

Submission to the Disability Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability



December, 2022

Recommendations

Recommendation 1: Educate Australia's healthcare providers about ME/CFS

Disbelief and inappropriate management from GPs prevent patients from receiving correct care. As demonstrated in this submission, such disbelief and misunderstanding leads to violence, abuse and neglect of people living with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS).

There is a significant need for greater GP education, for those already practicing and for medical trainees in undergraduate programs. This will ensure the next generation of people with diseases like ME/CFS and Long COVID don't suffer the same stigma or poorly informed healthcare. As this submission demonstrates, proper recognition of disease impact by the medical profession influences how people with the disease are perceived and supported by government and society.

Recommendation 2: Update Australia's outdated clinical guidelines to reflect internationally agreed safe and best practice care for people with ME/CFS

This submission provides a number of examples where people with ME/CFS have been made worse by treatments recommended in Australia's outdated (20 year old) clinical guidelines. It is a matter of urgency for Australia to update its clinical guidelines for ME/CFS, to ensure Australian ME/CFS patients have access to the best possible care, based on current understanding of the disease and latest evidence.

As ME/CFS research continues to evolve, clinical guidelines quickly become outdated. Current Australian clinical management of ME/CFS is out of step with international best practice and ME/CFS patients are at risk of harm. As detailed in this submission, the use of outdated treatment techniques are one form of violence and systemic neglect against this patient cohort.

Recommendation 3: Support people with ME/CFS with an expanded national, multi-disciplinary telehealth team of allied health professionals who will coordinate patient care and provide support for health system navigation

As demonstrated in this submission, people with ME/CFS do not routinely receive appropriate, coordinated, shared care. Further, they face barriers accessing evidence-based information and integrated non-clinical support, all of which can inhibit symptom management and recovery. It is critical that ME/CFS patients are empowered to understand their unique needs and become partners in their own care.

People with ME/CFS have been neglected and abused by a healthcare system that does not understand their needs. An Optical Care Referral Pathway (OCRP) should be developed that places people with ME/CFS at the centre of care decisions. There is a successfully operating Telehealth model in place that has been evaluated and its expansion should occur through a multi-disciplinary clinician consensus process that includes people with ME/CFS, carers and allied health professionals to establish the elements of quality care that should be offered. A thorough monitoring and evaluation process would similarly ensure the OCP is delivering efficient, appropriate and equitable care.

Recommendation 4: Fund collaborative, translational research studying the links between ME/CFS and Long COVID.

Research into the cause and possible treatments for ME/CFS is essential to validating and providing hope for people living with this disease. Long COVID provides a new and already documented opportunity for further research into post-infection disease, with researchers establishing strong links between ME/CFS, Long COVID and other post-infection diseases.

There are manifestly insufficient resources available for translational research to ensure new research is efficient and effective, and that existing findings from ME/CFS research are used to provide clear guidance into cause and treatment options. In addition, if treatments are found that help people with Long COVID, these are potentially applicable for people with ME/CFS. People with ME/CFS should be used as comparison cohorts to people with Long COVID, in addition to healthy controls.

Recommendation 5: Create two new strategies to create sector wide focus and collaboration on Long COVID, ME/CFS and other related post-infection diseases

Current predictions suggest up to 325,000 people may be affected by Long COVID, in addition to the 250,000 living with ME/CFS. Our health and disability systems must move quickly to support this growing cohort of post-infection patients, and to manage the impending public health crisis and consequent economic impacts posed by Long COVID. With more than half a million people in the coming years affected, and experiencing some level of disability, by post-infection disease, **Emerge Australia recommends Post-infection Disease becomes the 10th National Health Priority Area.**

In addition, EmERGE Australia recommends collaborative development of a **National Post-infection Disease Strategy** to address the disabling impact of Long COVID, ME/CFS and other post-infection diseases. A National Post-infection Disease Strategy would allow for the allocation of funds that address the interface between post-infection disease and disability. Both of these strategies would improve the disability related stigma and lack of care many people with ME/CFS face, as documented in this submission.

Recommendation 6: Expand Medicare access to telehealth and provide equitable access to government support for people with ME/CFS, Long COVID and post-infection diseases.

People with ME/CFS experience neglect from the healthcare system when they are denied access to medical appointment. In March 2020 the Federal Government provided access to a range of Medicare-subsidised services via phone or video call in response to COVID-19. This decision enabled people with ME/CFS to access essential health services for the first time in years. Previously, many of these patients could not attend in-person clinics because of the severe effect on their health. Attending appointments in-person can cause people living with ME/CFS to experience post-exertional malaise for hours, days or weeks afterwards.

While some telehealth services are now permanently accessible through Medicare, rebates for complex specialist consultations and longer telehealth consults ceased in June 2022. EmERGE Australia urges the

Royal Commission to make recommendations to Federal Government to make Medicare rebates permanently available for long and short consultations for people with chronic illnesses, who are otherwise unable to attend clinics.

Further, Emerge Australia recommends for the requirement for an annual, face-to-face GP appointment be removed for chronically unwell people. This requirement excludes patients who are entirely bed-bound – those who are most unwell – from accessing services they need. Alternatively, where an annual face-to-face appointment is required, funding should be made available for home visits to ensure patients receive the care they need. An appropriate MBS item needs to be developed for remuneration of necessary home visits as part of the Telehealth Program for bed-bound and housebound patients.

Develop appropriate assessment guidelines

Just as many medical practitioners face challenges providing appropriate care to their patients due to out-of-date clinical guidelines, Centrelink and National Disability Insurance Scheme (NDIS) assessment staff similarly lack access to information to accurately assess clients with ME/CFS.

Anecdotal evidence suggests many people with ME/CFS are rejected from the NDIS or Disability Support Pension (DSP) because their disease was considered temporary and treatable. However, many gain access on appeal. This apparent pattern of rejection followed by a successful appeal suggests that ME/CFS is either poorly understood by assessors and/or that assessment guidelines are not fit for the purpose of assisting decision makers.

Improving assessment accuracy is critical to reduce the well documented number of incorrect first round assessment decisions and subsequent assessment rounds. This would improve timely access to the support people disabled by ME/CFS need, while reducing operating costs sustained through the appeals process.

Tailored guidelines are needed to provide assessors with accurate information about the fluctuating nature and permanency of ME/CFS for most patients. Such guidance would also help build understanding of the disabling nature of symptoms and the delayed response of post-exertional malaise. Emerge Australia would welcome the opportunity to collaborate on the development of such guidelines with the National Disability Insurance Agency (NDIA), Centrelink, the ME/CFS community and clinical experts.

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1. About Emerge Australia

Emerge Australia is the national patient organisation providing services and evidence-based education about myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). While research is yet to confirm the cause of ME/CFS, a majority of people with ME/CFS can attribute onset of symptoms after viral infection.¹ At Emerge Australia, we:

- deliver patient-centered, consultative services to empower patients and encourage self-care;
- increase patient literacy with well-informed, medically sound information, aligned with global consensus;
- educate GPs and allied health professionals about the diagnosis and treatment of ME/CFS and Long COVID;
- advocate for people living with ME/CFS and Long COVID, to raise awareness, recognition and investment into finding a biomarker, treatments and a cure, and;
- have strong sector connections with the ME/CFS community, health professionals, government and leading ME/CFS research groups across Australia and internationally.

Increasingly, Emerge Australia also works with those impacted by post-acute sequelae of COVID-19, otherwise known as Long COVID. Long COVID may increase the number of people living with ME/CFS; current research estimates 45% of people with Long COVID meet the diagnostic criteria for ME/CFS.¹ Evidence from our own, growing Long COVID community suggests Long COVID patients are already facing similar obstacles and challenges as people living with ME/CFS. However, as data gathered for this submission pre-dates Long COVID, we focus solely here on the experiences of people with ME/CFS.

2. About myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a multisystemic, highly disabling disease characterised by post-exertional malaise (PEM). PEM is a worsening of symptoms such as fatigue, pain and cognitive impairment following physical or mental effort. Other common symptoms of ME/CFS include problems with sleep, thinking and concentrating, orthostatic intolerance, dizziness and hypersensitivity to light and sound. ME is classified as a neurological disorder by the World Health Organization.

While ME/CFS can affect anyone of any age, gender or socio-economic or cultural background, there are some noteworthy patterns:

- Women are three times more likely to be affected than men²
- The two most common ages of onset occur between the ages of 10 to 19 years and 30 to 39 years. The average age of onset is 33 years^{3,4}

¹ C. Kedor, et al. (2022). 'A prospective observational study of post-COVID-19 chronic fatigue syndrome following the first pandemic wave in Germany and biomarkers associated with symptom severity'. *Nature communications*, 13(1), 1-13.

² Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Board on the Health of Select Populations, & Institute of Medicine. 'Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness' *National Academies Press (US)* (2015).

³ P. Rowe, et al. 'Myalgic encephalomyelitis/chronic fatigue syndrome diagnosis and management in young people: a primer' *Front Pediatr*, 5 (2017), p. 121.

⁴ I. Bakken, et al. 'Two age peaks in the incidence of chronic fatigue syndrome/myalgic encephalomyelitis: a population-based registry study from Norway 2008-2012' *BMC Med*, 12:1 (2014), p. 167.

- Approximately 25% of people experience severe symptoms, leaving them housebound or bedbound⁵
- People with ME/CFS score more poorly on quality-of-life surveys than patients with rheumatoid arthritis, multiple sclerosis, depression, heart disease, cancer and lung disease.^{6,7,8}

Despite the significant number of people who live with ME/CFS, and the severity of disability it can cause, the disease remains widely misbelieved, or disbelieved. There are two primary reasons for this. First, the disease is largely invisible, unless you know what to look for. Unlike someone with a broken leg, people with ME/CFS don't have immediate proof of their illness. We discuss the significance of invisible disability further in section 2.1, below. Second, as 75% of people with the disease are women, sexism has influenced perceptions of ME/CFS.⁹ Women with the disease have been labelled hypochondriacs, attention seekers and misdiagnosed as being depressed. Unfortunately and inaccurately, these beliefs persist.

Misbelief and disbelief have resulted in systemic discrimination from the medical profession and exclusion from adequate research funding. This systemic discrimination continues to be perpetuated by out-of-date clinical guidelines, lack of healthcare provider education and limited primary and translational research to identify a biomarker, or treatment options. As a cohort of disabled people, the combination of stigma, neglect and harm (abuse) due to old guidelines, graded exercise therapy, lack of medical education and very limited medical research is significant and, arguably, unheard of in any other chronic disease.¹⁰

⁵ Committee on the Diagnostic Criteria for ME/CFS. 'Beyond Myalgic Encephalomyelitis'.

⁶ C. Kingdon, et al. 'Functional Status and Well-Being in People with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Compared with People with Multiple Sclerosis and Healthy Controls' *Pharmacoeconomics- Open*, 2:4 (2018).

⁷ L. Nacul, et al. 'The functional status and well being of people with myalgic encephalomyelitis/chronic fatigue syndrome and their carers' *BMC Public Health*, 11 (2011).

⁸ M. Núñez, et al. 'Health-related quality of life in chronic fatigue syndrome versus rheumatoid arthritis as control group' *Journal of Chronic Fatigue Syndrome*, 14 (2008).

⁹ Murray, Day and Tobbell (2019). 'Duvet woman versus action man: the gendered aetiology of Chronic Fatigue Syndrome according to English newspapers' *Feminist Media Studies*, 19:6.

¹⁰ For example: M. Dimmock, A. Mirin and L. Jason (2016). 'Estimating the disease burden of ME/CFS in the United States and its relation to research funding', *Journal of Medicine and Therapeutics*, 1:1; R. Nisenbaum, et al. (2003). 'A population-based study of the clinical course of chronic fatigue syndrome' *Health and Quality of Life Outcomes*, 1:1; Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Advisory Committee (2019). 'Myalgic Encephalomyelitis / Chronic Fatigue Syndrome Advisory Committee Report to the NHMRC Chief Executive Officer' *Australian Government*. Available at <https://www.nhmrc.gov.au/about-us/publications/mecfs-advisory-committee-report-nhmrc-chief-executive-officer>.

2.1. ME/CFS is an invisible illness

ME/CFS is a fluctuating, chronic disease. For most, it is an invisible illness. Although it can be highly disabling, this means it is often ignored. Unlike those with a visible disability, whose disability is immediately taken as fact, invisible illnesses have to be believed. This means they are subject to ignorance, bias and questioning whether the disability even exists.

There are two ways ME/CFS is invisible. First, ME/CFS is a fluctuating disease that does not cause visible disability. Often in the case of mild-moderate severity, people living with ME/CFS will have good days and bad days. On the good days, they will often be told that they “look well”, implying no underlying disability or illness. Second, often for people with moderate-severe symptoms, few people will see them. They live their lives house- or bed-bound, in a lifelong lockdown. Although those with moderate-severe symptoms are more likely to require a wheelchair and other, visible aids, they rarely leave the house. As described in this submission, they are often cut off from the world, social interactions, and medical care.

The following quotes are from people living with ME/CFS, who responded to our survey for this submission. These quotes have been selected because they aptly describe a number of common experiences respondents provided about living with this invisible illness:

- *They don't understand as they don't see me at my worst.*
- *People see you walking around doing normal activities and think you are well. They don't see you collapse with fatigue when you get home. Family have seen me like this for over 30 yrs, so think it is just 'me'. Very hard to gain understanding or empathy from anyone, except those who have it.*
- *My experience of living with ME/CFS is like fighting a slow-motion, drawn-out drowning under a thousand misunderstandings, mis-expectations, missed opportunities to perceive what I *can* offer and what I *can* achieve, without sacrificing the same quality of life available to people without ME/CFS. What a waste! For everyone!*

ME/CFS, as an invisible illness, challenges people’s understanding of disability. For those who are uneducated about the disease, their ignorance and apathy often lead to disbelief and stigma. This disability and stigma, leads to violence, abuse and neglect. Such treatment leaves many people living with ME/CFS experiencing shame, humiliation and trauma. This sequence of behaviour and its consequences were evident in the vast majority of stories from respondents to our survey. Examples, and the settings in which they took place, are included in section 4. *Results*.

3. Methodology

In 2020, Emerge Australia conducted two, short online surveys with our ME/CFS community. The surveys were open for approximately 3 months, from January 9 to April 4, 2020. They were advertised on Emerge Australia's Facebook page, e-newsletter and other social media groups for people with ME/CFS. Qualtrics online survey software was used to ask respondents multiple choice and open text questions, all optional to complete. Survey questions can be found at *Appendix 1*.

The first survey was interested in experiences of people living with ME/CFS. This first survey could also be completed by carers on behalf of people living with ME/CFS. The second survey was for carers alone, and asked them to reflect on their own experience. A total of 172 people completed the first survey about the experiences of people living with ME/CFS and 23 people completed the survey about the experiences of carers.

In addition to these surveys, we also draw on results from another quantitative data source, Emerge Australia's triennial Health and Wellbeing Survey, last held in 2019.

4. Results

Results from our survey for the Disability Royal Commission come from 172 respondents, of whom:

- 161 live with ME/CFS
- 8 were carers, responding on behalf of the people they cared for with ME/CFS
- 3 were from individuals who both had ME/CFS and were a carer of someone else with ME/CFS
- 78 respondents (44%) were bedbound/housebound as a result of their symptoms.

Violence, abuse and neglect were most related to the experiences of people living with ME/CFS. Respondents did not discuss exploitation, so is not a focus in our submission.

Experiences of both people living with ME/CFS and their carers occurred across all aspects of life. As one respondent succinctly stated: "*The stigmatisation of ME/CFS is institutionalised.*" People living with ME/CFS have experienced violence, abuse and neglect in all aspects of life: health, education, employment, accommodation, transport, government support and society. Such widespread places of violence, abuse and neglect indicate the significant amount of systemic change required to ensure people with ME/CFS are appropriately treated.

Beyond the violence, abuse and neglect documented in the *Results*, some clear themes were evident from our survey for this Royal Commission. These themes of ignorance, apathy, disbelief, stigma, shame, humiliation and trauma all either help to explain why people with ME/CFS experience violence, abuse and neglect, or the ongoing effect such abuse has on their lives. Some of these themes are particularly common to people with ME/CFS because of the invisible nature of the disease, and the long history of disbelief our community has had to endure, while others will be shared experiences among many who live with a disability.

4.1. Violence and abuse

In the following section, we use qualitative and quantitative data to provide examples and incidence rates of violence and abuse in a number of settings. We begin with health, as this was the most reported place of violence and abuse among respondents. Central themes in these examples were disbelief and stigma associated with ME/CFS. We described some of the reasons for this with a brief history of the disease in section 2. *About myalgic encephalomyelitis/chronic fatigue syndrome*, and further expand below. The other central theme was the lack of reasonable accommodations made for people with ME/CFS, once again due to lack of education about the disease.

