Care for Under 65 packages. Whilst people are offered a lesser package in the interim, the wait times to receive the lesser packages are often 6-9 months as well. This means that after going through the process of applying and being rejected by NDIS, wait times can exceed two years to obtain any services.

6.5 Co-payment required for Aged Care Services

With the Aged Care system, a co-payment is required to access services. Whilst some providers waive or reduce these costs there are no guarantee that this will happen in every case.

A person under 65 with ME/CFS is a very different demographic than that of a typical elderly client. The Aged Care calculator is based on a typical elderly person who owns their own home, and has very little expenditure, whereas people with ME/CFS typically don't own their own home or if they do, may have a mortgage, have lots of medical and pharmaceutical expenses, and may have full time carers and dependents.

The Aged Care system is geared towards the elderly and not the younger disabled person.

6.6 Inadequacy of Aged Care for Under 65s scheme for those with a disability

Aged care is not easily compatible with the needs of clients with significant and profound disabilities requiring high levels of care. As stated in the Productivity Commission's 2011 report on Disability Care and Support[xxii], a key goal in the disability sector is "enablement"; that is, supports that go toward maximising the independence and social inclusion of individuals.

In contrast, the aged care sector focuses its supports on the end-stage of people's lives. As stated in the report's supporting documents: "Forward-looking aspects of life - like job opportunities, owning a house, and living independently from familial carers - are not targets for the aged care system."

The report's supporting documents, the Productivity Commission recognised that:

> *"... the kinds and persistence of disability presenting in the disability system are more varied than in the aged care system, requiring a greater diversity of responses. They involve a large mix of conditions (and co-morbidities), a wide span of intellectual capabilities, complex behaviours and support requirements."*

The aged care sector lacks the expertise to adequately support people with disability, particularly a significant disability such as ME/CFS. The philosophical differences between the care requirements of each group are significant. Society now accepts in disability support an ethos of independence and empowerment - a rights-based approach. Historically, this has been much less the case in the aged care sector, which is more to do with personal assistance either in the home or aged care facility. There is no sense of the broader context of a person's life goals and community participation.

If they are a parent they may have dependent children that they are needing to provide for. If they have not met the requirements for the Disability Support Program they may be required by Centrelink to work. They may have elderly parents who need their care. They may be spread very thin to find the money needed for the co-payment due to not being on a pension, having no access to their super and having financial demands put on them by dependents.

7 Disadvantages people with ME/CFS face once rejected for NDIS or Aged Care

7.1 Loss of existing supports

Once rejected by NDIS for access, many of our members have lost their existing supports, such as home help, support programs and transport options.

Many traditional providers and councils are no longer providing support for those who do not have an NDIS package. Other providers have had their funding roll over into the NDIS, but have then found that people are not getting funding to use their services and have therefore had to shut their doors.

In one case, a woman lost her lawn mowing after being rejected for NDIS as they said although they acknowledge her ME/CFS was a permanent condition, it didn't meet the lifelong criteria even though her GP wrote it was permanent and lifelong. Her provider lost HACC funding and was only funding NDIS clients. She was eventually given CHSP funding for two hours cleaning a fortnight as her HACC was two hours a fortnight. She also needs assistance with food preparation and other daily living needs but is unable to get that assistance.

Even when people have not lost their services, there is great uncertainty as to whether their existing services will continue. In another case, a woman was told continually over the past twelve months that she would lose her community transport service at the end of June, 2018 but was told at the last minute that were keeping on a small amount of clients ineligible for NDIS and that her service would be continued under continuity of support. She then had to go through another process to prove she was still disabled enough for the service to continue.

This lack of certainty of services leads to great anxiety as to how the person is going to cope with no services.

7.2 Isolated

People with severe or very severe ME/CFS who are housebound or bedbound are by the nature of the condition socially isolated. They also have very few opportunities to partake in community life. [xxiii]

ME/CFS is already a poorly misunderstood condition. Many people with ME/CFS have lost family and friends due to the condition as maintaining relationships becomes harder the more the condition progresses.

Without disability supports people with severe and very severe ME/CFS become increasingly more isolated from the outside world. This leads to poorer health outcomes and mental health.

