LIFELONG LOCKDOWN:

Lessons Learned from the Health and Wellbeing Survey of Australians Living with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) 2019

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Thanks

Emerge Australia thanks Kerrie McCure for generously volunteering her time to copy edit this report. We're grateful to contributions by Fiona Marsden in drafting the report and Roger Dench in survey analysis.

Most importantly, thank you to everyone in the ME/CFS community who participated in our survey and assisted in its dissemination.
We could not do our work without you.

Emerge Australia is the national patient organisation in Australia representing up to 250,000 people living with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS).

Established in 1980, Emerge Australia provides a range of services and supports to people living with and affected by ME/CFS in Australia.

Research and publication by Emerge Australia, October 2020

www.emerge.org.au

Ross House
247 - 251 Flinders Lane
Melbourne VIC 3000

Table of Contents

Foreword

For too long, the experiences of people living with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) have been overlooked and misunderstood by the medical sector and the broader Australian community, with devastating results. *Lifelong Lockdown: Lessons Learned from the Health and Wellbeing Survey of Australians Living with ME/CFS 2019* is the second national survey of its kind conducted by Emerge Australia. We hope that the findings presented here will increase awareness and understanding of what it is like to live with this chronic, highly disabling condition.

Lifelong Lockdown goes to print as many Australians begin to emerge from a period of self-isolation and lockdown in response to the global COVID-19 pandemic. Our findings demonstrate that for many people living with ME/CFS, a life in lockdown is the norm. Throughout 2020, many of us have experienced frustration at being unable to socialise with friends, attend family events, participate in our favourite sports or leisure activities, and interact with colleagues at work. For people with ME/CFS, these were already all-too-common experiences when the survey was completed in 2019.

ME/CFS is a multisystemic, highly disabling condition characterised by post-exertional malaise (PEM), which can be understood as a worsening of symptoms such as fatigue, pain and cognitive impairment following physical or mental effort. Twenty-five per cent of people with ME/CFS are housebound or bedbound as a result of their symptoms. For many, the onset of ME/CFS heralds the beginning of a lifelong lockdown – permanently locked out from daily experiences that healthy people take for granted.

For the vast majority of survey respondents, the onset of ME/CFS made it difficult or impossible to remain in work and education — 89 and 88 per cent of respondents respectively had stopped or significantly reduced hours in paid work and education. Of those who remained in work, education or training, only 19 per cent received support from their employer or institution to do so. It is clear that more help is required from employers and education providers. One silver lining from our experience with COVID-19 has been the much greater accessibility of working from home and online learning. It is our hope that employers, schools, TAFEs and universities will embrace the opportunities afforded by technology so that people living with ME/CFS can remain engaged in work and education.

At present, there are no known cures or effective treatments for ME/CFS. For many people, returning to work in any form is not a possibility. Our survey gives evidence that many people with ME/CFS live in financial instability and poverty, unable to access appropriate care, support or healthcare services. Shockingly, 73 per cent of survey respondents had an annual income of $25,999 or less, indicating that at least two-thirds are living below the poverty line.[1] The cost of healthcare services and medications is a significant barrier to accessing support and managing symptoms. Many people living with ME/CFS also require support from carers. However, despite the low income of most respondents, only 25 per cent received any financial support to pay for carers. Just 9 per cent indicated that family members received Carer Allowance despite 69 per cent of respondents indicating that they require help with day-to-day tasks.

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[1] The Australian Council of Social Services (ACOSS) and University of NSW define the poverty line in Australia as $457 a week for a single adult, or $23,764 per annum.

Access to quality healthcare is also constrained by a lack of practitioner knowledge about ME/CFS, further compounded by ongoing stigma around the condition. In recent years we have been heartened to see a growing awareness of ME/CFS and the implications of living with the disease. However, many survey respondents indicated that being believed or heard by the medical profession continues to be a significant issue when seeking care.

As the national patient organisation in Australia, providing support and advocating for people living with this chronic and highly debilitating condition, Emerge Australia is committed to working with medical practitioners and service providers to improve the quality of care available to people with ME/CFS. We will continue to advocate for the Royal Australasian College of Physicians ME/CFS clinical guidelines to be revised with up-to-date, fit-for-purpose guidance, as recommended by the *Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Advisory Committee 2019 Report to the National Health and Medical Research Council's Chief Executive Officer,* and for telehealth services to be made permanently available for people with chronic illnesses as COVID-19 recedes.

We will also continue to focus on working with governments to ensure that people living with ME/CFS and their carers are appropriately supported. Too many people are locked into a cycle of poverty and locked out of accessing the quality of life that we all deserve.

While the findings of our survey are deeply troubling, they present immense opportunity to improve the current situation for people living with ME/CFS. The recent lockdown experienced by all Australians may help to foster greater understanding of the experience of housebound and bedbound people, including those with ME/CFS, along with a newfound appreciation of the hardship that comes with living on a low income.

Without more understanding of ME/CFS and access to appropriate care and support, the onset of ME/CFS will continue to lock sufferers out of the daily life they experienced when they were well. The findings from this survey further increase our understanding of what it is to live with ME/CFS and we hope that it will help us and others to better support people with the condition.

Dr Heidi Nicholl

Chief Executive Officer

Emerge Australia

Key Findings

Our survey showed that people living with ME/CFS are locked down by a complex combination of multiple symptoms which can lead to an inability to undertake everyday activities without assistance. Despite this, many face significant barriers to accessing appropriate support. This includes financial support - an unacceptable number of survey respondents live in financial insecurity and poverty.

Diagnosis and onset (Section Two)

- The average age of symptom onset was 29 and the largest group of participants (30 per cent) experienced their first symptoms between the ages of 11–20. This indicates the importance of appropriate education and early career support for young people with the condition.
- Only 6 per cent of respondents had experienced a significant improvement in their symptoms over time.

Locked out of everyday life (Section Four)

- Our survey showed that 88 per cent of respondents stopped or significantly reduced their educational activities after they developed ME/CFS. Similarly, 89 per cent of respondents stopped or significantly reduced their paid working hours.
- Less than half the participants (49 per cent) were engaged in some form of work, education or training at the time of taking the survey. Adjusted for those aged 18–64, this figure stood at 51 per cent for respondents of working age. By comparison, 83 per cent of Australians aged 15–64 were engaged in work and/or study in 2019 in either a full or partial capacity (1).
- The proportion of people in part-time work almost doubled after onset, indicating that many had to drop back from full-time work because of their illness.
- Eighty-five per cent said that ME/CFS had significantly affected their ability to engage in social activities. This rose to 98 per cent for people with severe or very severe symptoms. This indicates a significant need for social support and has implications for the mental health of people living with ME/CFS.
- Of those participants currently in work, only 19 per cent reported that they had received specialist support for ME/CFS from their employer. The most common support provided by employers was flexibility regarding working hours, start times, rostering considerations and working from home. It is clear that more assistance from employers and education providers is required for people who are well enough to remain in work or education in some capacity if they are adequately supported.

Income and financial support (Section Five)

- More than two-thirds of survey respondents live below the poverty line. Improved access to adequate financial support is crucial to enable people with ME/CFS to maintain a reasonable quality of life.
- Fifty-seven per cent of survey participants reported that they had lost income between developing ME/CFS and the time they took the survey. Ninety per cent of people who had been earning $52,000 to $64,999 at time of onset reported that they had lost income.
- Despite the majority of respondents living on a very low income, expenditure on medical appointments and medications was high: 38 per cent of participants reported that they spend $1–$50 per month on conventionally prescribed medications, while 41 per cent spend $51 or more per month.
- In November 2019, the average income in Australia was ~$1,720 per week or $89,440 per annum. Just 5 per cent of our respondents had an annual income of over $91,000 per annum. Almost 95 per cent of people living with ME/CFS as represented by this survey earn below the average Australian income.

Access to support (Section Six)

- While 56 per cent of respondents reported that they receive support from family and 13 per cent from friends, just 9 per cent indicated that their carer/s received Carer Allowance to assist with this. Ninety per cent of carers were financially unsupported in their role as carer. This causes inter-generational financial burden in the case of parents and compounds financial stress for domestic partners.
- Forty-five per cent of participants reported that they receive government-funded services (federal, state and local), while 25 per cent reported that they had been able to access non-government or community-based disability supports.

Practitioner knowledge (Section Seven)

- Asked to rate their GP's knowledge of ME/CFS, 48 per cent of respondents said they were poorly or very poorly informed. Significant work is required so that medical professionals are confident in delivering appropriate care to people living with ME/CFS.
- Only 31 per cent of respondents regarded health professionals as a key source of information about ME/CFS.

Opportunities to improve the healthcare experience for people living with ME/CFS (Section Eight)

- The greatest barrier to accessing services was service providers' lack of knowledge about ME/CFS, followed by the cost of accessing these services.
- Respondents said that better-informed specialists, allied health professionals and GPs would most directly improve their health and wellbeing.

Background

This survey was conducted by Emerge Australia, the national body in Australia representing up to 250,000 people living with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) (2).

Established in 1980, Emerge Australia is a patient membership organisation which provides a range of services and supports to people living with and affected by ME/CFS in Australia. This includes a telehealth nurse service and an 'InfoLine' which provides the community with information on everything from symptom management to how to access financial supports and services. Emerge Australia advocates for improved recognition and understanding of ME/CFS, more effective treatments, and research into biological causes of the disease. Our research team produces a fortnightly research digest and collaborates on a number of research projects currently underway in Australia.

ME/CFS is a debilitating and often highly disabling multisystemic illness. ME has been recognised as a neurological disease by the World Health Organisation since 1969. The following is known about ME/CFS:

- Twenty-five per cent of patients are classed as severe and are housebound or bedbound (4).
- Up to 70 per cent of patients are too ill to work (4).
- Patients with ME/CFS score more poorly on quality-of-life surveys than patients with multiple sclerosis, stroke, diabetes, renal failure, lung disease and various cancers (5).
- Up to four times more women than men are affected (6–8).

Methodology

The survey was conducted from 25 March to 31 May 2019 using Qualtrics online survey software. Participants were invited to complete the survey over several sittings if they wished. The survey asked participants to respond to 60 questions which covered demographics, caring responsibilities, experience of symptoms, experience of medical and other services, and the effect of living with ME/CFS on social and economic circumstances. Questions were a mixture of mandatory and optional. The majority of questions were multiple choice, and where 'other' was provided as an option, participants were able to provide further detail.

The survey was advertised to members of Emerge Australia and to the broader ME/CFS community through the Emerge Australia quarterly journal, Facebook page and e-newsletter, as well as through other social media groups for people with ME/CFS.

A total of 1,055 people who met the criteria (over the age of 18 and living with ME/CFS) took part in the survey and are included in this analysis. This is a significant increase on the first Health and Wellbeing Survey which analysed data from 610 valid responses. This suggests increased awareness of Emerge Australia and a strong interest in participating in research among people living with ME/CFS.

Analysis was undertaken by Emerge Australia and Dench Analytics.

SECTION 1:

PARTICIPANT CHARACTERISTICS

DEMOGRAPHICS

All demographic questions in this survey were mandatory.

Which Australian State or Territory do you live in?

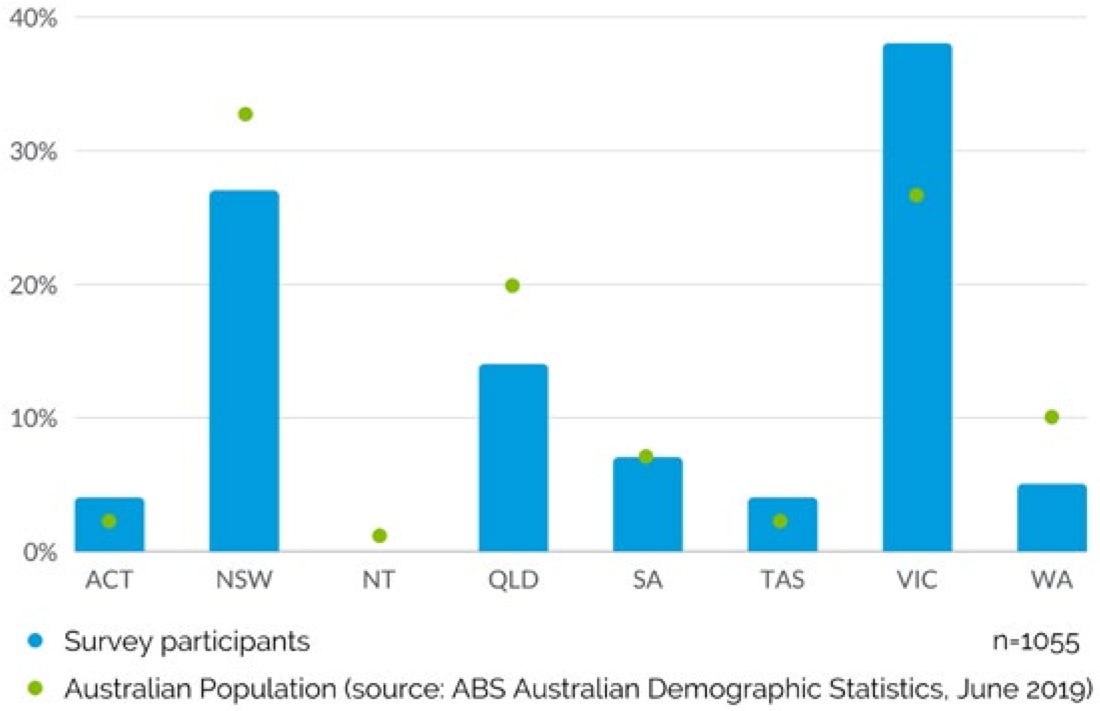

Figure 1.1: Which Australian State or Territory do you live in?

In comparison with national population statistics, ACT (4 per cent of our respondents), Tasmania (4 per cent) and Victoria (38 per cent) are somewhat overrepresented in this survey's findings, while NSW (27 per cent), Queensland (14 per cent), NT (0.3 per cent) and WA (5 per cent of our respondents) are slightly under-represented. The percentage of participants hailing from SA (7 per cent) was the same as national population figures. The 2019 survey is more reflective of the state population distribution than the 2015 survey, indicating that Emerge Australia is increasingly national in its reach.

How would you describe your locality?

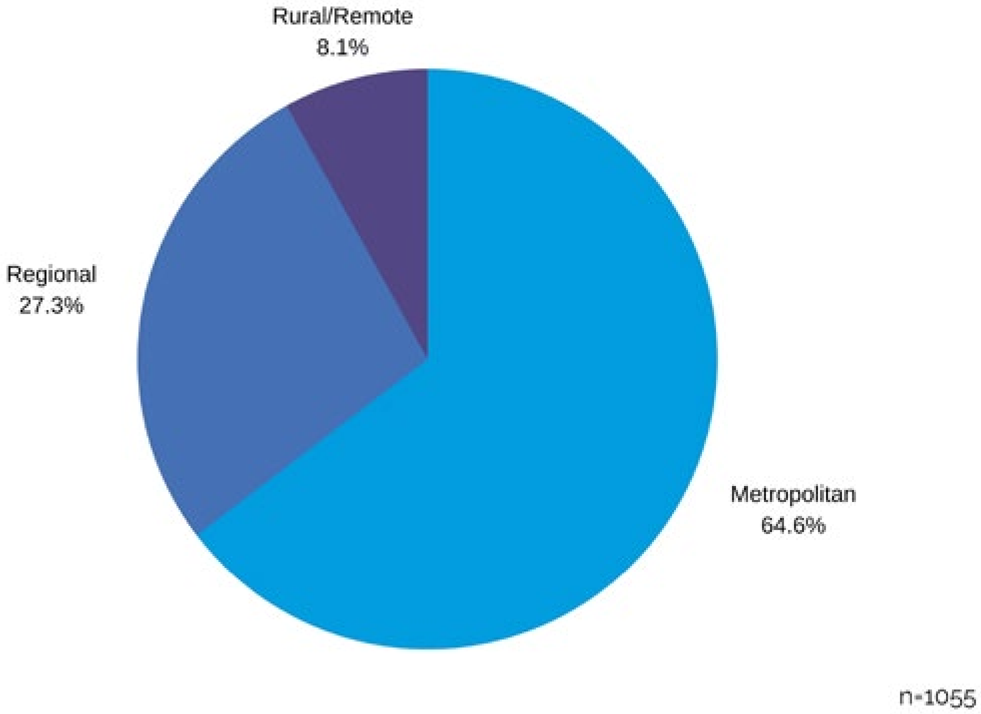

Figure 1.2: How would you describe your locality?

Sixty-four per cent of participants self-classified as living in a metropolitan area, followed by 27 per cent living regionally and 8 per cent remotely. The proportion of respondents describing themselves as metropolitan dwellers is slightly higher than in the previous survey (64 per cent vs 60 per cent), while the proportion of those living in rural/remote areas was down from 12 per cent to 8 per cent. It is unclear whether the metropolitan increase and rural/remote decrease are due to demographic changes or are simply a natural variation between surveys.