The examples of violence and abuse included in this section are a small sample of those submitted to Emerge Australia. Individual examples were selected to show breadth and consistency of experience across all facets of life. The violence and abuse these people experienced is not acceptable and completely avoidable with greater education, understanding and empathy about ME/CFS and invisible illnesses.

a) Health

The most reported place of violence and abuse among survey participants was in the health system. Using the Royal Commission's definition of 'violence and abuse'¹¹, our survey asked participants if they had experienced violence or abuse when accessing hospital facilities or seeking medical advice including through practitioners such as GPs, specialists and allied health professionals. Emerge Australia provided a number of examples for what violence and abuse could constitute in these settings, for example:

- A requirement to use inappropriate facilities in order to access care, such as medical/hospital facilities with bright lights, loud sounds, nowhere to lie down/rest, long wait times, or lengthy processes, all of which can exacerbate ME/CFS symptoms.
- Responses from medical professionals which made you feel humiliated or verbally abused.
- Coercion to undergo harmful treatments.

Figure 1 shows 81% of respondents experienced violence or abuse in a medical setting. Most concerning in these data is the 8% of respondents who experienced violence or abuse 75-100% of the time.

¹¹ The Royal Commission defines 'violence and abuse' as including assault, sexual assault, constraints, restrictive practices (physical and chemical), forced treatments, forced interventions, humiliation and harassment, financial and economic abuse and significant violations of privacy and dignity on a systemic or individual basis.

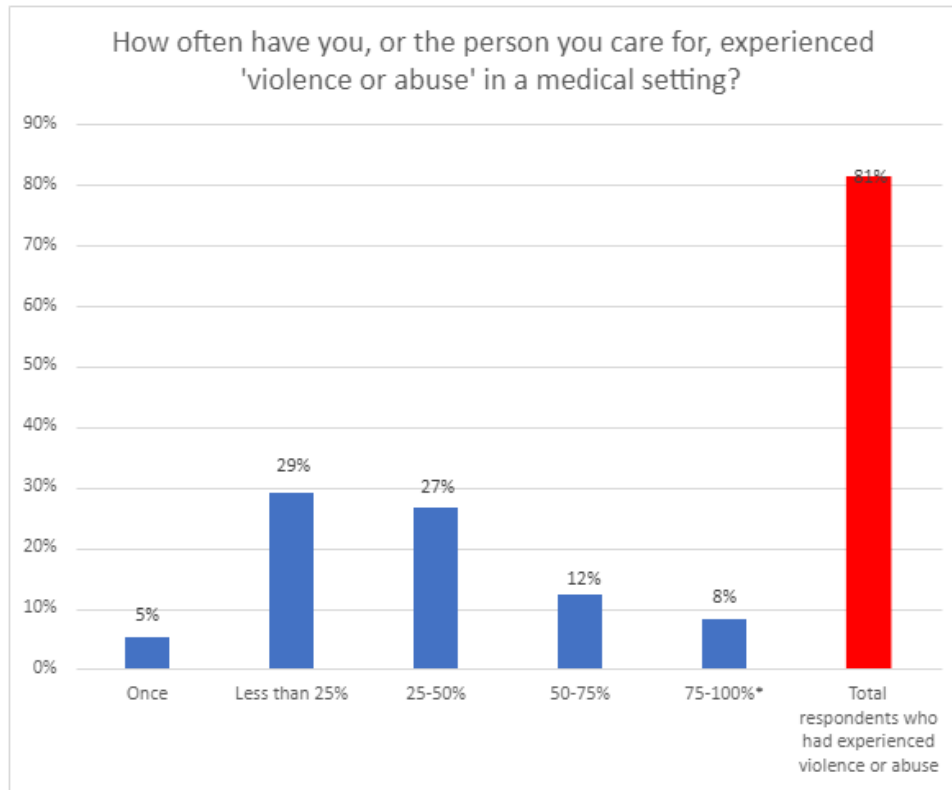


Figure 1: How often you, or the person you care for, experienced 'violence or abuse' in a medical setting?

This data may be explained by the sequence of behaviour outlined in section 2.1. *ME/CFS is an invisible illness*, where ignorance leads to abuse. Data from two other sources support this theory:

1. **Emerge Australia's 2019 Health and Wellbeing Survey** identified the leading obstacles to accessing healthcare for people with ME/CFS:
 - 73% said healthcare practitioner lack of knowledge
 - 68% said outdated or incorrect information.

2. **Emerge Australia's telehealth nurse service**, from consultation with more than 1000 people living with ME/CFS, found:
 - 17% were satisfied with the healthcare system
 - 35% have a supportive GP
 - 69% were anxious or very anxious about engaging with the healthcare system
 - 70% manage their symptoms on their own.

This data demonstrates the average patient experience starts with poor healthcare practitioner knowledge and information. This typically leaves patients feeling unsupported, dissatisfied and anxious about the healthcare system. More than two thirds of people who participated in the 2019 Health and Wellbeing survey said they preferred to manage their health on their own, with no support from a GP.

Qualitative data from our survey for the Royal Commission provides examples of how the health system has failed to meet patient needs or provide care. The types of ‘violence or abuse’ they experienced are also described.

i. Disbelief

The foundation of problems people with ME/CFS experience in the healthcare system comes from disbelief about ME/CFS as a real illness.¹² It is quite common for people with ME/CFS to attend a number of doctors before they find one willing to help. On average, it takes between 2 to 5 years to gain a diagnosis of ME/CFS in Australia,¹³ however it often takes much longer. Sometimes, diagnosis delays are because the GP doesn’t believe in ME/CFS, other times it is because the GP doesn’t know what to do with someone with ME/CFS:

- *I have been to a lot of GPs who refuse to believe that ME/CFS is a real illness.*
- *I saw six different GPs over three years before one took me seriously.*
- *I just felt that they viewed me as though I was a hypochondriac that I was fine and just making a fuss. They didn’t take into account the pain and pure fatigue I was feeling or how much it took to even get there. It was like I was being blown off.*
- *The main problem has been medical practitioners not taking ME/CFS seriously, with comments such as: is that really a disease?*
- *I was told by a Dr to “get up and live your life!” At that time, I couldn’t stand for more than 10 minutes, 2-3 times a day.*
- *They view it as a non-disease.*

When a disease is not visible or believed, the other explanation is that it must be in the patient’s head. People with ME/CFS are often wrongly diagnosed with mental health issues, like stress, anxiety and depression. Medications are, incorrectly, prescribed accordingly, or no care provided at all:

- *Another GP kept insisting I take antidepressants although I kept explaining I wasn’t depressed.*
- *Gave my dentist info sheet on ME/CFS to explain my condition, explained multiple times that my nervous system gets overwhelmed in the chair and I start shaking and I can’t control it. Thought she understood but started shaking uncontrollably and she said there is no adrenalin in the injection you are just doing this to yourself. I felt humiliated and physically overwhelmed.*

¹² Pheby et al (2021). ‘A literature review of GP Knowledge and Understanding of ME/CFS: A report from the socioeconomic working group of the European network on ME/CFS (EUROMENE). *Medicina*, 57:7.

¹³ Emerge Australia, ‘Health and Wellbeing Survey 2019’.

- *Being told it is all in my mind and to seek psychiatric care. Refused admission to ED via Ambulance "because I had an extensive admission history" i.e. I was a hypochondriac.*
- *If I develop a physical illness not related to my condition ... doctors ignore it and just think it is a symptom of my fatigue, or my mental health issues. I am scared that I will die young because I just don't bother reporting symptoms to doctors anymore.*

Most of these instances of neglect are due to a lack of education about ME/CFS. As discussed in section 2, very little is known about the disease, and many continue to incorrectly believe it is a psychological disease. There are two primary consequences: no treatment or harmful treatment. In the case of no treatment being proscribed, respondents reported how no one would take responsibility for their care:

- *Told my health was too complex, they can't help me but I should go to my GP and see specialists. Discharged when I wasn't well enough to walk or feed myself and didn't have anyone to look after me.*
- *I have watched my mother whom has ME/CFS at emergency be told her heart symptoms are not anything before any tests were undertaken. Both her parents died from heart attacks at 66, she's 62.*
- *Once, a GP told me I was "a difficult patient because I wanted answers". Another GP verbally abused me, saying he would not give me medication I wanted, which was hypertension medication that I have always had to stabilise my BP!*

Disbelief about the biological nature and severity of symptoms is widespread in the medical profession. Rheumatologists and immunologists were particularly mentioned by respondents:

- *The rheumatologist who was supposed to provide me with a diagnosis and report was unwilling to do so because he doesn't believe in CFS/ME or Fibromyalgia.*
- *Specialist Rheumatologist - blaming me for my illness and for my lack of activity causing further medical issues, and putting down the specialist MECFS Doctor I used to see. He had made me cry the last 2 times I have seen him. He seriously needs to develop / learn more care and empathy!*
- *I was originally diagnosed with ME/CFS in Westmead Children's Hospital in 1993 when I was 15. When I was 30 I had a major flare up and was told by my GP to see an immunologist. This immunologist told me there was no such thing as ME/CFS and treated me for Rheumatoid Arthritis. When the tablets didn't improve my symptoms and made me worse, he sent me to a Rheumatologist who had me do a bone scan. When the bone scan showed no damage to my bones, the Rheumatologist said there was nothing wrong with me, I was just suffering from lethargy and needed to exercise more. He said he didn't need to see me again. When I paid for the appointment the receipt said under Description: "The patient has a psychological condition which has manifested itself from birth."*

A contributing factor to finding someone able to help is the lack of specialty in ME/CFS. Patients must rely on their GP to coordinate care, or try to get an appointment with one of the few GPs in Australia who are experienced with ME/CFS. These GPs are often extremely expensive and extremely busy.