7.3 Unable to get to appointments

As stated in Section 6.1 of this submission, getting to see a GPs or specialists is extremely hard for a person with severe or very severe ME/CFS. Many people are reliant on support workers or specialist services to help them get to appointments. When they lose these services, the quality of healthcare that they receive deteriorates further.

7.4 Have to give up employment or volunteer jobs

Whilst the NDIS encourages work in volunteer or paid positions, the Aged Care system does not. An individual will be deemed ineligible for Aged Care for under 65s if they hold a paid position. This leaves many in a catch 22: if they are deemed ineligible for the NDIS, and are required to apply for support through Aged Care for under 65sthey will need to give up their paid position, and therefore are forced to live below the poverty line on Newstart or on the Disability Support Pension. Perversely, the NDIS rejection is discouraging those who are able to work from doing so.

Poverty is common amongst those with disabilities. In the Poverty in Australia 2016 report, the Australian Council of Social Service found that in 2013-14, 510,900 adults with a disability (or 15.8%) and a further 328,100 with a disability that included a core activity limitation (or 17.8%) were living below the poverty line. The definition for core activity limitation is a person who has a disability or long-term health condition and also has a profound, severe or moderate limitation with core activities, which are defined as communication, mobility or self-care[xxiv].

ME/CFS can cause significant impairment and disability that have negative economic consequences at the individual and societal levels.[xxv] People with less severe ME/CFS who are able to work in volunteer, casual or part time positions often do so at great detriment to their health. They often need significant assistance in order to keep their ability to work. Our support systems should be encouraging and supporting those who are able to work, to do so. People with disability shouldn’t have to choose between paid employment and accessing the supports they need.

7.5 High rates of suicide

ME/CFS sufferers have a seven fold risk increase of suicide due to isolation and stigma[xxvi]. This can be attributable to lack of medical and disability care, not being listened to by physicians, needing daily support from family and friends, and not having the ability to earn a living outside of the home.[xxvii]

Being denied access to NDIS and having support services taken away, will increase the risk of suicide in an already venerable group of disabled people.

8 Case studies

8.1 Case Study 1

I am 54 and I have had ME/CFS for 37 years with a history of CPTSD.

I suffer from muscle fatigue, brain fog, short term memory loss, and functional neurological symptoms associated with ME/CFS.

Since being denied NDIS after being told I did not meet the criteria, the only support I have had is home help from a provider. I was however, told that will stop in 2020 because home help will only be available for those over 65 and I will therefore need to find alternative support.

I have also applied for ACAT, but because I have a casual job, I am not eligible. I have been advised to reapply for NDIS. I have been assessed by Neurological Council of WA and is supported by an employment agency who are helping me retain some paid casual work. I am presently on Newstart and needs to work 20 hours a fortnight.

There are severe limitations with my current level of services as there is no support for cognitive difficulties and Neurological symptoms. Also, without my home help I may be unable to continue working and my disability may deteriorate.

There is no other service offering available to support me if I am found not eligible for the NDIS on my second attempt of applying.

8.2 Case Study 2

For 3 years I was under Aged Care and then due to my dystonia and I was transferred to Disability SA. I also have very severe ME/CFS, Fibromyalgia and incontinence. Only my dystonia was considered a disability. I am completely bedridden and I cannot walk or stand or sit as I have severe autonomic issue.

The only reason I can transfer to NDIS is because I’m already on disability services so I qualified through the C list entry points.

However, neither the health system nor the NDIS fix my issue of not having access to basic health care as I have to use stretcher transfers to get to GP. My GP will not come to me and I don’t think she has any idea how sick I really am. If I do get a stretcher transfer to see her I suffer severe PEM and it lasts for 3 to 4 weeks at least.
Unfortunately, not all people with disabilities can just access mainstream services. In particular private specialists who are not accessible at all either by wheelchair or stretcher transfer.

8.3 Case Study 3

I have been disabled with severe ME/CFS for 4 years. I have been trying to get access to NDIS for over two years because I was in a trial site. I tried to get access to disability services during this time but was repeatedly told that I could only access services in my area if I was in the NDIS.

Considering that the NDIS is only meant to service those with a permanent, severe impairment this left a massive shortfall in services in my area for those with chronic illness, impairments that were episodic or those which fell slightly outside of what they deem as severe.

My own impairment has been judged by my doctors and OT as permanent, severe and debilitating; NDIA disagree.