In 2016, 90 per cent of the Australian population lived in urban areas, and 10 per cent in rural areas, as classified by the ABS (9).[2] With 92 per cent of survey participants self-classified as living in a metropolitan or regional area, and 8 per cent in rural areas, this is broadly reflective of the Australian population.

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[2] Under ABS classification, 'urban' indicates an area comprising urban centre/s with 1,000 or more residents.

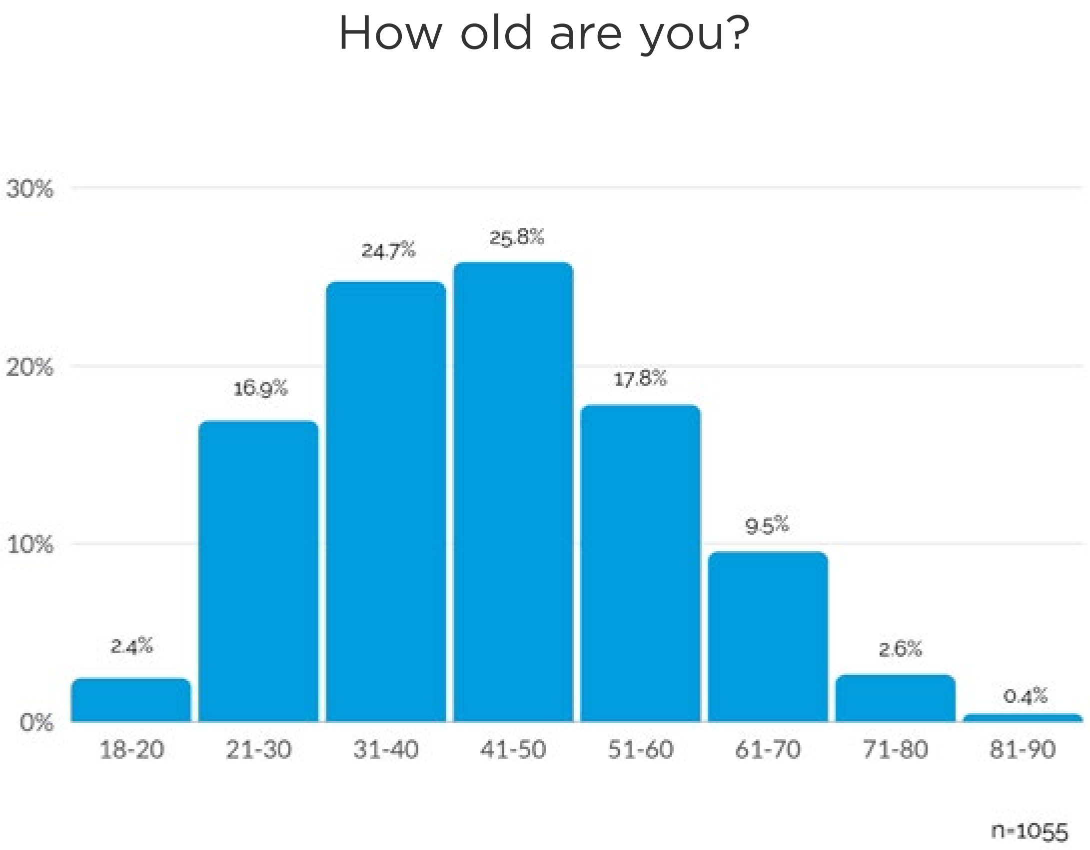


Figure 1.3: How old are you?

Respondents ranged in age from 18–87, with an average age of 43. Only four people who took part were above the age of 81, representing 0.4 per cent of participants. Twenty-five participants (2.4 per cent) were between the ages of 18–20. Emerge Australia intends to undertake future surveys targeting children and young people living with ME/CFS to improve our understanding of their specific experiences.

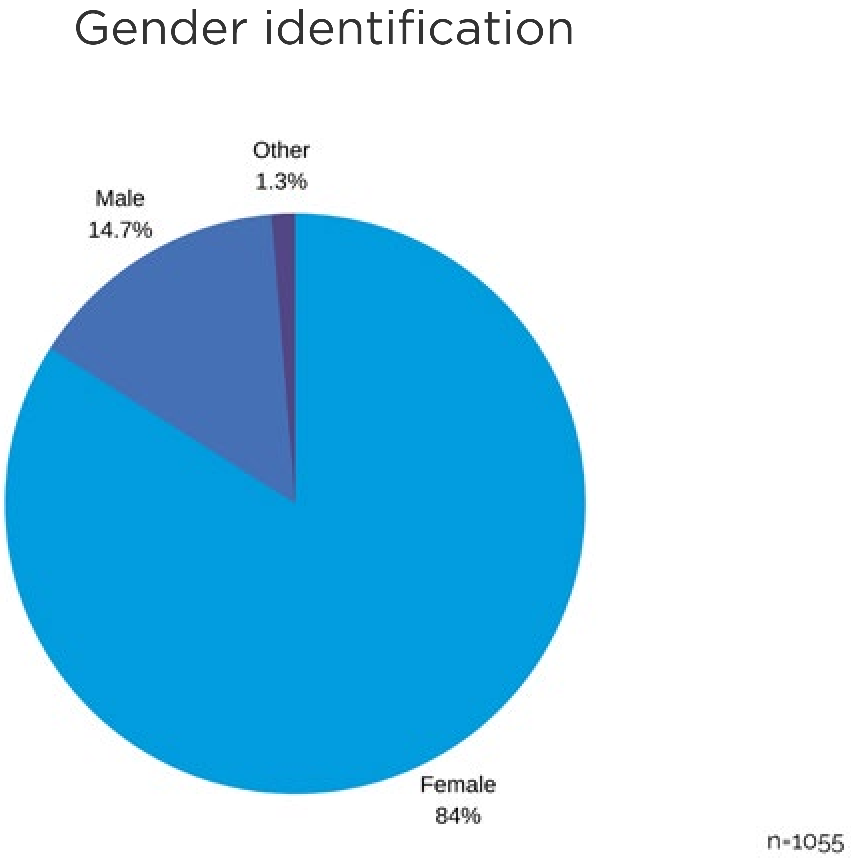


Figure 1.4: Gender identification

Eighty-four per cent of participants were women, compared with 80 per cent in the previous survey. This is slightly above globally recognised estimates that 80 per cent of people with the condition are women. In contrast to the 2015 survey in which no participants selected ‘other’, 1.3 per cent of participants in this survey identified as non-binary, gender fluid or trans.

The proportion of respondents who identified as male dropped from 20 per cent to 14.9 per cent. It is difficult to draw conclusions from the change in gender ratios. However, the drop in male respondents may lessen this survey’s usefulness as a basis from which to form policy regarding the ways that ME/CFS may affect boys and men differently from girls and women.

What is your genetic background?

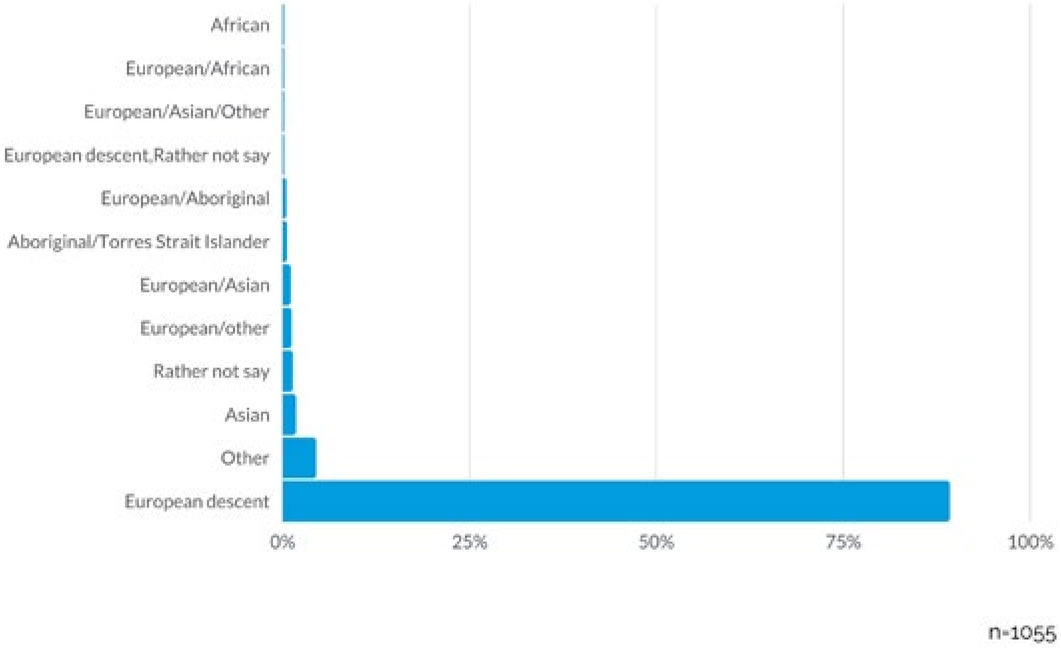


Figure 1.5: What is your genetic background?

The genetic or ancestral background of participants was overwhelmingly European, with 89.2 per cent indicating that they had a wholly European background, and a further 2.7 per cent indicating some European ancestry. Only 1.3 per cent of participants did not indicate their ancestry. The majority of those who selected 'other' were of mixed ancestry. Note that participants were able to select all categories that applied for this question.

An estimated 76 per cent of the Australian population have European ancestry (58 per cent Anglo-Celtic, 18 per cent other European), while 21 per cent identify their ancestry as non-European, and 3 per cent as Aboriginal and/or Torres Strait Islander (10).

With only 9.2 per cent of participants in this survey hailing from non-European ancestry, including only 0.8 per cent identifying as Aboriginal and/or Torres Strait Islander, this survey is not fully representative of Australia's population diversity and is likely not fully representative of the ME/CFS population.

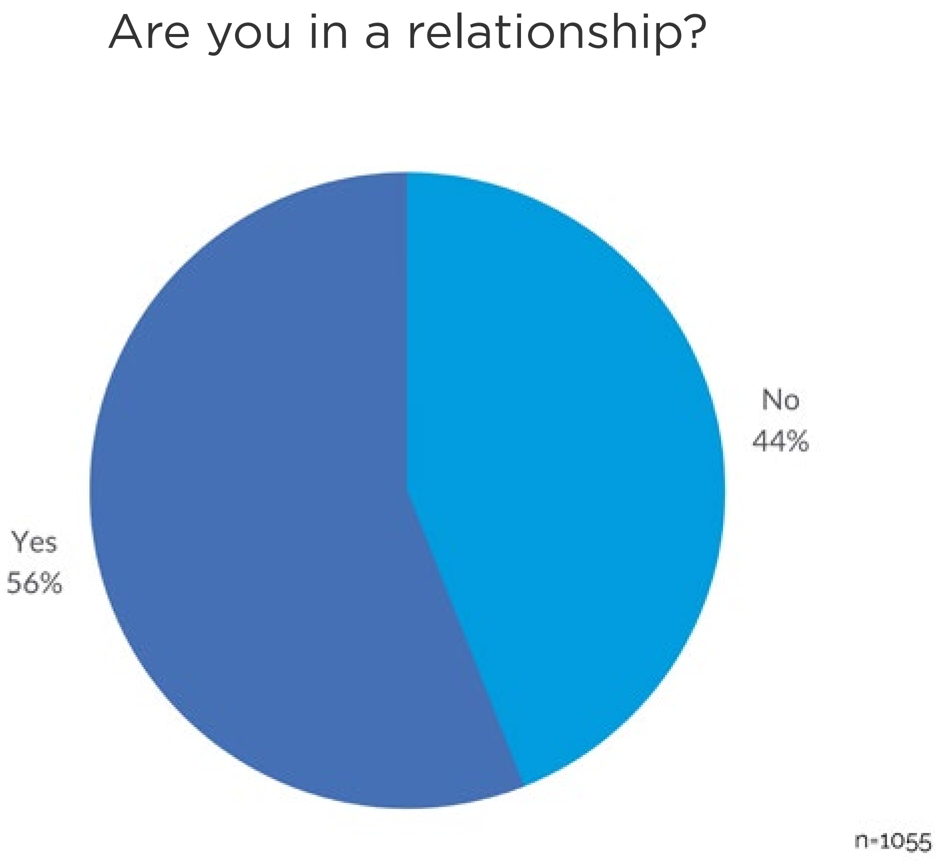


Figure 1.6: Are you in a relationship?

A majority of people who completed the survey were in a relationship (56 per cent). Partners often provide a key source of support and care to people living with ME/CFS, as explored in Section Six.

LIVING ARRANGEMENTS AND CARE ROLES

Do you provide care to others?

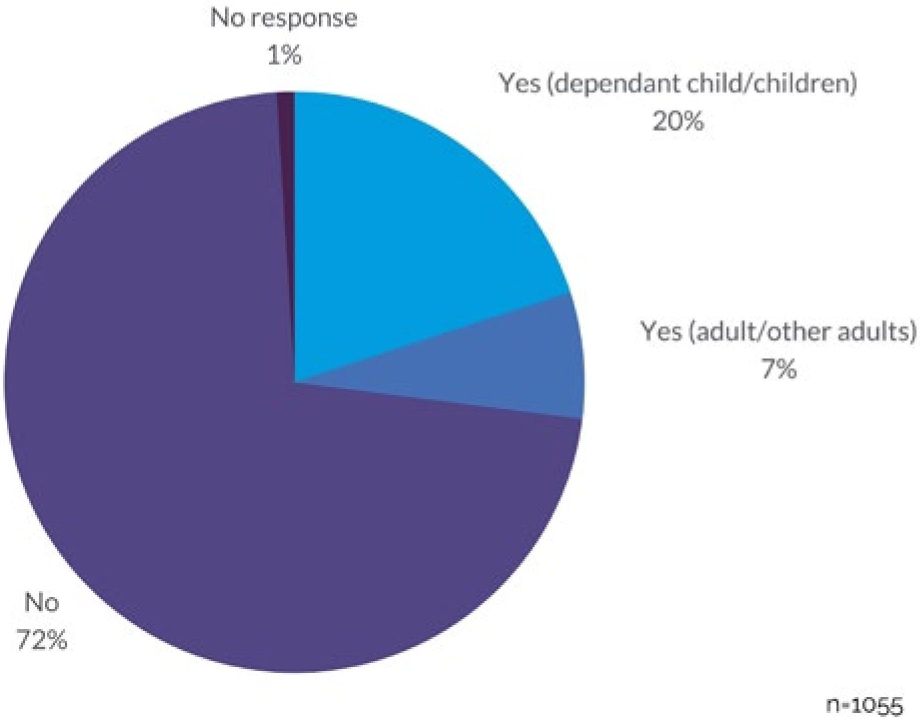


Figure 1.7: Do you provide care to others?

Understanding assistance needs and sources of support for people living with ME/CFS in Australia was a key focus of the 2015 survey. The 2019 survey builds on this by seeking to understand the role people with ME/CFS may provide in caring for others.

The majority (72 per cent) of people who participated in the survey did not provide a caring role to others in their life. Of those who did, 20 per cent provided care to a child or children, and 7 per cent to another adult such as an elderly parent or partner. People in these situations can face considerable difficulties in balancing their caring responsibilities with the need to minimise exertion and reduce the risk of worsening their ME/CFS symptoms.