Recently, one of these rare ME/CFS GPs died, leaving hundreds of patients – some of whom are extremely unwell – with no one to take on their care:

- *I moved from Brisbane to Melbourne so I could attend a specialist CFS clinic. Unfortunately, after my first appointment, the lead practitioner died, & as he had not completed the training of the other doctors in the clinic, it closed. I think the CFS community needs to support the training of specialist doctors so that there are medical practitioners who do understand our illness, & do know things that have helped other sufferers, who we can see. It is exhausting constantly having to educate people who mostly are just humouring you anyway.*

For young people, disbelief and abuse from the healthcare system can be even more devastating. This young person didn't have a parent who believed in their disease, or support from the healthcare system:

- *Mostly as a young adolescent where I was reliant on my parent to advocate for my care and attention. My symptoms were largely ignored and my parents downplayed them. I lost faith in the medical systems for a long time - I felt ganged up on, made to feel like I was lying and that my symptoms were simply depression or that I was making things up.*

Another young person, this time over the age of 18, did have a supportive parent. But in this situation, this support was still not enough because the healthcare provider did not deem the respondent's cognitive impairment 'real':

- *I am 22 years old and live at home. My parents are heavily involved in managing most aspects of my medical care and interactions with the medical system. Often, particularly during stressful/complicated events (such as admission to hospital for an operation and ganglion cyst aspiration) my mum and I have had significant difficulty in getting my wish for my mum to speak on my behalf, be present in discussions with medical personnel and be involved in any decision I might have to make in regard to medical care, respected, even when we have presented official legal documentation (statutory declaration) because I'm officially an adult and not considered to have a 'real' cognitive impairment. This issue has occurred in both public and private hospitals in the context of both in-patient and out-patient procedures with administrative staff, radiologists, nurses, and doctors.*

The abuse that people with ME/CFS experience will continue to occur because of Australia's outdated clinical guidelines. Those who are diagnosed with ME/CFS face being prescribed two, harmful or ineffective treatments that are still recommended by Australia's clinical guidelines: cognitive behaviour therapy (CBT) and graded exercise therapy (GET). Both these treatments have been removed from international guidelines for managing ME/CFS due to their ineffective and/or harmful nature.¹⁴ These respondents describe how these treatments have caused worsening of symptoms which, for many, have been permanent:

¹⁴ National Institute for Health and Care Excellence (2019). 'Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management'. Available at: <https://www.nice.org.uk/guidance/ng206>; Centers for Disease Control and Prevention (2021). 'Clinical care for patients with ME/CFS'. Available at: <https://www.cdc.gov/me-cfs/healthcare-providers/clinical-care-patients-mecfs/index.html>.; Bateman, L, Bested, AC, Bonilla, HF, et al (2021). 'Myalgic encephalomyelitis/chronic fatigue syndrome: Essentials of diagnosis and management'. Mayo Clinic Proceedings, 96:11, 2861–2878.

- *Specialists and doctors as well as exercise physiologists that believed GET is the cure to ME/CFS and pushed me to do it. As a result I relapsed and had to stop work. I remain predominantly house bound and haven't been able to return to work since.*
- *GP recommended GET/CBT program which ultimately caused serious decline in my health.*
- *A psychiatrist refused to listen, and went ahead with treatment that cause[d] a relapse*
- *Coercion to do exercise therapy despite having tried it twice and got worse, coercion to take psychiatric medications without mental illness, contemptuous treatment, esp by specialists and hospital dr and nurses, being repeatedly told I am not sick and I have a somatising psychiatric condition where I express repressed emotions through physical complaints. I have been told that my hypersensitive reactions to medications which involved anaphylactic type reactions were anxiety. Lots of gaslighting.*

As this last section demonstrates, outdated, incorrect beliefs about ME/CFS have caused significant harm to this patient cohort. Frustratingly, such abuse is unlikely to change until Australia's 20-year-old clinical guidelines are updated, and widespread GP education about the real and disabling nature of the disease is implemented.

ii. Reasonable Accommodations

Reasonable accommodations for people with ME/CFS can be very easily achieved and provide significant assistance to the patient. Despite this, one of the most common examples of abuse reported in our survey for the Royal Commission was a lack of reasonable accommodations. In the healthcare setting, these situations most commonly occurred in GP clinics and hospitals. Reception staff, nurses, GPs and specialists all failed to assist people with ME/CFS with simple accommodations.

Most people with ME/CFS have hypersensitivity to noise, light and smells. Many also have orthostatic intolerance (OI), which means they need to lie down to reduce symptoms and conserve energy. As these respondents explain, some healthcare providers actively did the opposite when reasonable accommodations were requested:

- *After asking for a quiet/dark space, hospital intentionally put me in the most loud and bright location saying it would be "good for me".*
- *A GP ridiculed me when I asked him to write bullet points of his recommendations due to cognitive dysfunction.*
- *On one occasion after [patient name] was afforded a bed in a medical clinic, the hostile nurse came back in and angrily said he didn't look unwell enough (the colour returned to his face once he was supine due to orthostatic intolerance), suggesting he was just lazy and kicked him back out to the wait room. The sitting upright triggered PEM which lasted for days and affected his sleep cycle for many weeks.*

Another example shows how this form of abuse led to neglect, when appropriate accommodations were not provided, and the respondent was rendered unable to care for themselves. This respondent was experiencing post-exertional malaise (PEM), a core symptom of ME/CFS, where the body has run out of energy and symptoms are at their worst. Even the smallest task can be extremely difficult to complete when in PEM:

- *[I] requested help from nurses with washing in bed with a basin and eating (I was at the time so sick I could not feed myself or sit up or wash myself). Nurses would bring me food and basins of water and put them on the over-bed table intentionally out of reach and refuse to help me with them. They TOLD me this was to motivate me to wash myself/eat independently. I ended up not being fed/washed for an entire week (except one pot of yoghurt fed to me by a visitor) until I self-discharged against their advice.*

The same respondent made a complaint about the care they received. The hospital's response does not consider the specific needs and energy limitations of people with ME/CFS, highlighting the systemic nature of the abuse and neglect these people experience:

- *I spent 6 months putting together a complaint (to the patient liaison person at the hospital) about the above things, and the ward's response was "We once again reinforce the importance of maintaining a maximal level of independence at all times for the benefit of your own rehabilitation" and they blamed me for discharging myself.*

However, this respondent is rare because they made a complaint about their care. Very few people who responded to our 2019 Health and Wellbeing Survey lodged a formal complaint about their medical provider:

- 4% lodged complaint against hospital or GP
- 2% about specialist
- 1% about allied health.

Abuse has made ME/CFS patients reluctant to make complaints, as they fear it will lead to withdrawal of care. The respondent below describes their fear to complain, compounded due to widespread disbelief in their ME/CFS, despite a clear and unnecessary medical intervention:

- *A doctor in hospital took blood pressure on top of my cannula site to cause deliberate pain and refused to move it further up the arm (where it should be taken). I didn't complain because I was too scared of the doctor.*

This section has demonstrated how mis- and dis-belief about ME/CFS among healthcare providers has led to the abuse and neglect of patients. In the following section, we provide examples of how similar ignorance has occurred for people with ME/CFS in society.

b) Society

98% of respondents to our survey for this submission had experienced violence or abuse in a nonmedical situation. This section covers a wide range of societal situations. The breadth of situations demonstrates how the disbelief and stigmatization from the medical profession has permeated into all other aspects of life. As one respondent put it, *“The biggest problems is understanding and appropriate support from the medical community. This will help the wider community to understand this illness is real.”*

We begin this section with examples of abuse from government social services, such as Centrelink and in-home care. This section concludes with a brief account of abusive, day-to-day interactions with the public.

i. Government support

Lack of research into the permanency, severity and biological causes of ME/CFS mean people find it extremely difficult to access to financial supports, like insurance, the disability support pension and NDIS. These people describe the abuse they experienced from doctors, specialists and insurance companies when seeking financial support:

- *I was verbally abused by a doctor carrying out an assessment for the DVA. He falsified his report, and I lodged a complaint with DVA and APHRA.*
- *The worst treatment has been from specialists who called themselves Fatigue Specialists. My partner was told they must leave the room, and then a second specialist was called into the room to shout at me because i had the temerity to suggest I'd like to try applying for DSP because i couldn't work and centrelink was insisting i shouldn't be on newstart anymore if i was so sick. I was told i was basically scum for burdening the taxpayer and was terrible for not believing the specialist could cure me (even though I'd read the medical research saying there is no cure, and he wanted me to do harmful and disproven exercise). I've subsequently been told i couldn't possibly be as sick as i claim or i wouldn't be able to attend the appointment, even though i had to undertake extreme measures to attend.*
- *After 30 years of severe ME and other permanent conditions, and 12 years with basic care, all care was taken from me by the NDIA. On two separate occasions an advocate went to ministerial intervention, the Commonwealth Ombudsman and the CEO's officer in order to get only some of the recommended NDIS care installed. The CEO's officer apologised for my treatment both times. 3 years into applying, I am still waiting for adequate therapy funding from the AAT. The systemic discrimination, neglect and suffering of the ME community has made my NDIS application the most traumatic experience of my life. Without the support of my carer, my advocate and my large team of long term medical professionals, I don't know how I could have coped. My carer is too traumatised to make a submission.*

- *In an insurance assessment report it was suggested I am very smart and I'm faking my illness but I'm too smart to get caught. Another insurance assessment report suggested my ME/CFS Dr by giving me a diagnosis had entrenched my 'illness belief' to such a dangerous level that he had caused a lifelong illness in me. That had he just ignored my symptoms That they could have used CBT to cure me.*

Such examples strongly suggest a lack of understanding of the disease, which means people living with ME/CFS cannot receive the adequate care or support to which they are entitled.

ii. *In-home care*

For those who did receive government support, in this situation in-home care, lack of understanding of the disease led to abuse:

- *Carers insisting I stand to help with food preparation etc, when too ill to do so, because they couldn't hear me about how sick I was.*

This respondent experienced sexual, psychological and physical abuse, including abuse that deliberately targeted their energy limitations:

- *Over the 9 years I have been bedridden I have had two private carers, both abusive. Both have sexually, psychologically and physically abused me in ways you can abuse anyone, but also abused me in ways specifically designed to harm someone with CFS, such as not letting me rest and pushing me to the point of collapse, meaning I can never get a chance to stabilise or improve.*

I have attempted to get outside support (eg HACCC) so I no longer have to rely on abusers to stay alive, but have been met with resistance, such as being told I could only get it under the condition I saw a) a psychologist I was too ill to see (I was largely non-verbal at the time) and couldn't leave my bed to see nor afford to pay b) housework help would only be provided if over a few sessions I would build up to doing all the work for myself. At this time I was eating several thousand kilojoules less than I needed as I was without meal support, showering every 2 months which took great effort and much recovery, and received no help with toileting leading to permanent bladder damage, and frequent bedwetting and having to sleep in urine soaked sheets that were changed only twice a year.

The abuse has had significant impacts on my physical and mental health, I have become totally isolated unable to see any friends, and I cannot access necessary medical care such as a very long overdue pap smear. I feel powerless, my quality of life is abysmal, and I think about suicide most days (I do not have a plan, I just wish euthanasia were an option for me).

As seen in this example, the consequences of this abuse touch on almost every aspect of living. This person was not receiving adequate care in a number of ways, from food intake to personal hygiene, to routine medical care. They continue to experience long-term physical and mental harm from this abuse.

iii. *The public*

25% of people with ME/CFS are house- or bed-bound. The remaining 75% are usually capable of leaving the house for appointments, although it may cause a crash. Those who are mild to moderate are often able to work and socialise, although usually with accommodations like disability stickers or reduced work hours. The experiences of people with ME/CFS in public range from passive aggressive abuse, to threats of violence:

- *Constantly face comments that indicate I'm just tired like everyone else is. People don't understand PEM; that there are temporary or permanent consequences to "pushing through". Friends snarkily comment that they'd feel better working fewer hours too.*
- *I have POTS [postural orthostatic tachycardia syndrome] which is a common symptom of ME/CFS. I have had 2 episodes in pubs which resulted in the management kicking me out because I looked drunk. My friends and staff members informed management of my condition (I was still out of it on the ground) and they said that they didn't care what condition I had, it looked bad for them (because I was in my early 20's) so they kicked me out.*
- *On multiple occasions I have received verbal and written abuse when parking in a disabled car space, with a valid disabled permit. The written abuse was strong, foul language telling me off for parking in a disabled space outside his mother's home. The verbal abuse was screaming in my face for parking outside the woman's home in the disabled parking spot her husband parks in. I believe both situations arose because the general population isn't educated about invisible illnesses, like ME/CFS and that such illnesses can render you seriously physically disabled at any age. I can't count how many times I have received more subtle responses from people for the same reason of ignorance.*

For this respondent, the church she attended did not accept the energy limitations of her ME/CFS, deeming her unsuitable to marry men from the same church:

- *I went to a church for 12 years and was accepted by a few people but those in leadership never accepted me as being of good character and motivation. They advised that I needed to participate more in their programs. They never understood the physical limitations I was living with no matter how many ways I tried to explain. Their lack of acceptance meant that I was seen as a young woman who was not suitable for marriage to young men of the church.*

These examples demonstrate the everyday situations people with ME/CFS experience violence and abuse. While some examples are more overt than others, the outcomes are the same: disbelief, stigma and unnecessary barriers to being included in society.

c) **Employment and Education**

The same themes in 4.1 a) *Health* and 4.1 b) *Society* sections are repeated here in 4.1 c) *Employment and Education*. Disbelief in the disease, and/or severity of symptoms, meant these respondents were not believed by their employer, and struggled to obtain accommodations in the workplace:

- *After I became sick with me/cfs from a virus, I was originally called names like “attention seeker”, “lazy” etc. Even though I tried so hard to continue working. My new boss didn’t support me because I had me/cfs and they believed it was psychologically caused.*
- *People at work (school) did not understand this disability and how it affects everyone differently. I was compared to someone with a much milder form of fibromyalgia and I was told to “buckle up” and “don’t let yourself go”. I was not able to get flexible hours so had to leave.*
- *Workplace abuse where supervisor refused to accept a medical certificate for ME/CFS. I had to get HR and union involvement before she would accept the certificate and supply appropriate desk, chair, monitors, working hours and training.*
- *One of the Managers where I was doing part time work subjected me to harassment because of my flexible working arrangements but made considerations for legal staff who were pregnant or had small children. It upset me so much I left the job.*

Briefly discussed in 4.1 a) *Health*, the abuse young people with ME/CFS experience can be particularly devastating. It can establish a poor relationship with the healthcare system and effect social and educational development. The young people below describe experiences of abuse at school and university. Lack of accommodations, either because of disbelief in the existence or severity of symptoms, and a lack of understanding about how symptoms are exacerbated are the consistent theme:

- *At my first high school... I felt like I was always having to defend myself against and validate my condition in many different situations such as being pressured to participate in activities e.g. PE on a particular day, science experiments involving extremely bright lights or strong smelling chemicals, that I knew would have an excessively negative impact on my health, requesting extensions or other academic/uniform/excursion etc. related adjustments.*
- *I had two particular male teachers in secondary school bully me into participating in sporting activities, even though I had a doctors certificate allowing me to not participate in sport. I also had another male teacher verbally abuse me in school as I missed out on an important exam due to being ill and when I came back to school called me out in front of the whole class asking why I wasn’t at school (even though my mum had phoned the school and explained my absence).*
- *A lecturer bullied me about my need to do an exam in special exam conditions: I'd followed all the instructions given by the uni as to how to arrange it, but then received an email going on about how I should've contacted the lecturer first (not in the instructions) and how it was all very inconvenient for him.*

Parents are often blamed for their child’s illness. The same misbelief about ME/CFS being psychological extends to parents, leaving them feeling like they are bad parents, enabling their child’s illness:

- *Humiliated when my parenting was called into question - suggestions a couple of times that I think my daughter will get well, she will. Like I'm making her sick.*
- *I'm tired of feeling like I'm being punished for having a child who needs care. So many people don't listen - doctors, school, support workers, etc - and put us in the 'too hard basket'.*

As this section has shown, parents, carers and people living with ME/CFS have all experienced violence and abuse because of people's poor understanding of ME/CFS. The stigma and discrimination these people have experienced is, in many cases, unique to ME/CFS and the limitations of the disease. However, there will be commonalities across all people living with a disability, visible or invisible. In the next section, we provide examples of neglect in health, society and employment.