My requirements were mainly for a wheelchair, cleaning services, help with shopping, cooking and safely picking up children from school, maybe an occasional supported outing with my kids. I am unable to safely go out on my own, I can't participate in any hobbies or social events, I am unable to cook and clean or even shower more than once a week.

Firstly, NDIS told me repeatedly that I "didn't need a functional assessment to be eligible" and just to "send whatever reports in that you already have". I had been deemed to have a Total Permanent Disability by Insurance on the strength of these reports, so even though I asked, the NDIA representative reassured me that I didn't need a functional assessment.

My doctors said it was permanent but NDIA said I did not meet that criteria. My doctors said that I had a serious impairment but NDIS said I did not.

I made sure that I gave NDIS a functional assessment, it was expensive to do this privately but confirmed my level of disability as severe.

NDIS referred to information from a website "Better Health Channel" to deny that my condition could be permanent and severely disabling.

NDIS said that I do not meet early intervention requirements because it is aimed at symptom relief and this is best provided through the Health system.

Subsequently I managed to find an OT through a Health service, I had to find this information myself because my doctors were at a loss for who to ask, they assessed me as needing better access to my house, a shower chair, and an electric wheelchair based on the severity of my mobility. I managed to get a wheelchair and shower chair through CAEP funding but then received an email:

"We have recently been directed that we are not able to see clients who have been rejected by NDIS. When I saw you last, we were still able to see clients who had been refused by NDIS during the transition period..... Below is the eligibility for CAEP and NDIS, Unfortunately as Chronic Fatigue and Fibromyalgia are not eligible as a recognised disability under Disability Services we are unable to continue to see you under CAEP."

So, I am left with no safe supports for myself and my children. I am unable to complete the most basic of tasks, bedbound and housebound, rejected by both NDIS and Health. My next option will be to try the aged care system, but I am 41 with 3 children. I am one of the lucky ones with good doctor supports, education and understanding about navigating the system, excellent extended family support. I have been fighting a two-year battle which if lose, will still see me needing a high level of support to live and to interact with the community.

8.4 Case Study 4

I am 36 years old and have ME/CFS, Fibromyalgia, Orthostatic Intolerance, Ankylosing Spondylitis, migraines, asthma, allergies, hypothyroidism and acid reflux. I am mostly housebound, only leaving the house about once a fortnight to go the chemist or for a medical appointment. I have to sleep at least 12 hours a day and spend the rest on the time on the couch.

I can only do the bare minimum of housework, such as loading and unloading the dishwasher, taking frequent breaks to rest and allow my heart rate return to normal. When the dust in my bedroom becomes too much because of my dust mite allergy, I use the vacuum cleaner, but this causes my heart rate to rapidly increase to the point where I feel like I have undertaken strenuous exercise and I have to stop without having done a proper clean. I cannot stand for very long due to the orthostatic intolerance, and so cannot prepare meals. I live on packaged food which in turns contribute to my low level of health.

I am not able to afford to pay privately for things like a cleaner, gardening and assistance with meal preparation, even those these things would significantly improve my wellbeing, as I am on the Disability Support Pension (granted on March 2018 after a long, stressful application and appeals process) and have to meet payment plans for significant debts I accrued while becoming sick and having to take significant time off of work (I have not be able to work for the past three and a half years).

I am reluctant to apply for the NDIS, as it seems to be an overwhelming and adversarial process, with the conditions I have only occasionally being accepted, but most often being rejected as being eligible for NDIS entry. My cognitive impairments caused by ME/CFS make it extremely challenging to read and comprehend information, which further complicates compiling and presenting the information required to make a successful application.

In June 2018 I discovered that I may be eligible for services through the Commonwealth Home Support Programme. When I called to enquire, I was told it was likely I would be eligible, but their funding had been frozen for the remainder of the financial year because of funding cuts and they would call me after the 1st of July if they were granted new funding. I have not received a call and so I assume that funding was not granted.

9 Appendix

9.1 ME/CFS Diagnostic Criteria

The Canadian Consensus Criteria[xxviii] requires the following symptoms for diagnosis of ME/CFS: fatigue, post-exertional malaise and/or fatigue, sleep dysfunction, and pain; have two or more neurological/cognitive manifestations and one or more symptoms from two of the categories of autonomic, neuroendocrine and immune manifestations; and adhere to item 7.