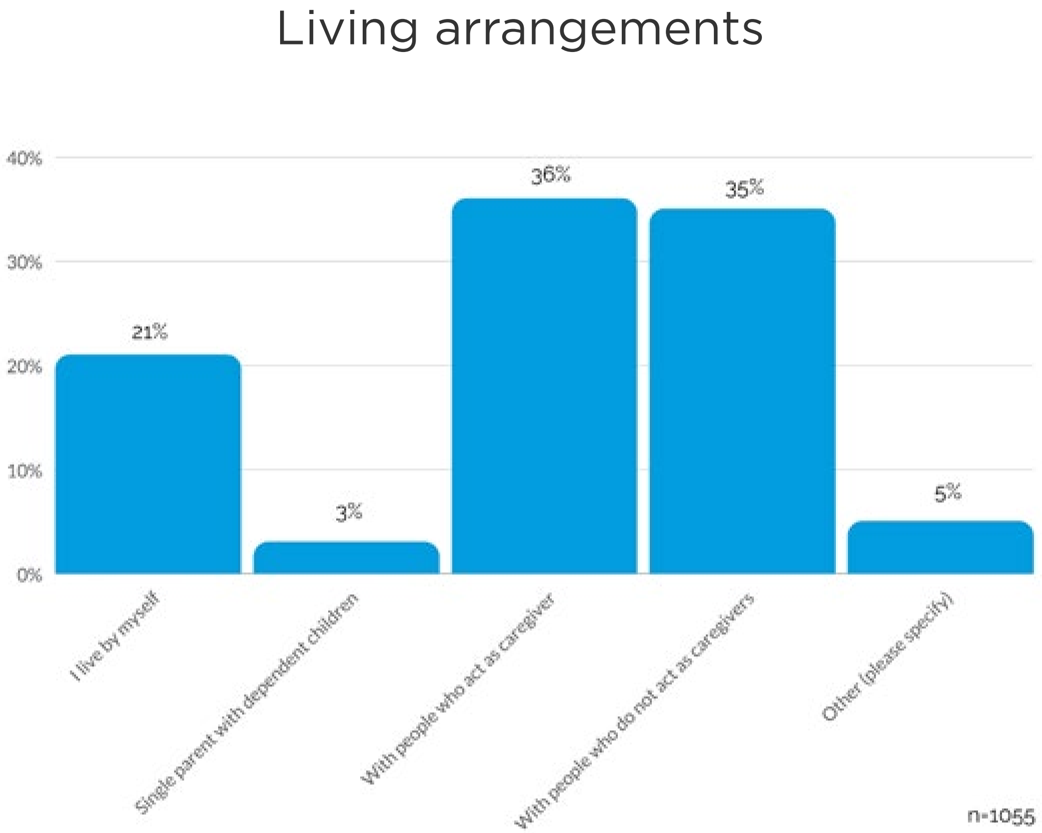


Figure 1.8: Living arrangements

Thirty-six per cent of participants lived with someone who also provided them with care. This included partners (13 per cent of all participants), parents (13 per cent) and housemates (1 per cent). While workable for some households, this arrangement can place considerable strain on relationships as the caregivers and recipients adjust to a situation they never expected to be in. Changes in the relationship, or concerns about changes in the relationship, between care providers and people living with ME/CFS – such as when parents age or a relationship breaks down – can be a significant source of stress.

A further 35 per cent of participants lived with people who did not provide them with care. Most lived with partners (23 per cent of all participants), with or without dependent children, and 5 per cent lived with parents who did not provide them with any care support. This lack of practical support may create varying degrees of disadvantage, depending on the severity of the illness.

Combining the 13 per cent living with parents who provided care, and 5 per cent living with parents who did not provide care, a total of 18 per cent of respondents – all over the age of 18 – lived with their parents. While the age at which people move out of their family home is increasing – 17 per cent of 25–29 year olds and 7 per cent of 30–35 year olds still lived at home in 2016 – our survey shows an over-representation of people living with ME/CFS remaining at home into adulthood (12). This indicates that some people with ME/CFS are locked into relying on parental care into their adult life. As parents age, caring for adult

Our survey shows an over-representation of people living with ME/CFS remaining at home into adulthood.

children with ME/CFS can be a source of financial and emotional strain, including worrying about what will happen when they are unable to continue this caring role.

Twenty-one per cent of participants reported that they live alone. It is well recognised that living alone can increase social isolation, and for people with ME/CFS it may also mean expending more energy on household and personal care tasks unless they can access adequate help from professional carers, family or friends. Conversely, depending on the severity of their ME/CFS, solo living can benefit people by minimising conversation, household noise, light and/or chemical exposure which may otherwise worsen symptoms. Many people with ME/CFS also use online technologies to reduce social isolation. Our next survey will further investigate the role of technology in supporting people living with ME/CFS.

Caring for dependent children while managing ME/CFS symptoms without support brings its own unique challenges. Three per cent of respondents lived as a single parent or carer with dependent children. The 5 per cent of respondents who selected ‘other’ included people who were homeless, people who lived alone but received support from visiting friends and family, people providing care to parents/partners/other dependents while also receiving care themselves, and people who lived alone but moved into and out of their family home as required when their condition deteriorated.

SECTION 2:

DIAGNOSIS & ONSET

DIAGNOSIS

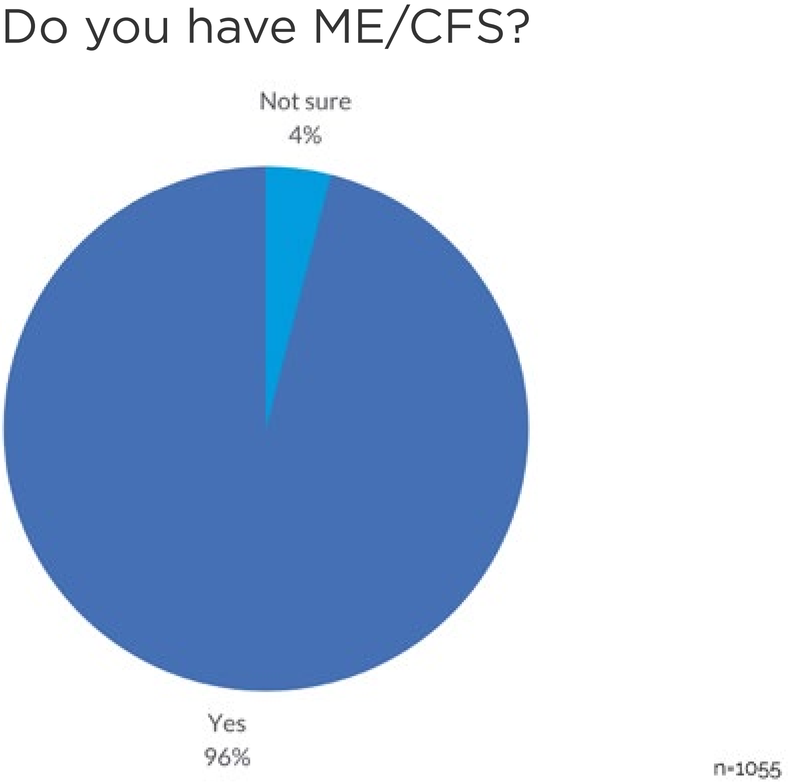


Figure 2.1: Do you have ME/CFS?

A large majority of participants (96 per cent) stated that they had ME/CFS, while a further 4 per cent were not sure. A 'no' response exited the survey. Note that responding 'yes' is not the same as having received a formal diagnosis of ME/CFS. It can be difficult to receive a diagnosis of ME/CFS, due partly to a lack of practitioners with a sound knowledge of how to diagnose the condition.

Have you received a formal diagnosis of ME/CFS?

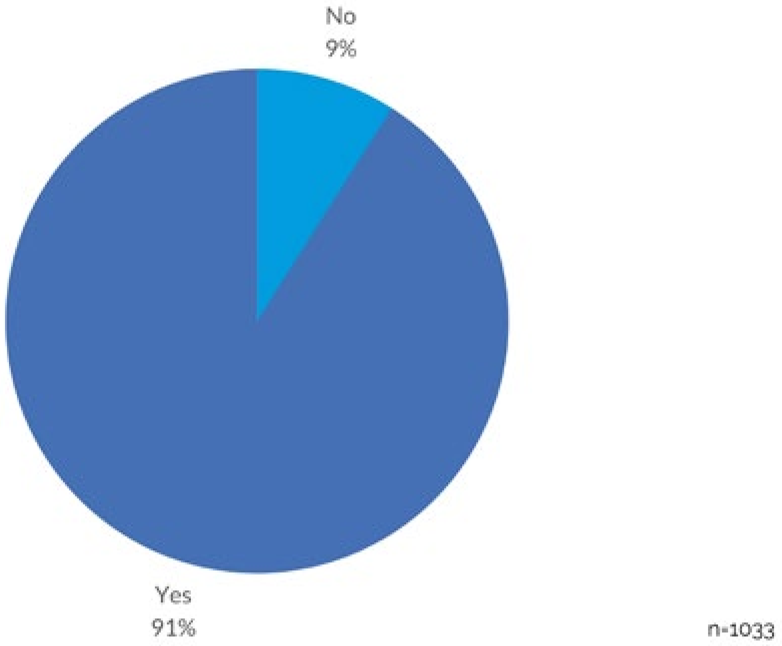


Figure 2.2: Have you received a formal diagnosis of ME/CFS?

While 96 per cent of participants reported that they had ME/CFS (in contrast to 4 per cent who were not sure), only 91 per cent had received a formal diagnosis. The lack of a formal diagnosis may be because of difficulties finding a knowledgeable doctor, problems getting to a doctor for rural/regional patients or those at the more severe end of the spectrum, or financial restrictions making medical consultations unaffordable. We discuss these issues later under Section Five: Income and Financial Support and Section Eight: Opportunities to Improve the Healthcare Experience.

How do you describe your condition?

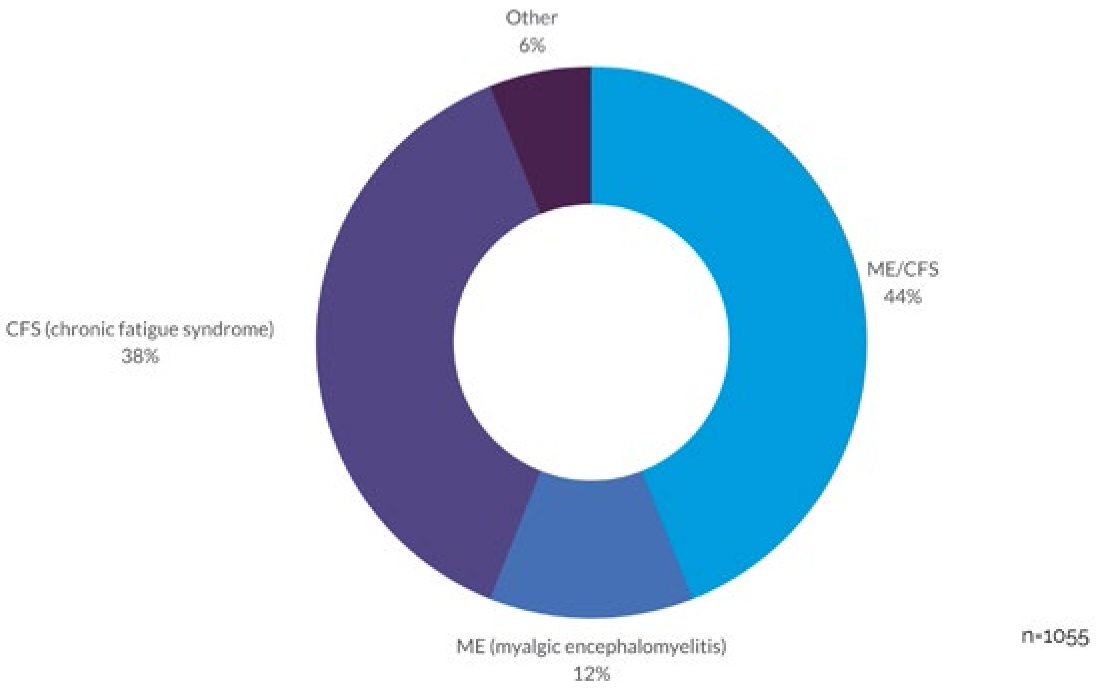


Figure 2.3: How do you describe your condition?

Forty-four per cent of participants used the term ‘ME/CFS’, combining the two names most commonly used to describe the condition. This preference for the term ME/CFS may reflect the fact that this is the term used by Emerge Australia and the term used throughout the survey. We use ME/CFS as it is inclusive of all labels used by people living with the illness.

While ‘ME’ was the earlier known term for the condition (the World Health Organisation has used this since 1969), ‘chronic fatigue syndrome’ has since become the more commonly used term among the medical community in Australia. Thirty-eight per cent of participants reported that they refer to their condition as ‘chronic fatigue syndrome’ (CFS).

The fact that 6 per cent of participants selected ‘other’ hints at the complexity that surrounds the labelling of ME/CFS. Some participants stated that they preferred using ‘ME’ but would label their condition as ‘CFS’ when speaking with someone who was unfamiliar with the term. Some noted that it took time and energy to explain ME and would therefore use CFS in some instances. This indicates the importance of educating the medical profession and broader community about using the term ‘ME/CFS’ or ‘ME’. A large number of people who responded ‘other’ said they had additional conditions such as fibromyalgia alongside ME/CFS.

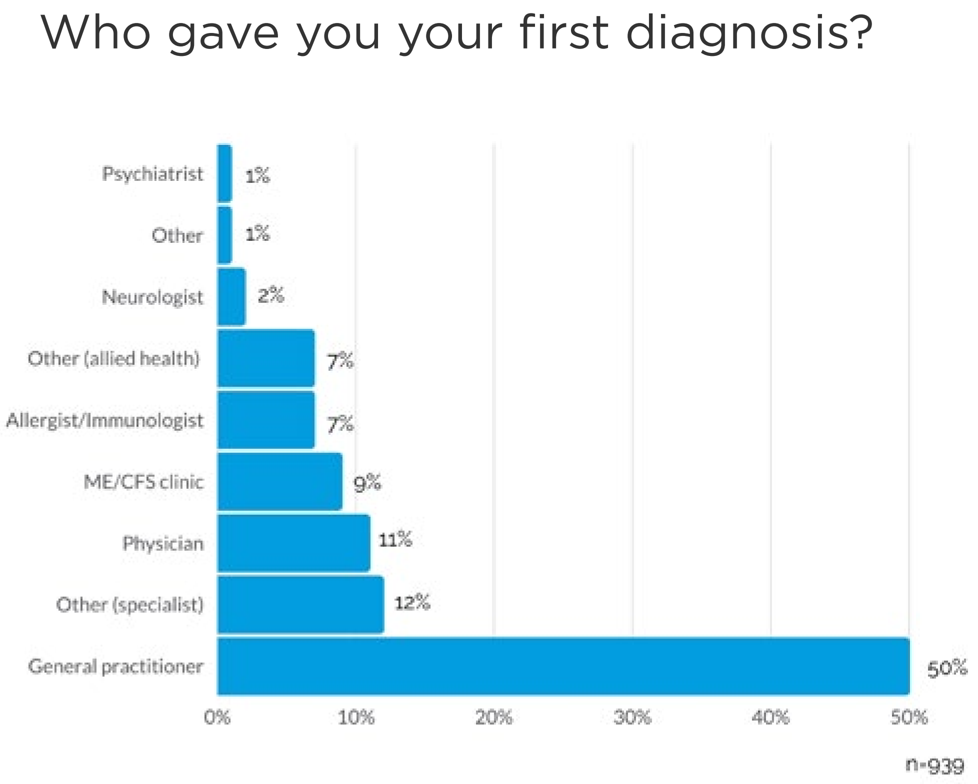


Figure 2.4: Who gave you your first diagnosis?

Of those participants who had received a formal diagnosis, the majority (50 per cent) received their first diagnosis of ME/CFS from a general practitioner. Twenty per cent of participants listed a range of 'other specialists' who diagnosed them, including endocrinologists, rheumatologists, naturopaths, sleep specialists, Chinese medicine practitioners, paediatricians, specialist GPs and psychologists. Endocrinologists and rheumatologists were the most commonly listed medical speciality listed as 'Other specialist'.

The prevalence of GPs in diagnosing the disease contrasted strongly with patients' perceptions of their GP's ME/CFS knowledge (see Section Seven: Practitioner Knowledge for more details). This underlines a longstanding need for better GP education about ME/CFS including confidence in diagnosis. We discuss this later in the report.

ME/CFS AND FIBROMYALGIA

Have you been diagnosed with fibromyalgia?

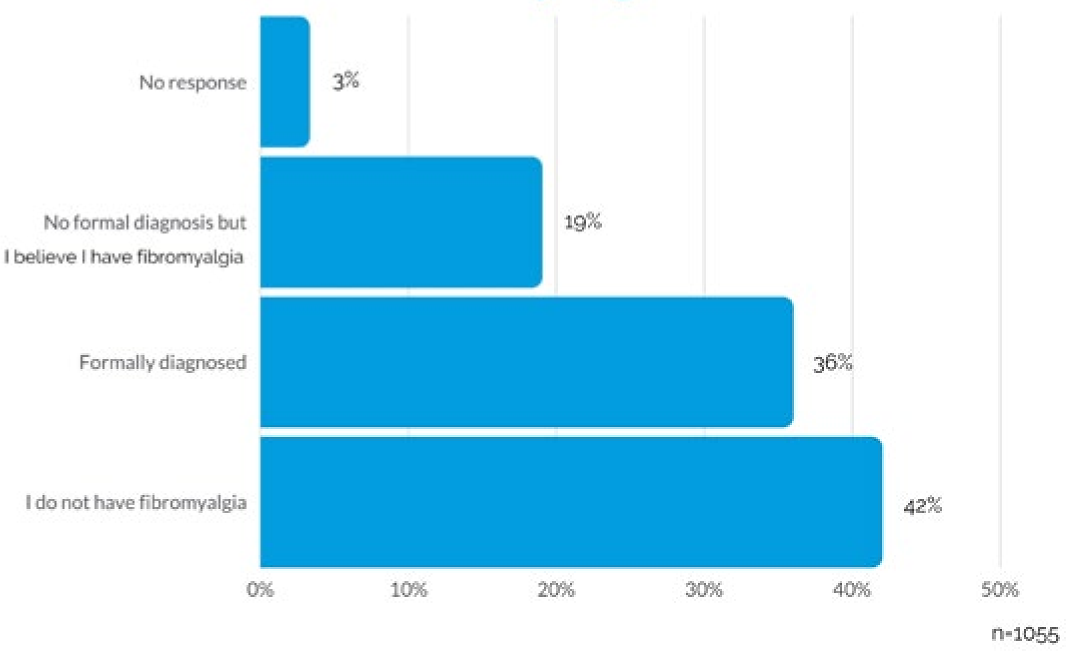


Figure 2.5: Have you been diagnosed with fibromyalgia?