4.2. Neglect

The Royal Commission defines neglect as including

physical or emotional neglect, passive neglect or willful deprivation. Neglect can be a single significant incident or a systemic issue that involves depriving a person with disability of the basic necessities of life such as food, drink, shelter, access, mobility, clothing, education, medical care and treatment.

Respondents to our survey for this submission reported experiencing neglect in a number of settings, including health, society and employment. We have selected a small number of examples to demonstrate breadth and common themes across these settings.

a) Health

As in section, *4.1 Violence and abuse*, we received an overwhelming number of responses about neglect in the hospital setting. In this section, we provide a selection of examples of neglect in the health setting experienced by people with ME/CFS. There are two key themes to this neglect. First is bias, where the respondent was not provided care due to their diagnosis of ME/CFS. Second is a lack of understanding by the healthcare provider about the needs of the person with ME/CFS. In some cases, a combination of both led to particularly shocking cases of neglect in the health setting.

This qualitative data is supported by the 93% of respondents to our survey who reported they had experienced neglect when accessing hospital facilities or seeking medical advice, as shown in *Figure 2*.

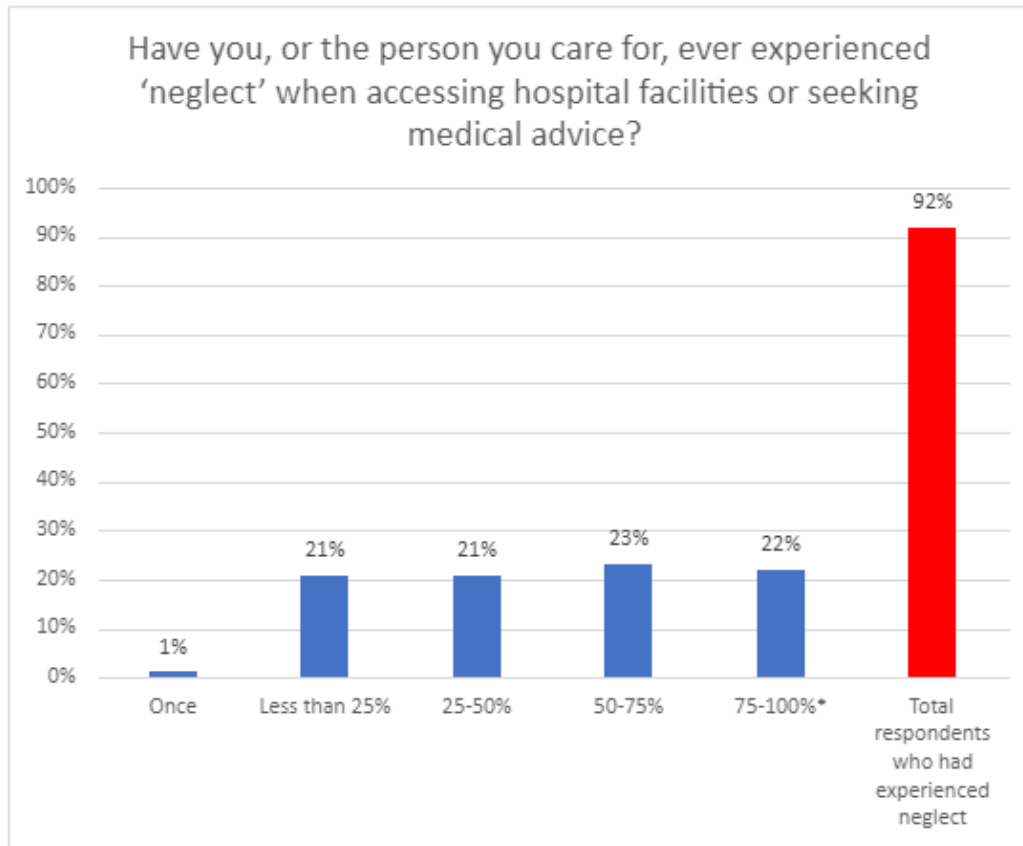


Figure 2: Neglect experienced % of the time when accessing hospital facilities or seeking medical advice

The following are examples of neglect experienced by people with ME/CFS in various healthcare settings. Not having a place to lie down was the most common form of neglect. For people with orthostatic intolerance, a place to lie down is the equivalent of ramps for wheelchair users: it is fundamental to access.

This is because orthostatic intolerance is a common comorbidity for people with ME/CFS. Orthostatic intolerance is where symptoms are exacerbated upon standing, due to poor circulation of the blood. Being able to lie down means people are at less risk of fainting, able to reduce other symptoms and better manage their energy expenditure.

These respondents explain situations where they were unable to lie down:

- I am primarily house and bedbound but received (non cosmetic) nasal surgery to improve my breathing. I was left on the floor of John Hunter Hospital after collapsing due to the mismanagement of Orthostatic intolerance and other ME related symptoms which were clearly discussed with all relevant Drs, staff and departments prior to admission. The specialist Dr and staff promptly left me unconscious on the floor while my carer and a student Dr attempted to help me regain consciousness. A nurse returned and threatened to "call security to take me to the E.D if I'm not out of their department in 10 minutes". I was on the hospital floor unconscious because the Dr had accidentally cut my nose while removing nasal stents and physically kept forcing me to sit upright to continue removing them despite my and my husband/ carers pleas to*

lay me flat before I collapsed. That was the 2nd incident in 4 weeks that I was physically man handled and forced to sit up and collapsed unconscious as a result. All medical staff involved had access to digital, physical and verbal instructions from my Dr's specifically related to my symptoms and risk management. Clearly all these were ignored, as were our verbals pleas to cease physical force and allow me to lay flat to prevent a collapse. This is unfortunately a common experience for us within the health system.

- *I have had trouble with ER when presenting with orthostatic intolerance, i was extremely dizzy to the point of throwing up on the ER floor and had to lie down on the ER floor and it took nearly 2 hours to take a preliminary blood pressure reading to find out how bad i was. The first Dr i saw was good and put me on IV saline (after extreme difficulty finding my normally prominent veins) which fixed me up. After change of shift, before the scheduled fluids were complete, a second doctor basically came and chucked me out, implying i was wasting their resources and orthostatic intolerance was not real.*

Many respondents provided descriptions of extreme neglect in the emergency department at hospital. All of these respondents were dismissed without adequate care, with some dismissed and told their ME/CFS, or their symptoms, were psychosomatic:

- *Had infection so went to ED said I had ME/CFS to triage nurse, he said we don't entertain that here, I couldn't face dealing with that ignorance so went home without seeing a Dr. And many more instances.*
- *I often collapse when I am having a flare up and I can't move or communicate, when this first started happening a couple of years ago, my parents called an ambulance. The paramedics were really kind to me but it was obvious they had no knowledge about ME/CFS. When I got to the hospital, I was stuck in a hallway under bright lighting and with lots of noise that made me feel really nauseous. Finally I got to see a doctor who basically said there was no reason as to why I collapsed and I didn't need to be in hospital. There was no follow up advice as to why this had happened or why I couldn't move afterwards or communicate at all, I was very much made to feel like I had made up everything.*
- *The most demoralising experience I had was when my husband, fearing I was dying, carried me into ED. I hadn't been able to eat or drink adequately for around 3 months. I had lost a lot of weight and was in and out of consciousness. The ED doctors were dismissive and left me unattended for long periods of time. After running some tests I was given 2L of IV fluids, electrolytes etc. And the head Dr of the ED told me there was nothing wrong with me and he believed I was deliberately starving myself & he couldn't do anything for someone who was making themselves unwell. Thankfully the next day, my GP organised for me to have daily IV fluids until I recovered enough to eat and drink normally.*

For this respondent, access to hospital care could only be achieved by presenting to emergency. It took three visits to the emergency department before they were admitted, each of these visits taking a significant toll on their physical health. Once admitted, the respondent was incorrectly diagnosed, which delayed appropriate care:

- In 2015 when I was 17, my adolescent general physician who I'd been seeing for 6 or so years at the Royal Children's Hospital in Melbourne, recommended a scheduled admission to the RCH to try and stabilise my severe spiralling crash (I was barely able to sleep, in constant agony, unable to eat properly, and unable to go to the toilet and things were deteriorating every day). This was sorted out with the hospital (I don't know how the process works) but the day before, my doctor was told they didn't have any spare beds anymore for non-emergency cases. The only thing she could recommend was that I go to emergency at the RCH and hope I could be admitted that way. My mum had to take me 3 times over the course of 2-3 weeks and the first two visits we stayed for hours without any result. Obviously the emotional, psychological and cognitive overexertion spending hours waiting in the emergency department greatly exacerbated my downward spiral. Despite communicating the urgency of the situation, my doctor was unable to get anywhere and the only advice she could give was to go back and refuse to leave. My mum and I did this, and I was finally admitted over 3 weeks after I was meant to be, in a significantly worse condition. Then, to make matters worse, the hospital doctors and nurses insisted that the symptoms I was displaying were consistent with a manic episode of bipolar disorder despite what I, both my parents, my specialist, and my GP said. Proper treatment (e.g. strong pain relief, anti-nausea medication, sleeping pills, IV hydration etc.) was delayed whilst discussion went back and forth re whether or not I was experiencing a manic episode. (I have not, at any point in my life, been diagnosed with bipolar or any other serious psychiatric disorder that could have accounted for my symptoms). This caused further emotional and psychological distress and made things even worse. I am still recovering from that crash now, in 2019, and there is a LONG way to go.*