1. **Fatigue**: The patient must have a significant degree of new onset, unexplained, persistent, or recurrent physical and mental fatigue that substantially reduces activity level.

2. **Post-Exertional Malaise and/or Fatigue**: There is an inappropriate loss of physical and mental stamina, rapid muscular and cognitive fatigability, post exertional malaise and/or fatigue and/or pain and a tendency for other associated symptoms within the patient's cluster of symptoms to worsen. There is a pathologically slow recovery period–usually 24 hours or longer.

3. **Sleep Dysfunction**:* There is unrefreshed sleep or sleep quantity or rhythm disturbances such as reversed or chaotic diurnal sleep rhythms.

4. **Pain**:* There is a significant degree of myalgia. Pain can be experi- enced in the muscles and/or joints, and is often widespread and mi- gratory in nature. Often there are significant headaches of new type, pattern or severity.

5. **Neurological/Cognitive Manifestations**: Two or more of the fol- lowing difficulties should be present: confusion, impairment of concentration and short-term memory consolidation, disorienta- tion, difficulty with information processing, categorizing and word retrieval, and perceptual and sensory disturbances–e.g., spatial in- stability and disorientation and inability to focus vision. Ataxia, muscle weakness and fasciculations are common. There may be overload1 phenomena: cognitive, sensory–e.g., photophobia and hypersensitivity to noise–and/or emotional overload, which may lead to “crash”2 periods and/or anxiety.

6. At Least One Symptom from Two of the Following Categories:

    a. **Autonomic Manifestations**: orthostatic intolerance–neurally mediated hypotenstion (NMH), postural orthostatic tachycardia syndrome (POTS), delayed postural hypotension; light-headedness; extreme pallor; nausea and irritable bowel syndrome; urinary frequency and bladder dysfunction; palpitations with or without cardiac arrhythmias; exertional dyspnea.

    b. **Neuroendocrine Manifestations**: loss of thermostatic stability– subnormal body temperature and marked diurnal fluctuation, sweating episodes, recurrent feelings of feverishness and cold extremities; intolerance of extremes of heat and cold; marked weight change–anorexia or abnormal appetite; loss of adaptabil- ity and worsening of symptoms with stress.

c. **Immune Manifestations**: tender lymph nodes, recurrent sore throat, recurrent flu-like symptoms, general malaise, new sensi- tivities to food, medications and/or chemicals.

7. The illness persists for at least six months. It usually has a distinct onset,** although it may be gradual. Preliminary diagnosis may be possible earlier. Three months is appropriate for children.

9.2 Comorbid Conditions

There are also a number of comorbid conditions that can occur with ME/CFS, Carruthers et al (2011).

- Fibromyalgia,
- Myofascial Pain Syndrome,
- Temporomandibular Joint Syndrome,
- Irritable Bowel Syndrome,
- Interstitial Cystitis,
- Raynaud's Phenomenon,
- Prolapsed Mitral Valve,
- Migraines,
- Allergies,
- Multiple Chemical Sensitivities,
- Hashimoto's Thyroiditis,
- Sicca Syndrome,
- Reactive Depression.
- Migraine and irritable bowel syndrome may precede ME but then become associated with it.
- Fibromyalgia overlaps.

9.3 Prognosis

The RACP (2002) guidelines[xxix] state:

> *In people who have been severely disabled and unable to work for more than five years, the probability of substantial improvement within 10 years is less than 10%–20%. This may be regarded as "permanent disability" for medicolegal purposes.*

In creating the Canadian Consensus Criteria Guidelines for ME/CFS (2003)[xxx], the expert medical consensus panel concluded from their literature review, combined with exceptional clinical experience of their committee that:

> *The quality of life (QOL) of ME/CFS patients show marked diminution which is more severe than in many other chronic illnesses. ME/CFS patients were most*

disadvantaged in terms of vitality, recreation, social interaction, home management and work. There is a general tendency for the clinical course to plateau from between six months and six years. In a nine-year study of 177 patients, 12% of patients reported recovery. The patients with the least severe symptomology at the beginning of the study were the most likely to recover but there were no demographic characteristics associated with recovery. Patient (sic) with comorbid fibromyalgia syndrome demonstrated greater symptom severity and functional impairment than individuals with CFS alone. Other studies suggest that less than 10% of patients return to premorbid levels of functioning. As the criteria become more stringent the prognosis appears to worsen...