Many people living with ME/CFS also live with fibromyalgia. While there are similarities between the conditions, the primary feature of ME/CFS is post-exertional malaise (PEM) and the primary feature of fibromyalgia is widespread pain. This is usually described as aching, stiffness and tenderness. The fact that up to 55 per cent of respondents said they had been formally diagnosed with, or believed they had, fibromyalgia, reflects how commonly this condition is experienced by people living with ME/CFS. Emerge Australia provides support to many people living with both ME/CFS and fibromyalgia.

ME/CFS SYMPTOM ONSET

At what age did you first notice symptoms of ME/CFS?

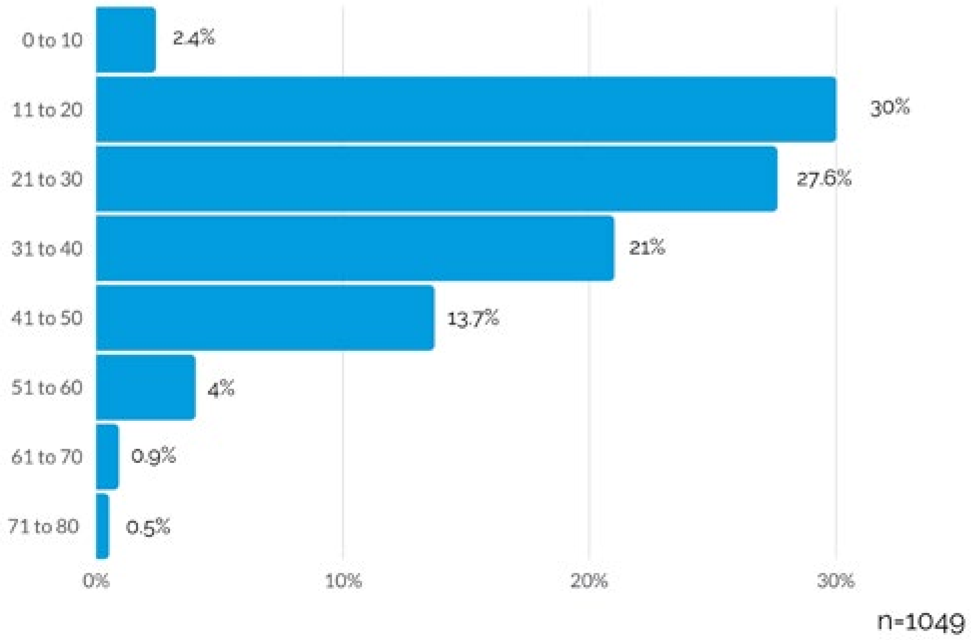


Figure 2.6: At what age did you first notice symptoms of ME/CFS?

Participants were asked at what age their ME/CFS symptoms were first noticed. The average age of symptom onset was 29 and the largest group of participants (30 per cent) experienced their first symptoms between the ages of 11–20. More than 50 per cent of people were diagnosed under the age of 30 and almost 80 per cent under the age of 40.

The average age of participants was 43, indicating that many had been ill for some years. Depending on the severity of their disease over the course of those years, being largely 'locked out' of ordinary life for so long has a profound effect on their ability to access education, pursue careers, earn an income, make and maintain social/personal relationships and access health care. (See Section Four: Locked out of Everyday Life).

2.4 per cent of participants (n = 25) reported that they experienced their first symptoms when they were children under the age of ten. These findings highlight the importance of better understanding of ME/CFS in children and young people. It should be noted that all survey participants were over the age of 18, and this survey therefore reflects the experience of adults living with ME/CFS.

How would you describe the initial onset of your ME/CFS symptoms?

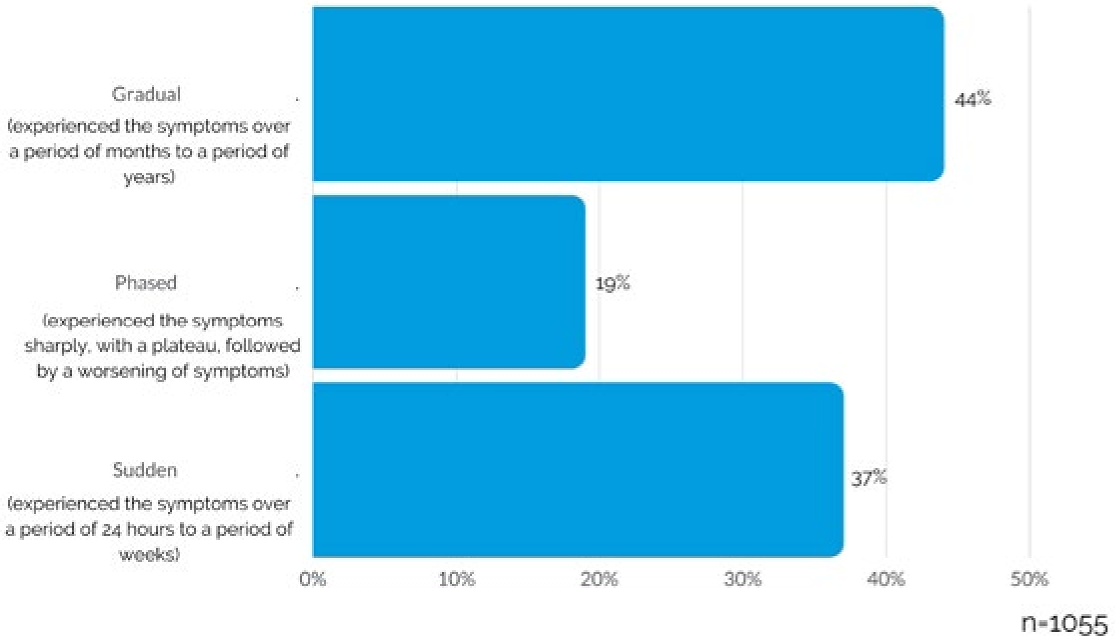


Figure 2.7: How would you describe the initial onset of your ME/CFS symptoms?

The experience of the initial onset of ME/CFS symptoms varied considerably between participants. Forty-four per cent experienced a gradual onset of symptoms over a period of months to years, while 37 per cent had experienced onset suddenly, in a period of 24 hours to a few weeks. A smaller group of participants (19 per cent) experienced their ME/CFS onset in a 'phased' manner, meaning that they experienced symptoms sharply, followed by a plateau and then a gradual worsening of symptoms over time.

> ***Only 6 per cent stated that they had experienced a significant improvement in their symptoms over time.***

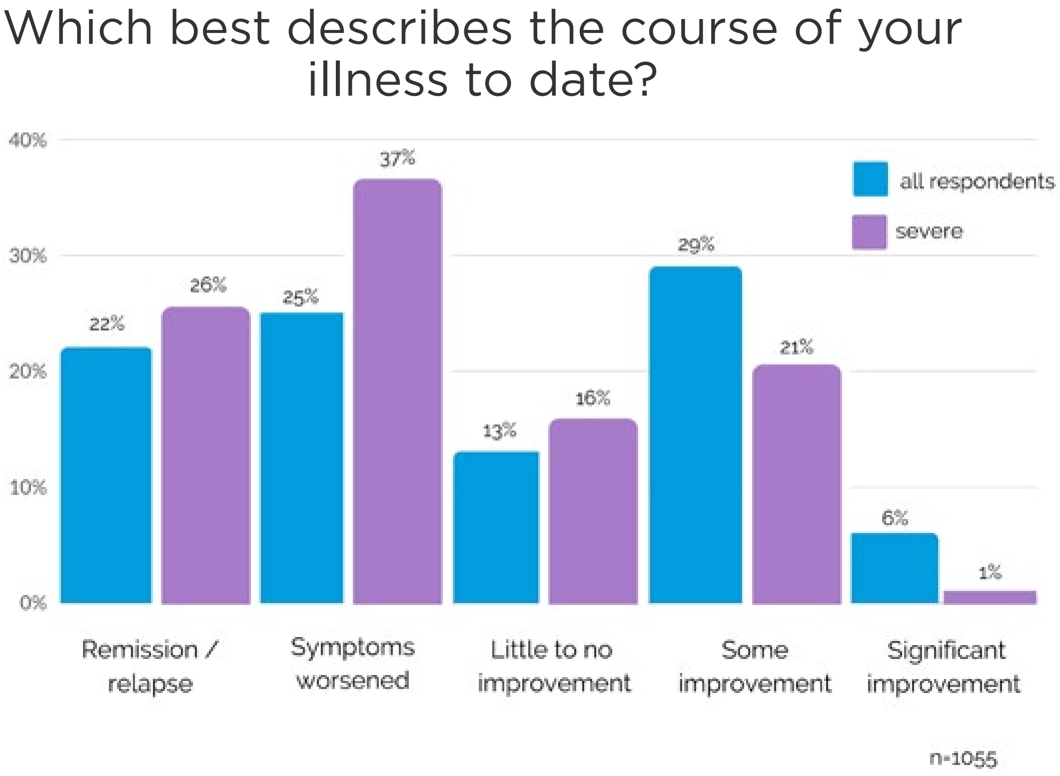


Figure 2.8: Which best describes the course of your illness to date?

While there have been numerous scientific advances in understanding ME/CFS in recent years, there is currently no cure for ME/CFS, nor any evidence-based treatments that are proven to be effective.

Of the people who participated in our survey, only 6 per cent stated that they had experienced a significant improvement in their symptoms over time. We would note that individuals who recover or experience a significant improvement in their symptoms might be less inclined to be aware of and participate in this survey, which could contribute to sampling bias; however, this figure is in broad alignment with other published data (13). Among those with severe/very severe symptoms (covered in the next section of this report), only 1 per cent had experienced a significant improvement. The majority of participants had experienced no improvement, or a worsening of symptoms. Almost a quarter (22 per cent) reported experiencing a remission period followed by a relapse over a period of years or decades.

It should be noted that people who participated in the survey skewed towards those with more severe symptoms and that their experience of the course of illness over time is not necessarily representative of all people living with ME/CFS in Australia.

SECTION 3:

SEVERITY AND EXPERIENCE OF SYMPTOMS

SEVERITY OF SYMPTOMS

Participants were asked to describe the severity of their symptoms over the past three months, ranging from mild (a reduction in activity levels compared with pre-illness), moderate (an approximate 50 per cent reduction in activity levels compared with pre-illness), severe (mostly housebound) and very severe (mostly or completely bedbound and requiring assistance with daily functions such as getting dressed or eating).

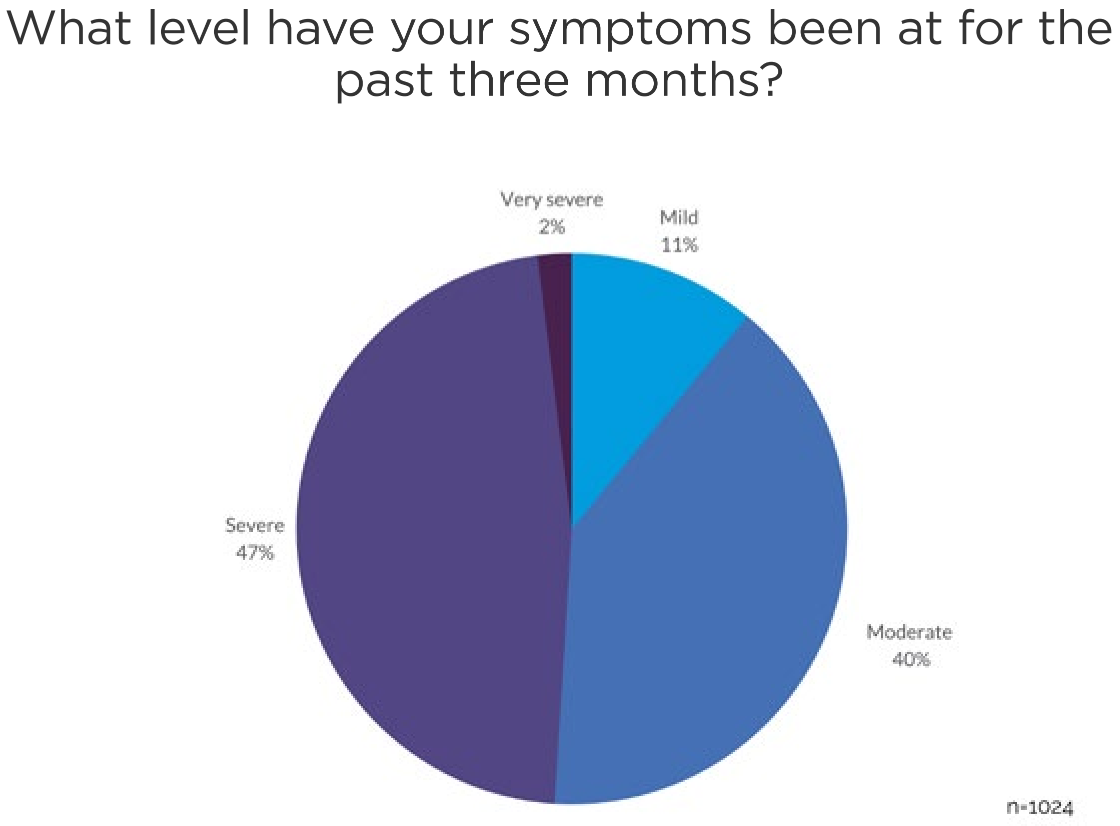


Figure 3.1: What level have your symptoms been at for the past three months?

An estimated 25 per cent of people living with ME/CFS are housebound/bedbound (4), indicating that people with severe and very severe ME/CFS are over-represented in this survey at 49 per cent combined.

The comparatively small proportion of patients describing themselves as mild (11 per cent) may be because the healthier people are, the less they are likely to be motivated to spend time on a survey of this nature. It may also indicate the fact that Emerge Australia is successful at reaching people with ME/CFS who are severely unwell. Conversely, the small proportion of very severe patients (2 per cent) may be because of the necessarily long and complex nature of the survey. For patients at the very severe end of the ME/CFS spectrum, the cognitive and physical exertion required to complete the survey would almost certainly act as a barrier to participation. Significant differences in findings between participants with mild/moderate symptoms, and severe/very severe symptoms are noted when relevant throughout this analysis.

Whatever their self-described level of severity, studies show that ME/CFS patients score more poorly on quality-of-life surveys than patients with multiple sclerosis, stroke, diabetes, renal failure, lung disease and various cancers (5), yet the disease remains one of Australia's (and the world's) most stigmatised, least understood and least researched illnesses. Greater understanding of ME/CFS within the medical community, in workplaces and among family and friends is required to improve the quality of life for people with this condition.

EXPERIENCE OF PRIMARY SYMPTOMS

The most widely accepted diagnostic criteria (2003 Canadian Consensus Criteria (14), 2011 International Consensus Criteria (15) and 2015 Institute of Medicine criteria (4)) all specify post-exertional malaise (PEM) as a mandatory symptom for diagnosis with ME/CFS. PEM can be defined as a marked worsening of symptoms such as fatigue, pain, cognitive difficulties, swollen lymph nodes and severe muscle weakness following physical and/or mental effort.

Do you experience the following primary ME/CFS symptoms?