People with ME/CFS often require additional assistance before and after medical procedures. This can be due to the extra toll hospital admission and surgery takes on energy capacity, and high sensitivity to environment and medications. As these respondents explain, hospitals did not take their needs into account:

- After a surgery for an issue unrelated to ME/CFS I was treated awfully by the nurse who was supposed to be caring for me post-op. After asking numerous times for pain relief, when she finally came to give me something I was unable to speak and too weak to lift my arm from under the blanket so she could access my cannula. She left the room and later told my doctor I had 'refused pain relief'. She also wouldn't help me with showering or dressing because that 'wasn't her job' even though pre-op I had made it clear to the hospital staff that I would need help with these things.*
- Ignored my chemical sensitivity in hospital causing me severe migraines and not medicating appropriately. Refusing to do genetic testing despite doctor referral.*

Due to many of the issues raised above, many people with ME/CFS decide to no longer access healthcare. For them, it is better not to seek medical help than suffer the violence, abuse and neglect they experienced in the past when engaging with medical services, as these respondents explain:

- In over 3 decades of attempting to find care and support for my severe ME I have failed completely. I now consider the medical profession to be detrimental to my physical and mental health. The dismissal and outright negligence and verbal abuse I have been subject to has cut*

deeper even than the actual loss of my life to ME.

- *We now often just don't go to the hospital for fear of being gaslighted. For example, I have an anaphylactic allergy that we will manage from home with steroids in the hope I can avoid the hospital.*
- *My son has received some excellent care in EDs, but currently he would have to be unconscious or near-death before he would return to the Emergency Department. It usually makes him much sicker after attending (for weeks) and they usually are too frightened to give him any medications anyway in case he has allergic reaction to them. It is actually terrifying knowing that the one place you should receive care in an emergency is really not equipped to understand and deal with situations that arise. When he's fragile - taking him to an environment like that is definitely abusive. We have to make that call.*

As mentioned in section 4.1, 25% of people with ME/CFS are house- or bed-bound. Respondents in this severe category describe particularly shocking, but all too common, situations of neglect. For example, it is extremely difficult for those most severely unwell with ME/CFS to attend medical appointments due to their level of disability, and the dangerous effect such visits have on their symptoms:

- *Ever-present knowledge that although I have a GP now that if she ever leaves the clinic then I can be hung out to dry with no GPs ever willing to take on new bedridden patients (she continues to see me as I saw her first when I was briefly able to use a wheelchair).*
- *Almost complete inability to see specialist doctors.*
- *Non-availability of home visit by a doctor. A visit to dr makes me worse afterward. Further tests are also unavailable to me.*
- *It is assumed I can physically attend medical appointments when to do so harms me.*

With extremely limited energy, many people with severe ME/CFS are too sick to apply for supports, resulting in neglect from the healthcare system:

- *Housing a young 24-year-old ME/CFS patient in the geriatric, dementia ward leaving the patient no alternative but to discharge herself due to safety risk.*
- *There are no supports to help those who need assistance but are too sick to apply. Social work won't help, disability advocates aren't available/won't help. If someone is bed bound on their own with no family support no one helps them.*

Such lack of support, and subsequent neglect from support services, meant this respondent felt humiliated and embarrassed due to their limited ability to care for themselves and their home:

- *In own home- don't have help or career or supportive partner so while not humiliated or abused by others as such, the fact that I cannot shower myself or bathe, or wash my own hair, can sometimes brush my hair, so, times brush teeth, can't shave legs or arm pits, can't do my nails- does humiliate me - as so, done who used to be very well presented with I, immaculate makeup/hair/nails - I see people's shock when they see me. I hate looking in the mirror and in*

fact have made habits not to as much as possible, adding the weight gain-...same thing goes for the house- used to be immaculate - now is filthy and am extremely embarrassed by it. So I say yes- these things have stripped dignity and feel humiliated when anybody comes to the door.

This respondent was able to get government support, the DSP, but the allowance was not enough to cover visits to allied health professionals:

- *Not able to access some of the providers I need to help reduce symptoms e.g. physiotherapist, occupational therapist & nutritionist as I can't afford to pay them on the DSP. Five visits on an extended care plan is not enough if you need to see someone weekly for months like I will need to see the physio. Can't get any help to pay for having massages which is probably the main thing that will help relax & ease inflammation in my muscles.*

Finally, greater support through Medicare was raised as another point of neglect. For these respondents, lack of Medicare funding restricts their ability to receive healthcare:

- *One of the biggest neglects is how Medicare is structured. That i can't see my doctor about 4 issues in one day, thus reducing the number of tiring trips outside the house, because there is no Medicare code for extra-long appointment. That i can't skype my specialist on Medicare (who is quite happy to on full fee) because all Medicare codes require in person attendance. I can just manage to attend appointments, but fear what might happen if i get worse. There needs to be better structures for remote appointments for housebound people under Medicare.*
- *Lack of access to medical and health care is discrimination. We need regular phone consults and home visits from a regular GP who knows us AND knows about CFS (not a random after-hours GP), a counsellor and allied health professionals. Lack of health care makes symptoms worse and decreases quality of life. This should be fully funded by Medicare for those who need it.*

These examples describe a healthcare system that does not understand or meet the care needs of people with ME/CFS. For some respondents, repeated and/or significant cases of neglect from the healthcare system has led them to decide they are better off without it. Shockingly, it is often those who are most unwell and in need of care who decide to no longer engage with Australia's healthcare system.

b) Society

82% of respondents to our survey for this submission have experienced neglect in a non-medical setting. Neglect in non-medical settings discussed below include the areas of transport, homelessness and social isolation.

These examples are broad, however carry a consistent theme of assumed choice – that somehow the person living with ME/CFS can choose their level of disability, and that the person withholding assistance is able to influence this. For example, one respondent reported their experience being denied a wheelchair at the airport, where the airline was able to choose whether to provide a wheelchair:

- *Qantas did not provide a requested wheelchair at the end of a trip, their employees sent me staggering all over the terminal to find a wheelchair, one of whom asked if I could walk why did I*

need a wheelchair. When my mother complained she was told a wheelchair request was just that - request only which may or may not be granted.

For this respondent, neglect took the form of a lack of information about support available to them due to their ME/CFS:

- *Took over 10yrs to be informed I was eligible for rebate on electricity due to my illness.*

Homelessness is a significant issue for people living with ME/CFS. For this respondent, a lack of affordable housing that catered to their health needs meant they found themselves homeless:

- *I have been unable to find housing since terminating the lease with an abusive flatmate. As a part-time student at University ... I went to the Housing Team for help. The Uni has just opened 2 new residential buildings near the campus so I thought there might be something there for Disabled students. It turns out this accommodation is for International Students and was priced accordingly. They were unable to offer me accommodation near the uni (or at all) that was affordable on the Disability Support Pension. The College environment and the Student Hostel environments are not suitable for me as I am hypersensitive to noise and get migraines. I have been homeless and couch-surfing since November. I cannot get an apartment as real estate agents cannot approve me for one on my DSP income. I'm not comfortable moving into another share house situation given my experiences and don't think I would be welcome given my sleeping schedule and need to be home alone so much. I am seeking help from a Homeless Charity tomorrow.*

Another disturbing consequence of the disbelief and/or misunderstanding about ME/CFS is the loss of relationships. These respondents report neglect from family and friends due to living with ME/CFS:

- *We have been forced to cut off contact with my husband's sister family - my son's uncle, aunty and cousins. Their inability to understand what ME/CFS is led to great family disharmony, including them calling my husband up and telling him he just was not disciplining our son enough, saying if we weren't so soft, he'd just stop malingering. This led to great personal distress given our son was in so much grief about the loss of his formerly great life that he had felt suicidal. Their misunderstanding about this condition despite many attempts to clarify it, has meant we now do not attend Christmas with his family anymore, another loss for our children.*
- *I have lost a relationship due to expectations of me unchanging following diagnosis and lost childhood friends who joined forces in a group conversation to say that I'm frustrating for cancelling plans or not committing to plans and that I just need to get out more and have more fun.*
- *Estranged from my family due to stigmatization and the associated neglect and abuse.*
- *I've had my entire step family just pretend I don't exist anymore.*
- *I have been "defriended" by most of my friends becoz they don't understand ME/CFS and I can't live up to their expectations. "You're not ill, you're just too busy." Once I pleaded to sleep at a*

"too busy" friend's house one night as I was too dizzy to drive home (1 and 1/2 hours away). After many years of friendship I am no longer welcome there.