While statistical studies estimate group prognosis, ***the individual prognosis, which is highly variable, must remain a clinical estimate****. To estimate individual prognosis more effectively, one must have ascertained the severity and course of the patient's illness and impairments in each of their aspects, as well as the patient's circumstances and the life-world to which they are responding. The patient's progress must be followed over a course of time, within a therapeutic relationship. One must have tried to eliminate aggravating factors that worsen the illness and to encourage ameliorating factors. Only then can one give a reasonably adequate individual prognosis. Early diagnosis may lessen the impact of the illness. Generally,* ***if one sees deterioration in a patient's health status over an extended time, one may expect that there would be continued deterioration****, whereas if improvement was noted over an extended time period, one may hope for continued improvement. However, in the Pheley et al. study there was considerable overlap of severity of illness between those who recovered and those who did not, which suggests that accurate predictions of recovery for an individual patient may not be feasible at this time. (Carruthers, et al., 2003, pp. 29-30)*

10 References

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[i] https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-19-living-independently-and-being-included-in-the-community.html

[ii] http://apps.who.int/classifications/icd10/browse/2010/en#/G90-G99

[iii] M, Carruthers B., van de Sande M. I, De Meirleir K. L, Klimas N. G, Broderick G, Mitchell T, Staines D, et al. (2011). “Myalgic Encephalomyelitis: International Consensus Criteria.” *Journal of Internal Medicine* 270, no. 4 (n.d.): 327–38. https://doi.org/10.1111/j.1365-2796.2011.02428.x.

[iv] Tucker, Miriam E. “Postexertion ‘Crash,’ Not Fatigue per Se, Marks Syndrome.” *Medscape Medical News*, November 4, 2016.

[v] National Organization for Rare Disorders (NORD), and Jason A. Leonard. “Myalgic Encephalomyelitis.” National Organization for Rare Disorders (NORD). Accessed May 21, 2018. https://rarediseases.org/rare-diseases/myalgic-encephalomyelitis/.

[vi] “ME/CFS - Pathways to Prevention - Advancing the Research on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome.” National Institutes of Health, December 8, 2016. https://prevention.nih.gov/programs-events/pathways-to-prevention/workshops/me-cfs.

[vii] Carruthers, M. van de Sande, B., Myalgic Encephalomyelitis - Adult & Paediatric: International Consensus Primer for Medical Practitioners, International Consensus Panel, 2012, http://emerge.org.au/wp-content/uploads/2014/06/Myalgic-Encephalomyelitis-International-Consensus-Primer-2012-11-26.pdf

[viii] Falk Hvidberg, Michael, Louise Schouborg Brinth, Anne V. Olesen, Karin D. Petersen, and Lars Ehlers. “The Health-Related Quality of Life for Patients with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS).” *PloS One* 10, no. 7 (2015): e0132421. https://doi.org/10.1371/journal.pone.0132421.

[ix] Unger ER, Lin JS, Brimmer DJ, et al. CDC Grand Rounds: Chronic Fatigue Syndrome — Advancing Research and Clinical Education. MMWR Morb Mortal Wkly Rep 2016;65:1434–1438. DOI: http://dx.doi.org/10.15585/mmwr.mm655051a4.

[x] Mathers, Colin, Vos, Theo and Stevenson, Chris 1999, The burden of disease and injury in Australia, Australian Institute of Health and Welfare, Canberra, A. C. T. pp. 197, 201, http://dro.deakin.edu.au/eserv/DU:30046704/stevenson-burdenofdisease-1999.pdf

[xi] http://www.abc.net.au/news/2018-07-18/chronic-fatigue-treatments-set-for-review/10007356

[xii] National Disability Insurance Scheme. (2014c, September 1). Operational Guidelines - Access - Disability Requirements (V. 3.2). Retrieved October 18, 2017, from Australian Department of Human Services: https://ndis.gov.au/html/sites/default/files/OGs-access-disabilityrequirements_0.docx , p. 10

[xiii] Mulligan and NDIA [2015] AATA 974 per Toohey and McCallum, Retrieved November 22, 2017, from Administrative Appeals Tribunal of Australia: http://www8.austlii.edu.au/cgi-bin/viewdoc/au/cases/cth/AATA/2015/974.html