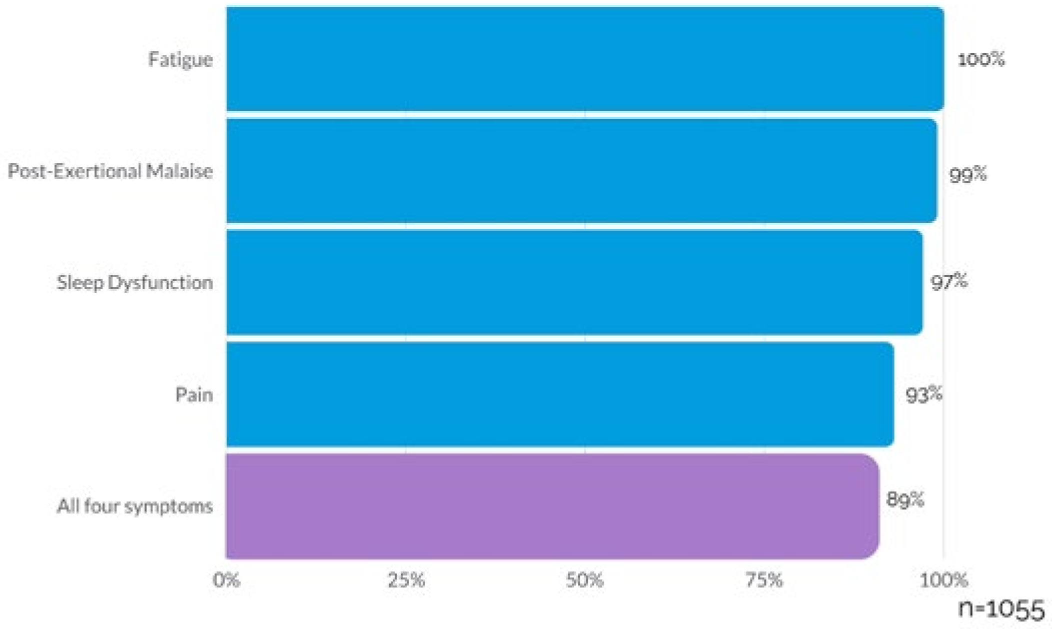


Figure 3.2: Do you experience the following primary ME/CFS symptoms?

Institute of Medicine (IOM) criteria (4) for diagnosing ME/CFS requires the presence of fatigue, PEM and sleep disturbances as the three core symptoms of the disease. It is therefore unsurprising that high numbers of respondents in our sample indicated that they experienced fatigue (100 per cent), PEM (99 per cent) and sleep disturbance (97 per cent).

In the IOM diagnostic criteria, fatigue is defined as profound, of new onset (not lifelong), not the result of ongoing or unusual excessive exertion and not substantially alleviated by rest. PEM is defined and discussed further in the following section as it is usually given as the cardinal symptom of ME/CFS. Sleep dysfunction includes unrefreshing sleep (that is, sleep that doesn't restore energy levels), sleep quantity or rhythm disturbances. While pain is not part of the IOM diagnostic criteria, it is nonetheless a very common symptom in our sample, with 93 per cent of respondents indicating that they experience pain. Pain is often widespread and may move around; it can manifest as joint or muscle pain or as significant headaches/migraine.

While ME/CFS is considered to be a heterogenous disease because the symptoms and severity experienced by people living with the condition vary widely, there are core symptoms which are commonly experienced by most patients. It is therefore unsurprising that these core symptoms were present in such high rates in our sample. The prevalence rates underscore a pressing need for more effective treatments to help manage these highly debilitating symptoms.

POST-EXERTIONAL MALAISE

The survey explored how people living with ME/CFS experienced PEM, including how quickly PEM was triggered after increasing physical and/or mental activity levels.

> *The onset of PEM varied greatly between participants, demonstrating how different the experience of ME/CFS can be between people living with the condition.*

How long after increasing physical activity and/or mental activity do you experience PEM?

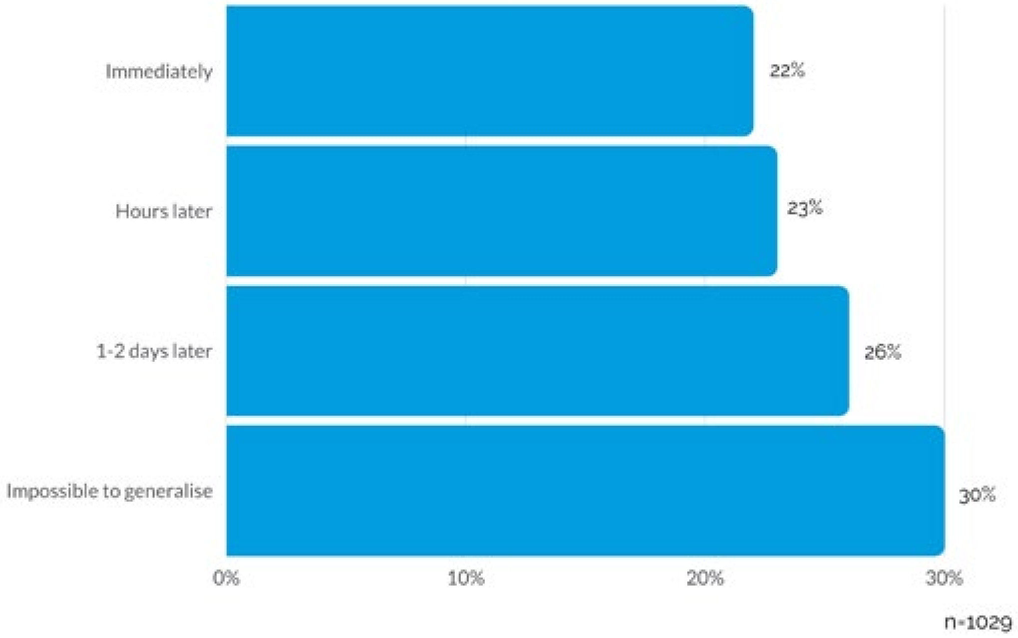


Figure 3.3: How long after increasing physical activity and/or mental activity do you experience PEM?

The onset of PEM varied greatly between participants, demonstrating how different the experience of ME/CFS can be between people living with the condition. This variability in the onset of PEM is also consistent with other studies (16).

How long does it take you to recover from PEM?

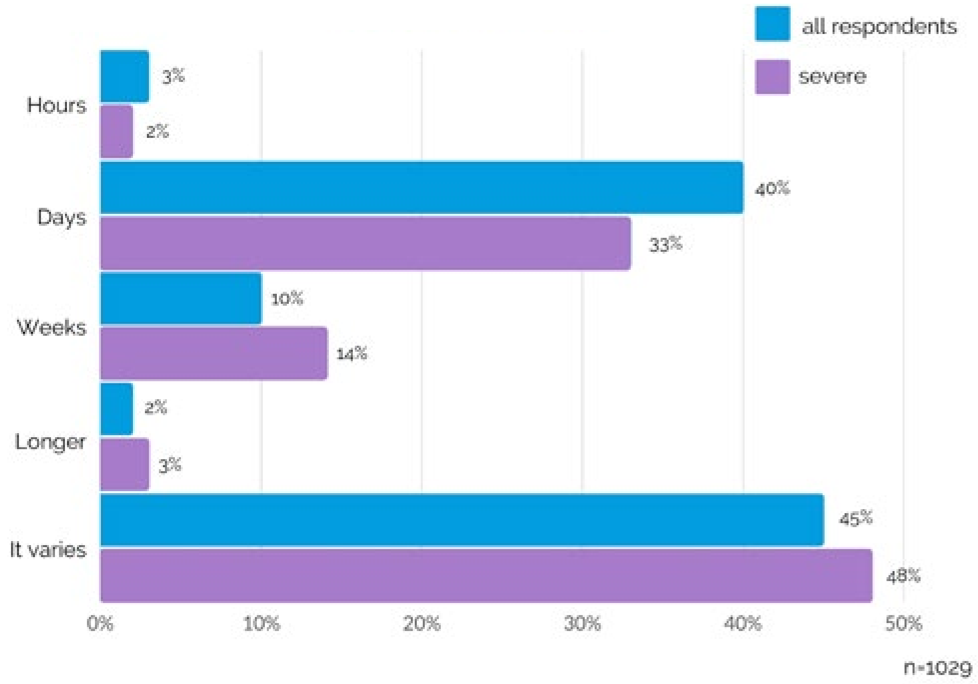


Figure 3.4: How long does it take you to recover from PEM?

Participants experienced different periods of recovery from PEM. Forty per cent said recovering from PEM usually took days (i.e. 24 hours or longer). Only 3 per cent of people indicated that they recovered in a matter of hours.

Anecdotal evidence suggests that recovery time varies according to illness severity and the degree to which the individual has exceeded their energy threshold. This was supported by our survey findings. Ten per cent of participants said their PEM could last for weeks. This was even higher (14 per cent) for survey respondents with severe/very severe symptoms.

People with severe symptoms were more likely to take longer to recover from PEM, and to find that their PEM recovery time varied, as compared to people who were less unwell. Variations in the time to recover from PEM amongst respondents in this survey also parallels those found in other studies (16) which is one of the defining features of myalgic encephalomyelitis (ME).

Perhaps most importantly for practitioners, family and carers to understand, PEM is almost always out of proportion to the nature and degree of exertion that caused it. Activities which are easily managed by healthy people, or even people with other chronic illnesses, can trigger PEM if they push the individual beyond their available energy. This varies according to the level of illness severity, but also within the individual. PEM is arguably one of the most disabling features of ME/CFS, particularly for patients at the more severe end of the spectrum. Patients not only have to contend with everyday baseline symptoms, but are further disabled by PEM in a way that far exceeds whatever activity caused it.

Whichever way it manifests in individual patients, PEM is not only the cardinal feature of ME/CFS, but adds to the ‘lockdown’ experience by redoubling symptoms and disability – further reducing the ability of people with ME/CFS to participate in activities that healthy people take for granted.

OTHER COMMONLY EXPERIENCED SYMPTOMS

Participants were asked to provide information on their experiences of other symptoms commonly associated with ME/CFS.

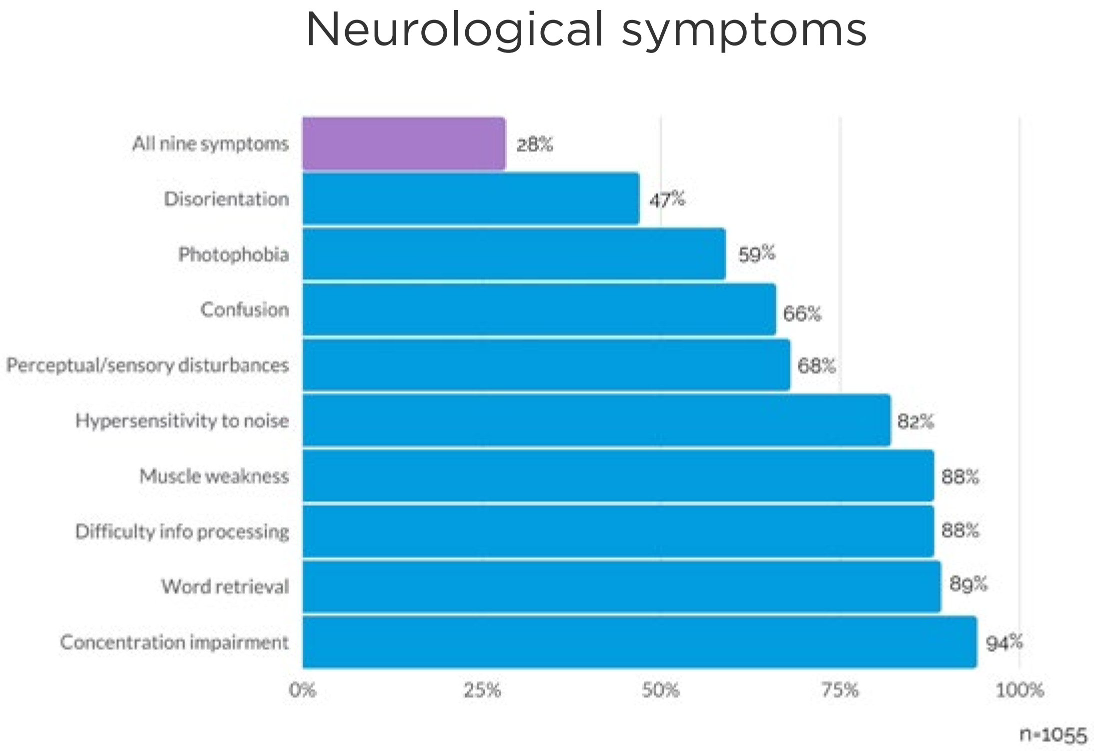


Figure 3.5: Neurological symptoms

Cognitive and other neurological symptoms are a common, limiting and frustrating aspect of living with ME/CFS. Many people find that previously simple tasks such as reading, information processing, recall and speech become difficult or, at times, almost impossible. Other symptoms like noise hypersensitivity can make it difficult to be around other people, further locking the patient out of everyday life.

> ***Previously simple tasks such as reading, information processing, recall and speech become difficult or, at times, almost impossible.***

Autonomic symptoms

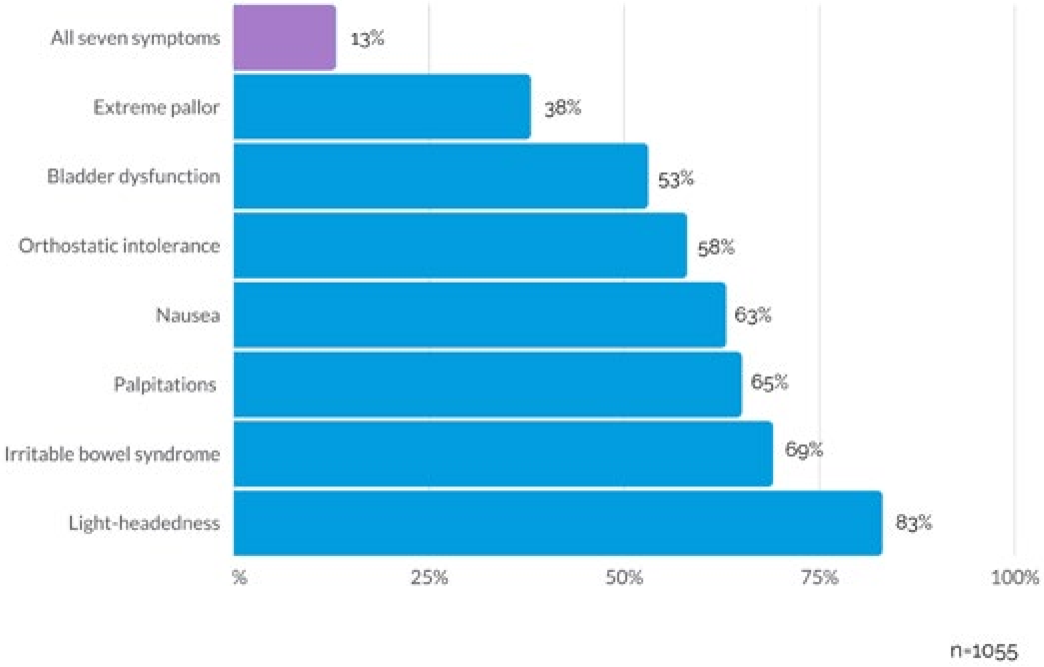


Figure 3.6: Autonomic symptoms

Dysregulation of the autonomic nervous system, which is responsible for managing a range of automatic functions like blood pressure, circulation, heart rate and digestion, is thought to play a major role in ME/CFS, and produces a range of disabling symptoms including light-headedness and orthostatic intolerance. Orthostatic intolerance includes experience of neurally mediated hypotension (NMH), postural orthostatic tachycardia syndrome (POTS) and delayed postural hypotension.

Neuroendocrine symptoms

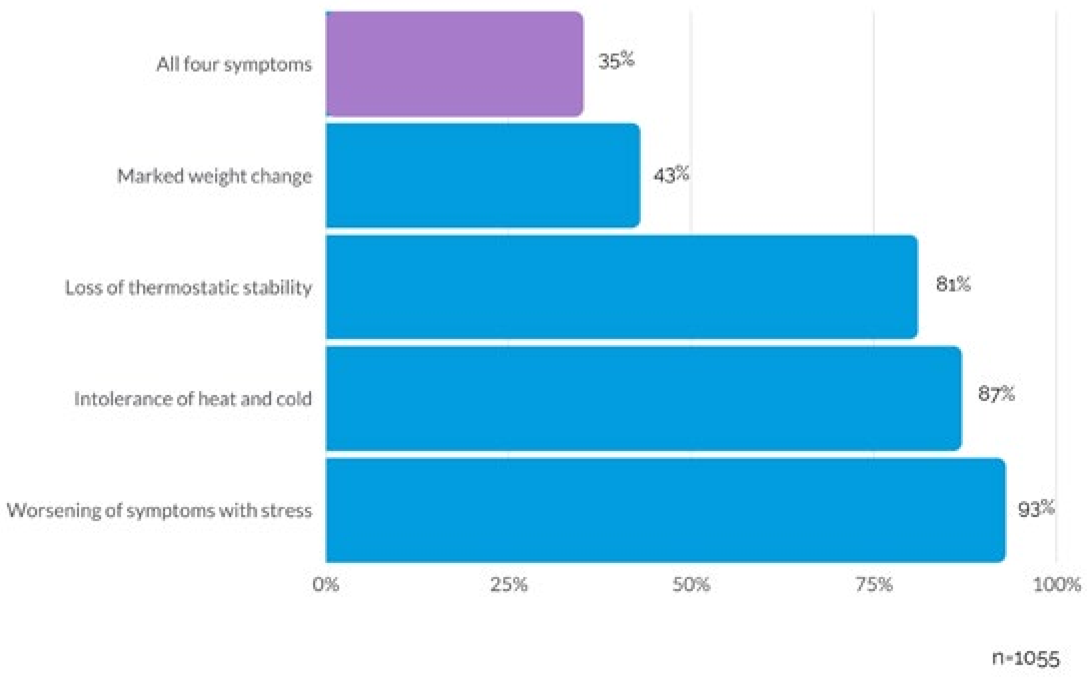


Figure 3.7: Neuroendocrine symptoms

Neuroendocrine cells make and release hormones which control many bodily functions. ME/CFS can affect the neuroendocrine system, leading to symptoms such as poor adaptability to stress and suboptimal temperature regulation.