This section provided a wide range of examples of societal neglect people with ME/CFS have experienced. The lack of understanding about the disease explained in previous sections extended here to assumed choice about the respondents' level of disability, or whether the family member, friend or service provider chose to believe their disability and/or need for support.

c) Employment

Emerge Australia's health and wellbeing survey found 89% of respondents ceased or significantly reduced paid work after illness onset, and more than two-thirds of people with ME/CFS live below the poverty line.¹⁵ Another study found unemployment rates ranged from 35% to 69%.¹⁶ The neglect discussed below is the withholding of reasonable accommodations at work, or withholding employment altogether:

- *Refused to allow me to work part time and then sacked me.*
- *Terminated from my job due to "poor performance" despite 6 months of medical certificates covering reduced hours.*
- *Early in 2019, when I first began to seek answers and a diagnosis after falling severely ill with a virus and unable to recover well - my employer treated me badly, unsatisfied with my performance at work. This employer prevented me from having the space to have the conversation with her about my illness and what I was doing to try and get better. I resigned due to a toxic and unhealthy, unsympathetic work environment.*
- *Workplace (at daily newspaper). Primarily from human resources personnel, two in particular; harassment, stigma, mistrust, innuendo, ultimatums, grudging attitude. Attempts over three years, while working and on paid and unpaid sick leave, to terminate my employment. My sense of the stigma, along with dealing with illness, affected my ability to effectively advocate for myself. Exacerbated ME, added anxiety and depression. They played on this.*

Denying these respondents belief in their illness and severity of symptoms, these employers neglected to take the health and wellbeing of their employees into account. Improving the rights of employees to access reduced hours and other accommodations will aid to reduce the significant financial and emotional stress that loss of employment can cause.

¹⁵ Emerge Australia. 'Health and Wellbeing Survey 2019'.

¹⁶ Emerge Australia. 'Health and Wellbeing Survey 2019'.

Conclusion

Emerge Australia would like to sincerely thank all of those people who participated in our survey for this submission, and for sharing your stories of violence, abuse and neglect. The number over responses was overwhelming, both in respect of how the system has failed you, and how many of you were willing to share your experiences. We are so very grateful you chose to use your precious energy sharing your experiences with us. Through your participation, you have enabled us to inform this Royal Commission about what it is like to live with a disabling, misunderstood and stigmatised invisible illness.

In this submission, we have explored a number of areas where people living with ME/CFS have experienced violence, abuse and neglect. The health setting was the most frequently reported, with disbelief and lack of understanding underpinning much of the violence and abuse respondents faced. The lack of understanding included the severity and disability ME/CFS can cause, as well as the ways symptom exacerbation can be minimised. A failure to provide reasonable accommodations, like a place to lie down, is a fundamental barrier to access healthcare for most people with ME/CFS. That such a simple request is unable to be accommodated is discrimination, and a blight on those who refused to provide such care.

Disbelief in the medical profession had a significant impact on how people with ME/CFS were treated in society, at school and at work. Respondents provided numerous examples across government support, in-home care and in public of the violence, abuse and neglect they experienced. Those still able to work or go to school faced verbal and physical violence and abuse. They struggled to obtain accommodations afforded to others, like reduced hours of work or more hours to complete assignments, and as a consequence, were often forced to leave.

People living with ME/CFS often feel loss of dignity and control over their lives due to the disabling symptoms of the disease. Distressing experiences of violence, abuse and neglect from family and friends were reported by respondents. Social isolation is already a significant issue for people living with ME/CFS, without the added isolation from family and friends who don't understand the illness. Often described as 'lazy' and 'attention seekers', it is not difficult to understand why people with ME/CFS find it easier to no longer have these people in their lives.

As noted in the recommendations, there are ways to decrease the likelihood of people living with ME/CFS experiencing violence, abuse and neglect. The common theme is to increase understanding about the disease. This must occur through education and research funding. Assessors for support, like DSP, NDIS and superannuation, should similarly receive education about ME/CFS and its core symptom, post-exertional malaise, so they can more accurately assess applicants. Emerge Australia strongly believes such education would increase the number of people with ME/CFS who are able to gain government support, which would significantly reduce financial stress and improve quality of life.

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Appendix 1 - Survey Questions

Q1. Do you have ME/CFS and/or are you a carer of someone with ME/CFS?

- a. Yes – I have ME/CFS
- b. Yes – I am a carer of someone with ME/CFS
- c. No

Q2. If you have ME/CFS, are you housebound/bedbound? If you are a carer for someone with ME/CFS are they housebound/bedbound?

- a. Yes
- b. No

Q3a. Have you, or the person you care for, ever experienced 'violence or abuse' accessing hospital facilities or seeking medical advice including through practitioners such as GPs, specialists and allied health professionals?

This could include:

- Coercion to undergo harmful treatments.
 - A requirement to use inappropriate facilities in order to access care, for example, medical/hospital facilities with bright lights, loud sounds, nowhere to lie down/rest, long wait times, or lengthy processes which can exacerbate ME/CFS symptoms.
 - Responses from medical professionals which made you feel humiliated or verbally abused.
- a. Yes
 - b. No

Q3b. How often have you, or the person you care for, experienced 'violence or abuse' in a medical setting?

- a. Once
- b. Less than 25% of the time
- c. 25-50% of the time
- d. 50-75% of the time
- e. 75-100% of the time

Q3c. OPTIONAL This space is available if you would like to provide further information about the experience which stands out most to you. Please try to keep your example concise. It is helpful for Emerge Australia to know the type of medical practitioner or facility that was involved in this experience (eg. GP, receptionist, hospital, public practice) and any reflections on how systems can be improved to avoid this happening to anyone in the future.

Q4a. Have you, or the person you care for, ever experienced 'violence or abuse' in a non-medical situation, such as at school, at work, with friends and family, or with formal or informal carers?

For people living with ME/CFS, this could include:

- Stigmatisation of ME/CFS, which could include harassment or humiliation about having ME/CFS.
- Significant violations of privacy and dignity in the workplace or at school, such as unwanted disclosure of your condition and experiences of living with a disability.
- A failure to provide suitable adjustments to enable symptom management at work, at school or in another non-medical context.

- a. Yes
- b. No

Q4b. OPTIONAL This space is available if you would like to provide further information about the experience which stands out most to you. Please try to keep your example concise. It is helpful for Emerge Australia to know the context of the experience (eg. Secondary school, type of workplace) and any reflections to prevent this from occurring in the future.

Q5a. Have you, or the person you care for, ever experienced 'neglect' when accessing hospital facilities or seeking medical advice through practitioners such as GPs, specialists, and allied health professionals?

This could include:

- Failure of medical practitioners/other experts to hear, believe, and/or understand the experience of living with ME/CFS, leading to an inability to access appropriate medical support and treatments.
- Failure of medical practitioners to provide home visit to people with ME/CFS, resulting in exclusion from medical care for housebound and bedbound individuals.
- An inability to access the medical documentation required to apply for financial support such as through the National Disability Insurance Scheme or Disability Support Payments.
- Lack of interest from medical practitioners/other experts in learning about/understanding ME/CFS.

- a. Yes
- b. No

Q5b. How often have you, or the person you care for, experienced 'neglect' in a medical setting?

- a. Once
- b. Less than 25% of the time
- c. 25-50% of the time
- d. 50-75% of the time

- e. 75-100% of the time

Q5c. OPTIONAL This space is available if you would like to provide further information about the experience which stands out most to you. Please try to keep your example concise. It is helpful for Emerge Australia to know the context of the experience and any reflections on how systems can be improved to avoid this happening to anyone in the future.

Q6a. Have you, or the person you care for, ever experienced 'neglect' in a non-medical situation, such as at school, at work, with friends and family, or with formal or informal carers?

This could include:

- Failure of employers/teachers/family and friends/carers or non-medical support services to hear, believe, and/or understand the experience of living with ME/CFS, leading to an inability to access appropriate support.
 - a. Yes
 - b. No

Q6b. OPTIONAL This space is available if you would like to provide further information about the experience which stands out most to you. Please try to keep your example concise. It is helpful for Emerge Australia to know the context of the experience and any reflections on how systems can be improved to avoid this happening to anyone in the future.

Q7. If you have any further comments that you would like Emerge Australia to be aware of about this survey, or when we develop our submission, please let us know here.