[xiv] Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, 2015, p. 259; Carruthers, et al., 2003, p. 50; Zinn, Zinn, & Jason, 2016a, p. 2; Dantzer, Heijnen, Kavelaars, Laye, & Capuraon, 2014, p. 44; Blease, Carel, & Geraghty, 2017, p. 553; White, Sharpe, Chalder, DeCesare, & Walwyn, 2007, p. 2; Green, Cowan, Elk, O'Neil, & Rasmussen, 2015, p. 861; Centers for Disease Control and Prevention, 2017; Green, Cowan, Ronit, O’Neil, & Rasmussen, 2014, p. 1; Gibson, et al., 2006, p. 8).

[xv] Better Health Channel. (2017, November 10). Chronic fatigue syndrome (CFS). Retrieved November 22, 2017, from State of Victoria: https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/chronic-fatigue-syndrome-cfs?viewAsPdf=true

[xvi] Baraniuk, J. N. (2017). Chronic fatigue syndrome prevalence is grossly overestimated using Oxford criteria compared to Centers for Disease Control (Fukuda) criteria in a U.S. population study. Fatigue: Biomedicine, Health & Behavior, p. 53, 5(4), 215-230. doi:10.1080/21641846.2017.1353578,

[xvii] Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, 2015, p. 264

[xviii] Vink, M. (2017b). Assessment of Individual PACE Trial Data: in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Cognitive Behavioral and Graded Exercise Therapy are Ineffective, Do Not Lead to Actual Recovery and Negative Outcomes may be Higher than Reported, Journal of Neurology and Neurobiology, 3(1), pp. 4. doi:10.16966/2379-7150.136

[xix] “Chronic Fatigue Syndrome. Clinical Practice Guidelines--2002.” *The Medical Journal of Australia* 176 Suppl (May 6, 2002): S23-56.

[xx] Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, 2015, p. 32

[xxi] Sheldon and National Disability Insurance Agency [2018] AATA 2560 (30 July 2018), Point 63, http://www.austlii.edu.au/cgi-bin/viewdoc/au/cases/cth/AATA/2018/2560.html

[xxii] https://www.pc.gov.au/inquiries/completed/disability-support/report

[xxiii] World Health Organization and World Bank Group, World report on disability (2011), p 263.

[xxiv] https://www.acoss.org.au/poverty/

[xxv] *Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness*. Washington (DC): National Academies Press (US), 2015.

[xxvi] Roberts, Emmert, Simon Wessely, Trudie Chalder, Chin-Kuo Chang, and Matthew Hotopf. “Mortality of People with Chronic Fatigue Syndrome: A Retrospective Cohort Study in England and Wales from the South London and Maudsley NHS Foundation Trust Biomedical Research Centre (SLaM BRC) Clinical Record Interactive Search (CRIS) Register.” *Lancet (London, England)* 387, no. 10028 (April 16, 2016): 1638–43. https://doi.org/10.1016/S0140-6736(15)01223-4.

[xxvii] McManimen, Stephanie L., Andrew R. Devendorf, Abigail A. Brown, Billie C. Moore, James H. Moore, and Leonard A. Jason. “Mortality in Patients with Myalgic Encephalomyelitis and Chronic Fatigue Syndrome.” *Fatigue: Biomedicine, Health & Behavior* 4, no. 4 (October 1, 2016): 195–207. https://doi.org/10.1080/21641846.2016.1236588.

[xxviii] Carruthers, B. M., Jain, A. K., De Meirleir, K. L., Peterson, D. L., Klimas, N. G., Lerner, A. M., . . . van de Sande, M. L. (2003). Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols. Journal of Chronic Fatigue Syndrome, 11(1), 7.

[xxix] “Chronic Fatigue Syndrome. Clinical Practice Guidelines--2002.” *The Medical Journal of Australia* 176 Suppl (May 6, 2002): S23-56.

[xxx] Carruthers, B. M., Jain, A. K., De Meirleir, K. L., Peterson, D. L., Klimas, N. G., Lerner, A. M., . . . van de Sande, M. L. (2003). Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols. Journal of Chronic Fatigue Syndrome, 11(1), 7.