Immune symptoms

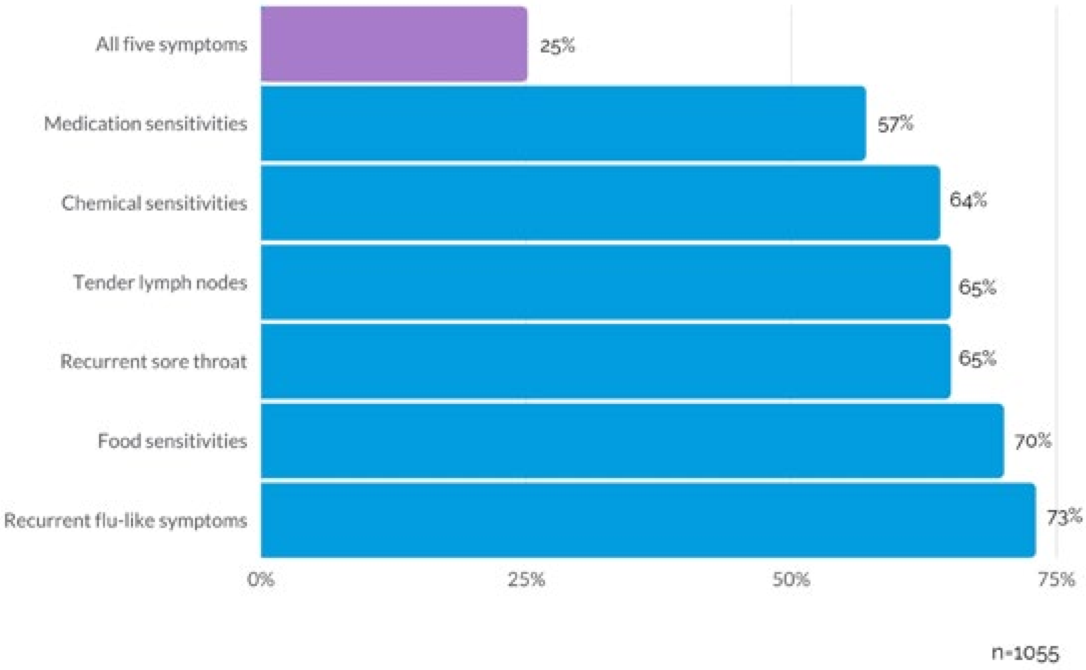


Figure 3.8: Immune symptoms

Immune system dysfunction has long been thought to play a key role in ME/CFS, with evidence of changes in natural killer cell function. Abnormalities in the functioning of cytotoxic CD8+T cells, natural killer cells and cytokines have been found in a number of studies (17).

SECTION 4:

LOCKED OUT OF EVERYDAY LIFE

LOCKED OUT OF EDUCATION AND EMPLOYMENT

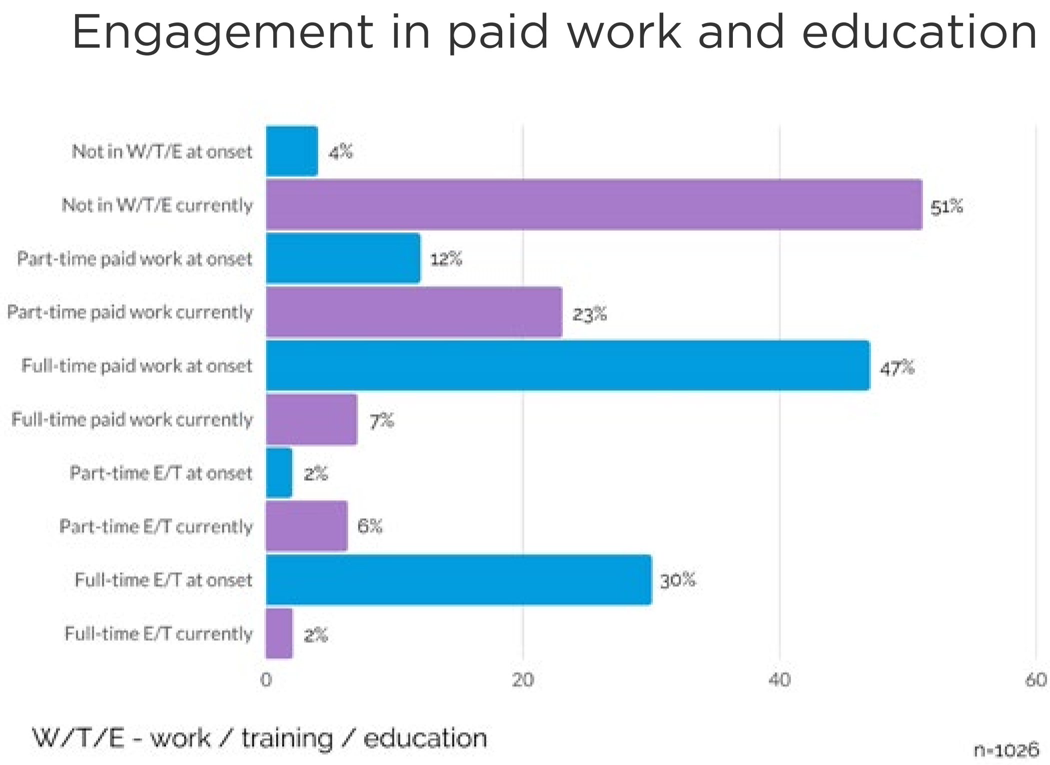


Figure 4.1: Engagement in paid work and education

Participants were asked about their engagement in a range of activities at the time of onset and at the time of undertaking the survey. Strikingly, more than half the participants (51 per cent) were not in any form of work, education or training at the time of taking the survey, in contrast to just 4 per cent of people who had been in this position before onset.

Adjusted for those aged 18–64, results showed that 49 per cent of working-age respondents were not engaged in work, training or education when taking the survey, in contrast to 3 per cent prior to onset. This means that just 51 per cent of participants of working age were engaged in work and/or study in a full or partial capacity, in comparison to 83 per cent of all Australians in 2019 (1).

Our survey found that the proportion of people in part-time work almost doubled after onset, indicating that many people had to drop back from full-time work because of their illness. Given that most survey participants were women, some of this shift may be attributed to the effects of having a child on working full time. In 2011, more than 50 per cent of women worked full time before the birth of a child, dropping down to 18 per cent after a birth (18). Considering that not all survey participants have children and that women with children on average return to full-time hours as their children get older, this attribution is likely to be minimal.

These figures underline the huge effect of ME/CFS on the ability of people to participate in activities that are central to daily life and financial security.

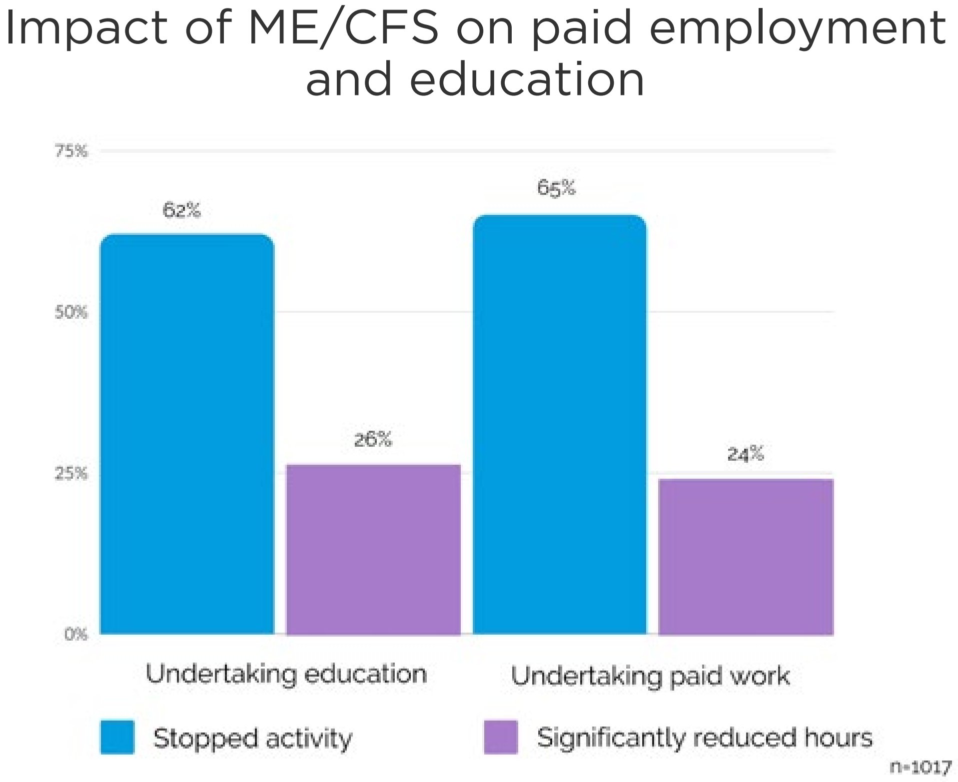


Figure 4.2: Impact of ME/CFS on paid employment and education

As Figure 4.2 demonstrates, 88 per cent of respondents stopped or significantly reduced their educational activities as a result of their symptoms. The significant decrease (28 per cent) in those undertaking full-time education or training (Figure 4.1) was not balanced with a corresponding increase in participation in part-time education (4 per cent increase).

While all survey participants were over the age of 18, this finding indicates how detrimental the onset of ME/CFS must be for children, teenagers and young people who develop the condition during what would be their crucial years in full-time education. Living with ME/CFS can therefore create significant barriers in attaining an appropriate level of high-school education to access university studies or training opportunities. It also affects young adults who may need to complete higher education or training to access career opportunities and begin earning the income they need to be independent – locking them out of the lives they may otherwise have led.

The figures are alarmingly similar when it comes to the world of work, with 89 per cent of respondents significantly reducing their working hours or stopping altogether (Figure 4.2). This may include people who stopped working in a previous workplace or profession and moved to a different role at reduced hours. For people with severe or very severe ME/CFS, the situation was unsurprisingly worse – 100 per cent of people in these groups had completely ceased work or significantly reduced their work hours, highlighting the importance of providing access to financial supports for this cohort.

89 per cent of respondents significantly reduced their working hours or stopped altogether after onset.

As will be explored in Section Five, loss of employment has a major effect on income. This may jeopardise the ability of people living with ME/CFS to pay mortgages, rent, bills and medical expenses. Paid employment also forms a major part of 'sense of self' – creating psychological implications from the need to reduce or give up work or a career. Only 2 per cent of participants reported that the onset of ME/CFS had not affected their ability to undertake education or employment. This highlights the importance of providing access to more supportive, flexible workplaces and educational opportunities.

At a macro level, the loss of education, training, employment, career prospects, income and superannuation for people with ME/CFS is likely to create significant productivity losses in local communities and in Australia as a whole. The ANCHOR Project is currently investigating the prevalence of ME/CFS and its social and economic burden on individuals, families, carers and Australian society more generally (19). The project is led by the University of Tasmania in collaboration with Deakin University and Emerge Australia, and funded by the Medical Research Future Fund. We are pleased that this important work is being carried out and look forward to learning from its findings.

LOCKED OUT OF DAILY LIVING ACTIVITIES

When it comes to the more mundane activities of daily living, our survey shows that two-thirds of respondents had to significantly reduce the amount of time they spent out of the house, while 8 per cent had to stop leaving the house altogether because they simply did not have the physical ability to do so. This reduction in physical capacity greatly affects the ability of people with ME/CFS to run errands, see friends or family and generally pursue activities that would otherwise make up the fabric of their lives.

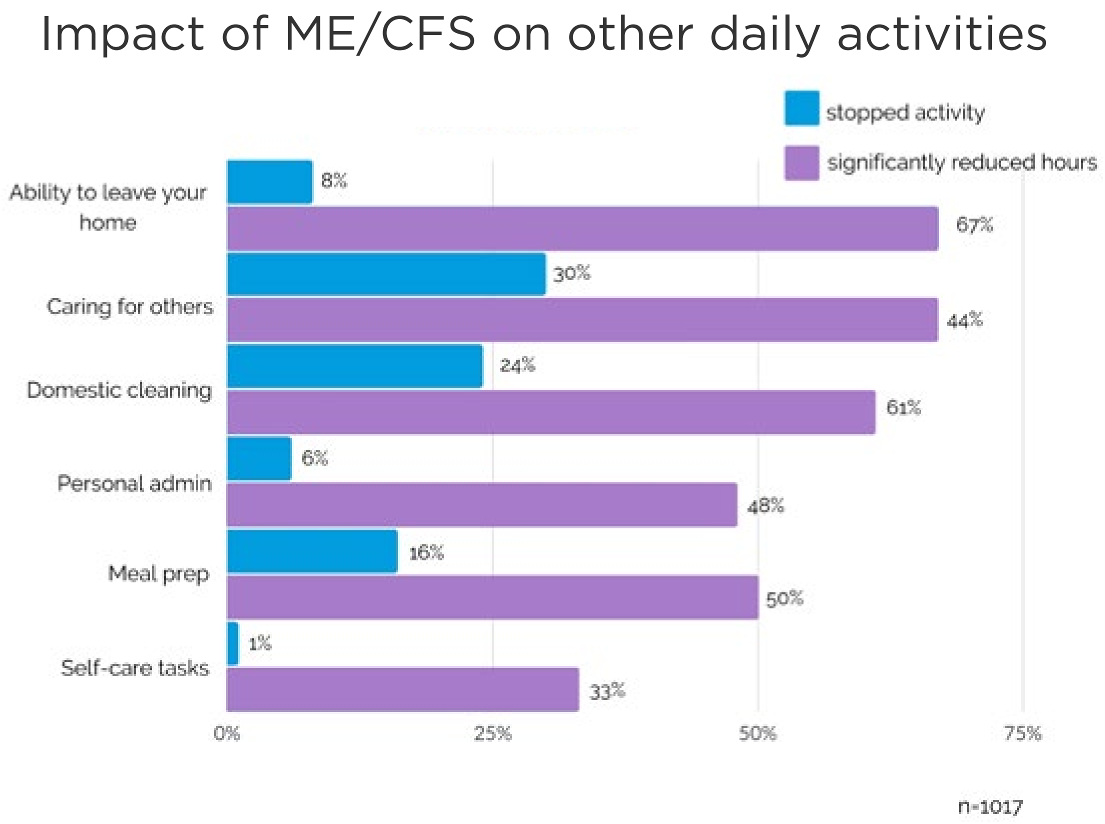


Figure 4.3: Impact of ME/CFS on other daily activities

Forty-four per cent of respondents were forced to significantly reduce the time they spent caring for others, while 30 per cent had to stop their caring responsibilities altogether. This kind of change in household dynamics can have a profound effect on relationships with partners and children, and household members may struggle to adjust to the change in circumstances.

Respondents also reported significant reductions in the time they spent on domestic cleaning, personal administrative tasks such as paying bills and meal preparation, and self-care tasks such as toileting, showering and eating.

People with severe or very severe ME/CFS experienced more significant adverse impacts on daily tasks such as meal preparation, personal administration and self-care. When even the most mundane activities of life become debilitating, an individual’s sense of agency and quality of life will inevitably decline.

LOCKED OUT OF SOCIAL ACTIVITIES

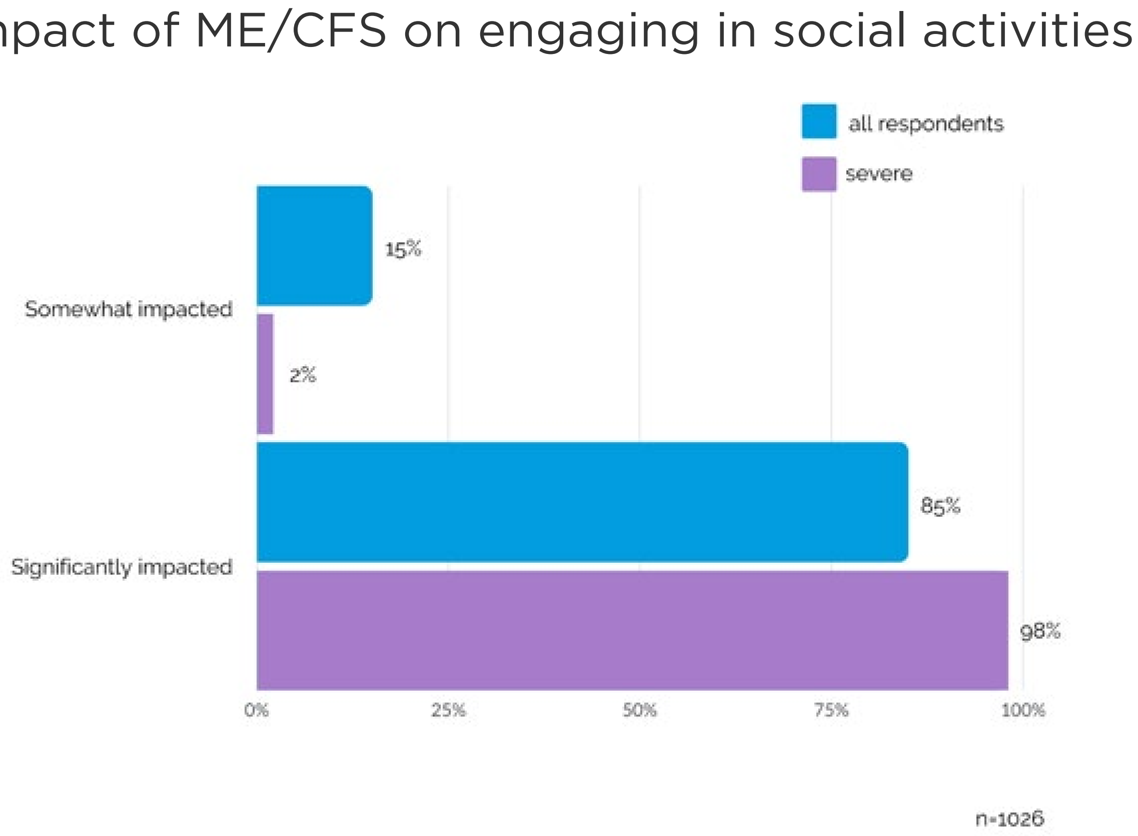


Figure 4.4: Impact of ME/CFS on engaging in social activities

Social connection and inclusion are important for mental and emotional health and wellbeing. Most people living with ME/CFS want social connection, just as they did when they were well but are often too ill to participate to the same extent, if at all.

Almost all survey participants felt that ME/CFS had affected their ability to engage in social activities. Just two respondents out of the 1,026 who answered this question said the onset of ME/CFS had no impact on their social lives. Eighty-five per cent said that ME/CFS had significantly affected their ability to engage in social activities. This rose to 98 per cent for people with severe or very severe symptoms.

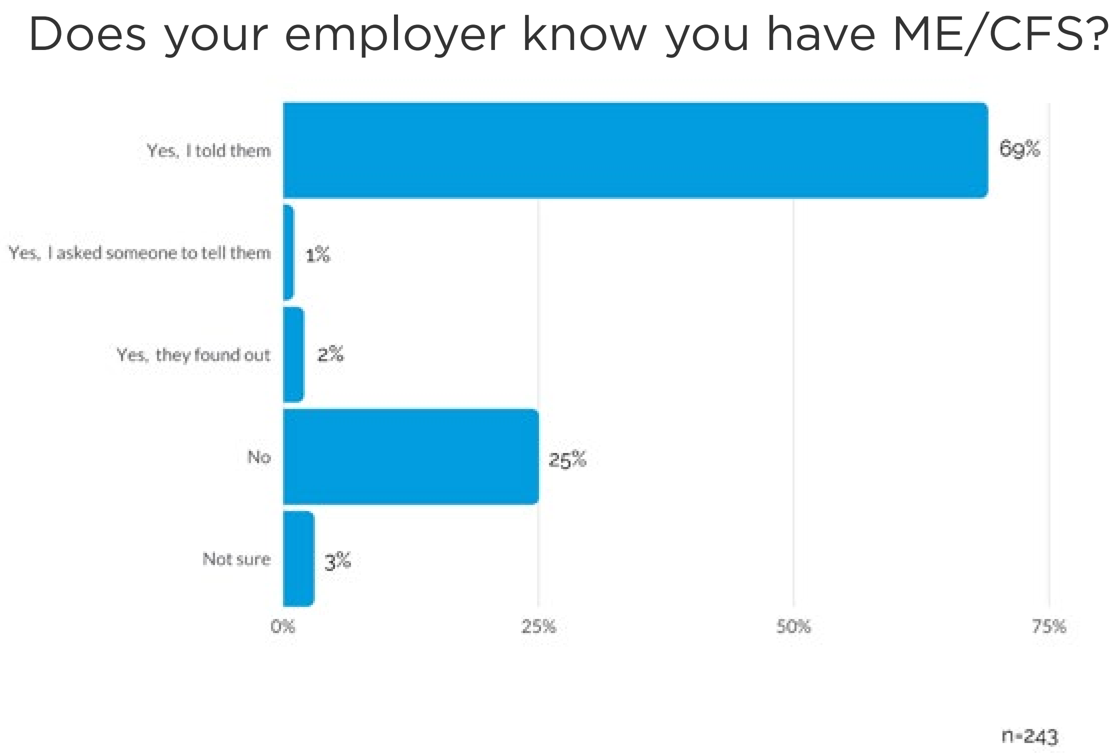


Figure 4.5: Does your employer know you have ME/CFS?

The majority of people (69 per cent) who reported that they are currently in work have directly told their employer that they live with ME/CFS, which is heartening. Twenty-eight per cent of people currently working say they have not told their employer or are not sure if they know, indicating that it is unlikely that formal adjustments have been made for those participants in their workplace.

> *Almost all survey participants felt that ME/CFS had affected their ability to engage in social activities.*

Of the respondents currently in paid work, volunteering or education, only 19 per cent said that their organisations provided specialist support for ME/CFS.

Have you experienced any specialist support at your workplace/educational facility?

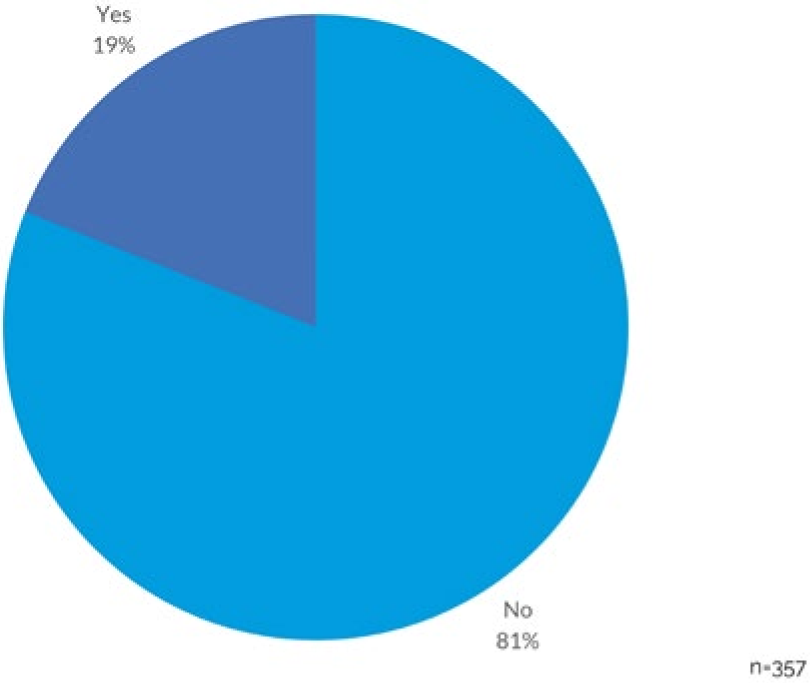


Figure 4.6: Have you experienced any specialist support at your workplace/educational facility?

Of the respondents currently in paid work, volunteering or education, only 19 per cent said that their organisations provided specialist support for ME/CFS.

The most common support provided was flexibility, including reduced work hours, late starts and flexible hours, and rostering considerations such as not being rostered on for two consecutive days (to allow for PEM recovery). Other supports included the ability to sit rather than stand while at work, opportunities to work from home, and longer and more frequent breaks. Some workplaces provided support from a disability employment service provider and occupational rehabilitation. At university, supports included longer exam times and extensions. Understanding and care were also noted as important supports.

SECTION 5:

INCOME AND FINANCIAL SUPPORT

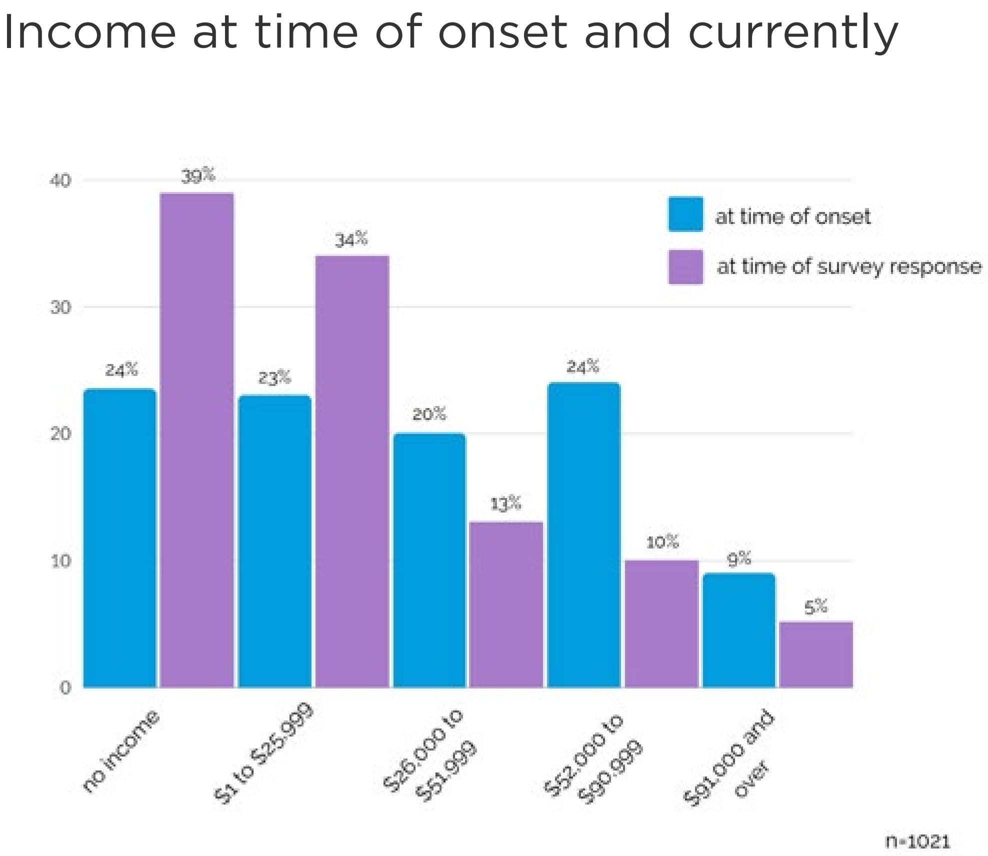


Figure 5.1: Income at time of onset and currently

Living with ME/CFS can have significant financial implications. As described in the previous section, onset is often followed by a significant reduction in or complete loss of employment. Perhaps one of the starkest illustrations of how ME/CFS locks people out of so many life opportunities is the difference between their employment income before and after they develop the illness. Fifty-seven per cent of survey participants reported a reduction in income between developing ME/CFS and taking the survey (Figure 5.1).

This is consistent with the survey's findings that ME/CFS forces people to move from full-time to part-time work, or to stop working altogether. With such a drastic change in their earning capacity, financial difficulty can become a significant factor in lives already stressed by dealing with a major chronic illness. Seventy-three per cent of survey respondents reported an income of $25,999 or less. The Australian Council of Social Services (ACOSS) and University of NSW have defined the poverty line in Australia as $457 a week for a single adult, or $23,764 per annum (20), meaning that the vast majority of our survey participants are living below the poverty line.

In November 2019, the average income in Australia was ~$1,720 per week or $89,440 per annum (21). Just 5 per cent of our respondents had an annual income of over $91,000 per annum. Almost 95 per cent of people living with ME/CFS as represented by this survey earn below the average Australian income.

COSTS ASSOCIATED WITH LIVING WITH ME/CFS

In addition to the fact that most participants lost income after developing ME/CFS, it is known that managing chronic illness is associated with significant costs. This survey sought to find out more about participants' expenditure on medicines and services to manage ME/CFS symptoms.

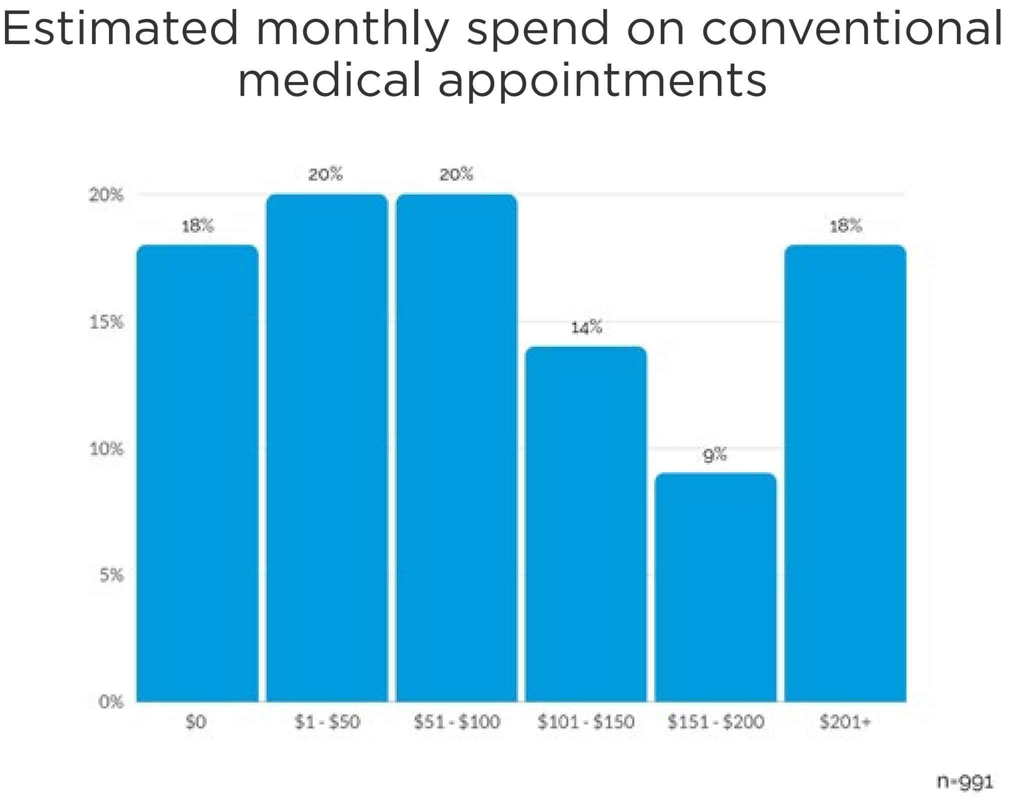


Figure 5.2: Estimated monthly spend on conventional medical appointments

Expenditure on conventional medical appointments was significant. While 38 per cent of participants reported spending less than $50 per month, only 18 per cent reported spending nothing. Twenty per cent reported spending $51–$100, and over 40 per cent reported spending more than $101 per month. Shockingly, 27 per cent of respondents reported that they spend more than $151 per month on medical appointments, and 18 per cent spend more than $201.

The vast majority of our survey participants are living below the poverty line.

Estimated monthly spend on conventionally prescribed medication

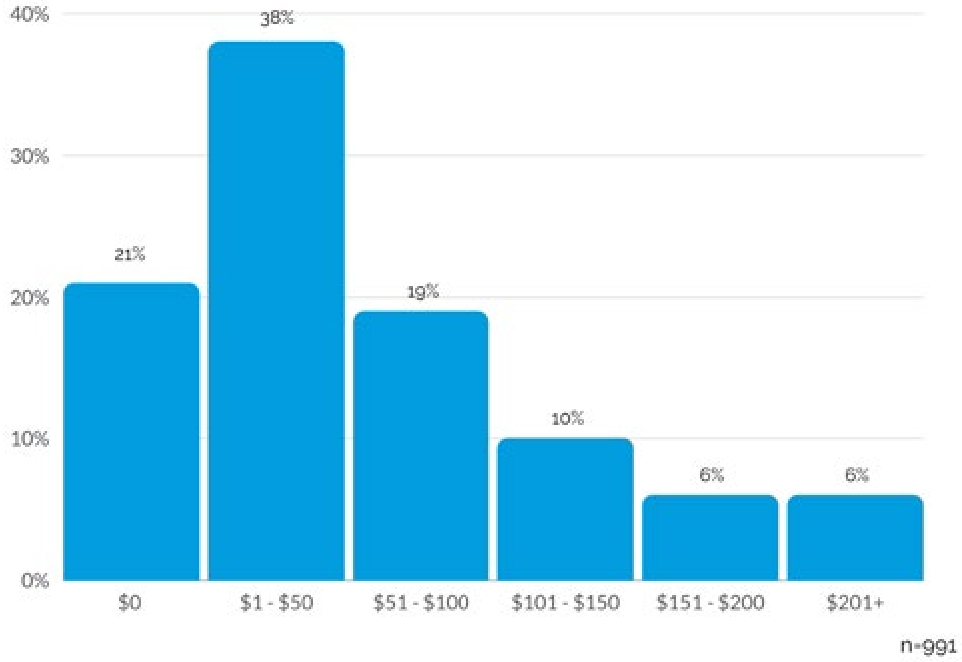
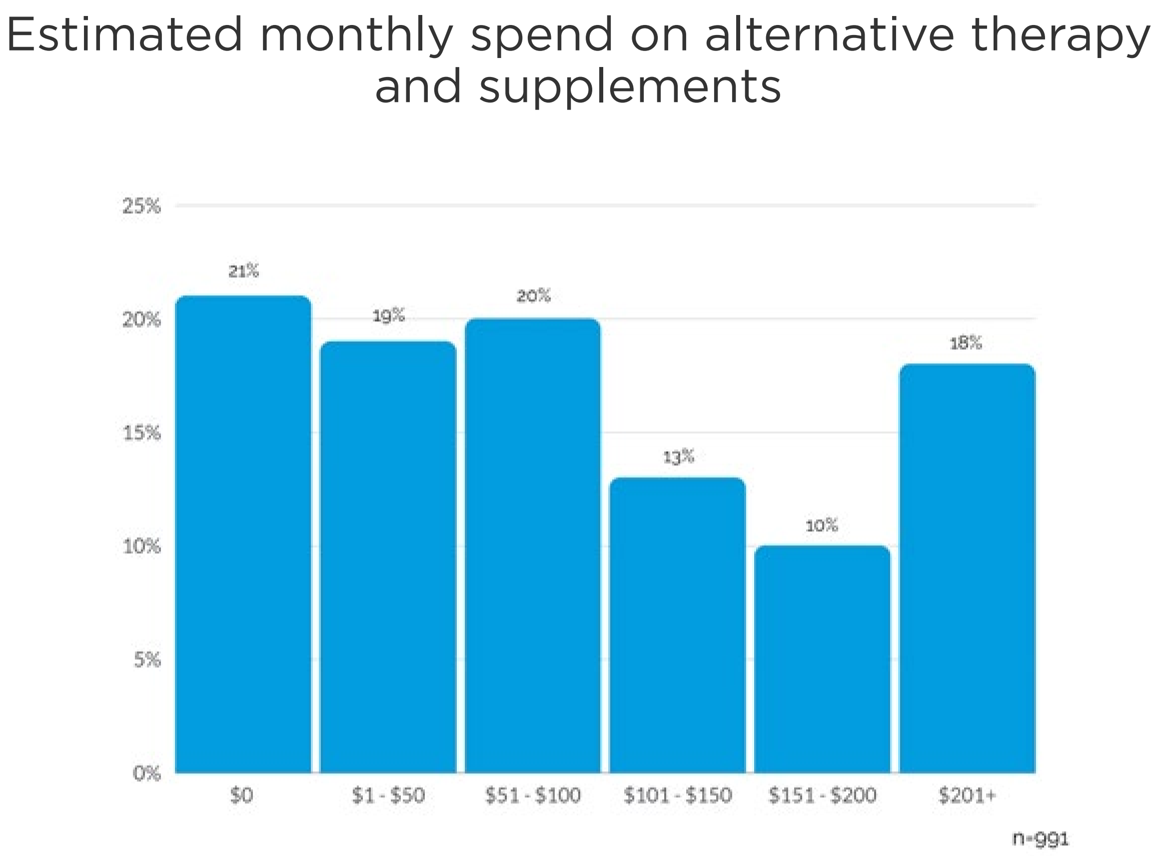


Figure 5.3: Estimated monthly spend on conventionally prescribed medication

Thirty-eight per cent of participants spent $1–$50 on conventionally prescribed medications, while 41 per cent spent $51 or more. Despite the availability of Pharmaceutical Benefits Scheme (PBS) concessions for people on low incomes, not all conventional medicines are covered by the PBS. This can add significantly to the cost of living for people with ME/CFS.



Estimated monthly spend on alternative therapy and supplements

Figure 5.4: Estimated monthly spend on alternative therapy and supplements

Almost 80 per cent of respondents said they spent money on alternative therapies and supplements to manage their ME/CFS symptoms. It is unsurprising that people would attempt to support their health in alternative ways due to the current lack of effective treatments. Forty-one per cent reported that they spend more than $100 per month on supplements.

Given that more than two-thirds of respondents live below the poverty line as defined by ACOSS (20), costs associated with medical appointments, conventional medicines and supplements are likely to be a significant financial burden on people with ME/CFS.

SECTION 6:

RECEIVING CARE AND SUPPORT

RECEIVING CARE

In keeping with findings that many people with ME/CFS reduce or stop daily activities after onset (Section Four), the survey also found that they received more care and support from others to complete these activities after being diagnosed with the condition. This indicates that friends and family who become supports to, and carers of, people living with ME/CFS are also significantly affected when their loved ones develop the disease.

	At onset	Currently
Participation in paid work	30%	70%
Leaving the house	35%	65%
Transport outside the home	35%	65%
Meal preparation	35%	65%
Personal administrative tasks	33%	67%
Self-care tasks	33%	67%
Shopping	33%	67%
Domestic cleaning	31%	69%
Leisure activities	30%	70%
Caring for others	29%	71%
Undertaking education	59%	41%

Figure 6.1: Help provided to participants in undertaking a variety of activities, at onset and time of survey participation

The rate of help that people received doubled for most daily activities from the time they became ill to the time they completed the survey. This underlines the significant levels of disability that people with ME/CFS are experiencing.

Education was the only category in which the help rate fell. This may reflect the drop-out rate for many people with ME/CFS, or in some cases, an individual making substantial adjustments of their own to keep studying in some way.

What is your source of support for daily activities?

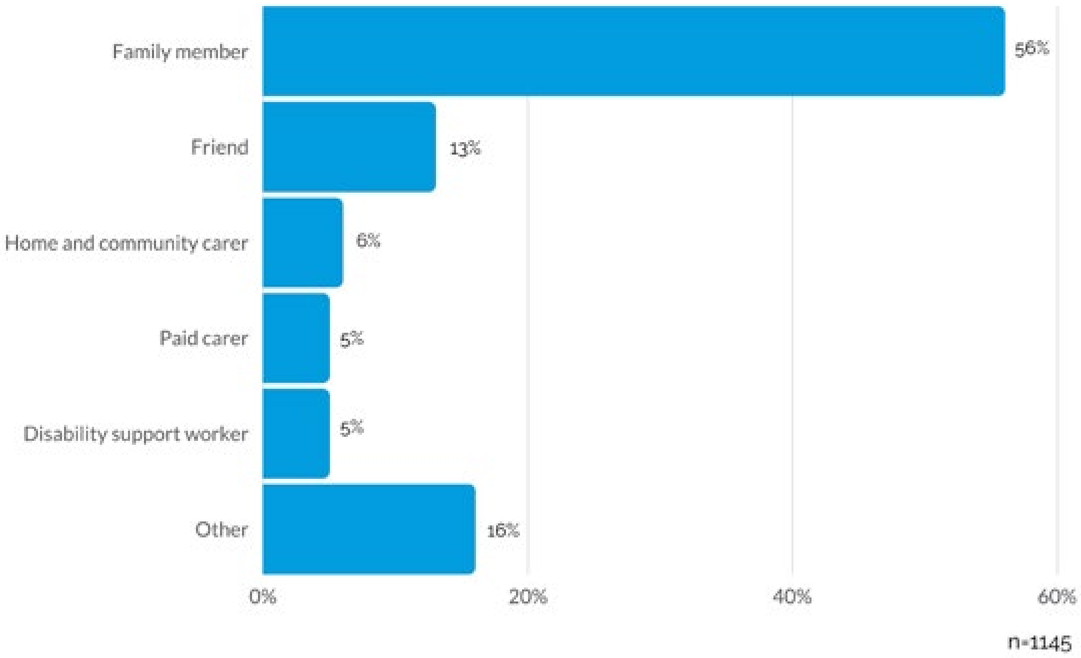


Figure 6.2: What is your source of support for daily activities?

Eighty-five per cent of participants specified that the support they received to undertake daily activities was from family members, friends or 'other' (many people included domestic partners in this category but also university and work-related supports).

Despite indicating that they require support for certain activities, Only 16 per cent of respondents reported that they received help from professional carers. Such a significant level of reliance on friends and family for people who report such high levels of disability is concerning. Care provided by friends and family can be less stable and reliable, can constrain carers in their ability to engage in work and education themselves, and can place significant pressure on relationships, including those between parents and children and between domestic partners.

Flexible working arrangements and university disability support workers were mentioned in the 'other' category, emphasising the importance of tailored assistance for those people with ME/CFS who are able to continue paid work or education in some capacity.

Which family member provides you with the most help?

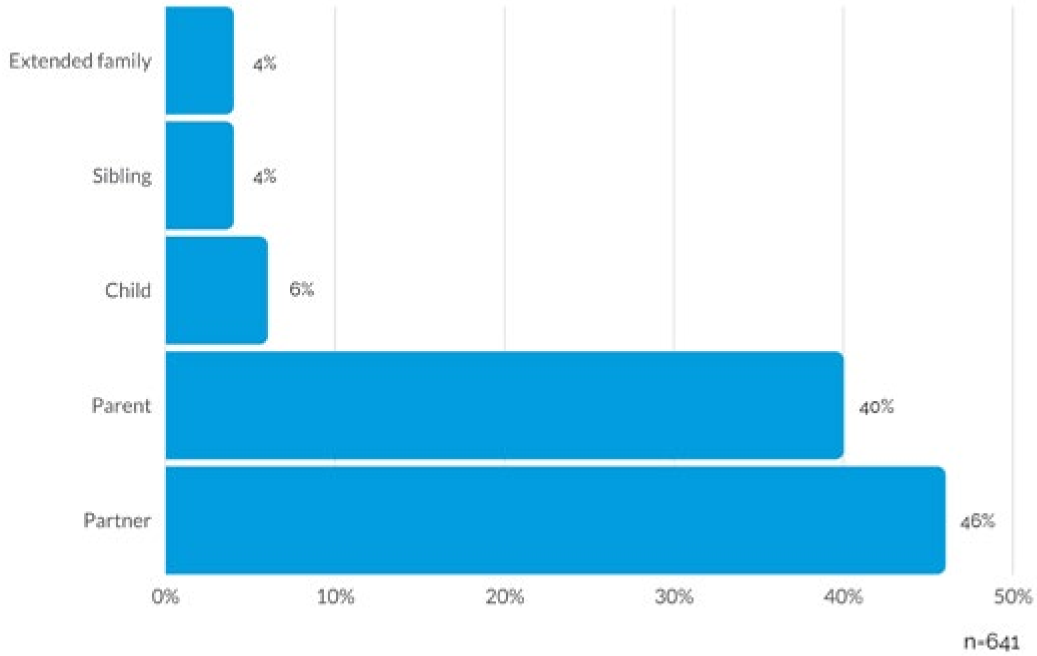


Figure 6.3: Which family member provides you with the most help?

When asked which family member provided the most help, 46 per cent of participants indicated that this came from partners. This was followed by parents at 40 per cent. Given that all participants in this survey were over the age of 18, this shows that many parents of people living with ME/CFS continue to be the primary support for their adult children.

Only 16 per cent of respondents reported that they received help from professional carers.

How much on average do you pay for support each month?

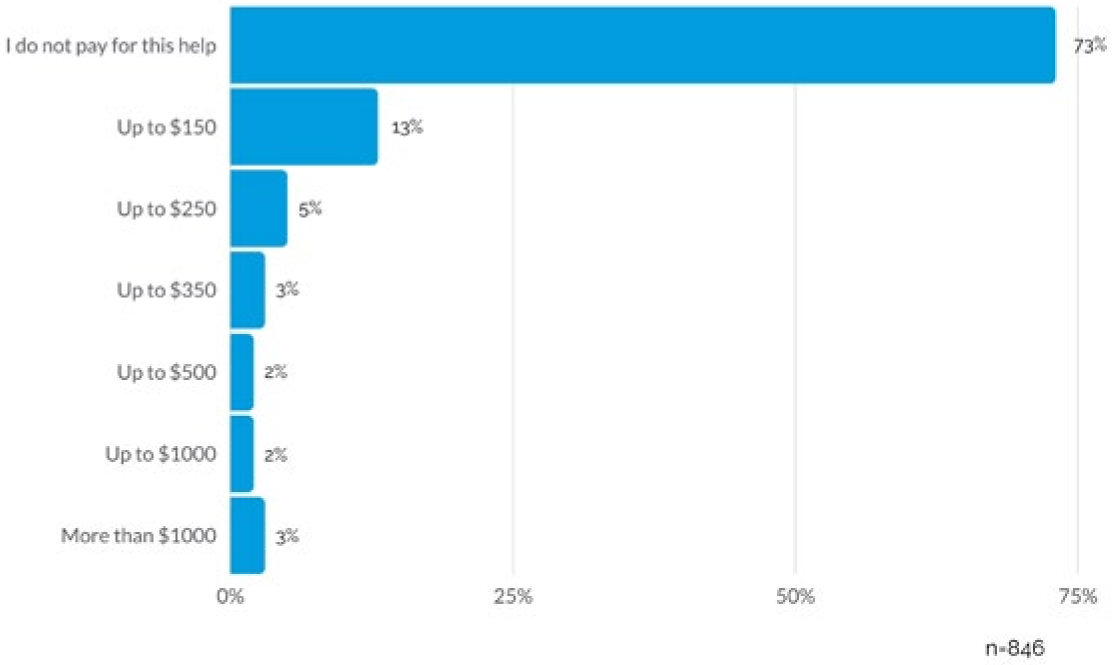


Figure 6.4: How much on average do you pay for support each month?

Participants were asked to estimate how much money they spent on care each month. The response to this question was comparatively low; however, there was a striking contrast between the number of individuals reporting that they were receiving care (Figure 6.1) and those who reported paying for this care. We explore subsidies for this care (NDIS or other forms of financial assistance) in the following section. For example, 69 per cent of participants reported that they receive support for domestic cleaning activities and 67 per cent for self-care tasks at the time of survey completion. Seventy-three per cent of respondents stated that they did not pay for this help (Figure 6.4). This indicates that the help they receive is unpaid and likely to be done by friends, family, partners or unpaid volunteers. The remaining 27 per cent of people who answered this question stated that they paid for some of the support they received.

Do you receive any subsidies for the support that you receive?

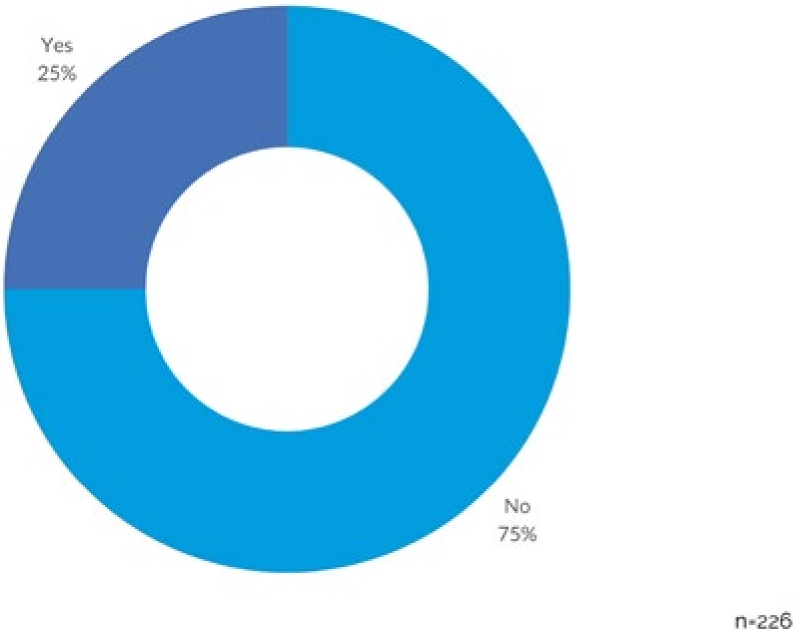


Figure 6.5: Do you receive any subsidies for the support that you receive?

Only a quarter of the people who indicated that they do pay for some of their support reported that they received subsidies for this assistance. The remaining 75 per cent wholly funded their own support.

Does anyone in your family or any of your friends who help you receive Carer Allowance?

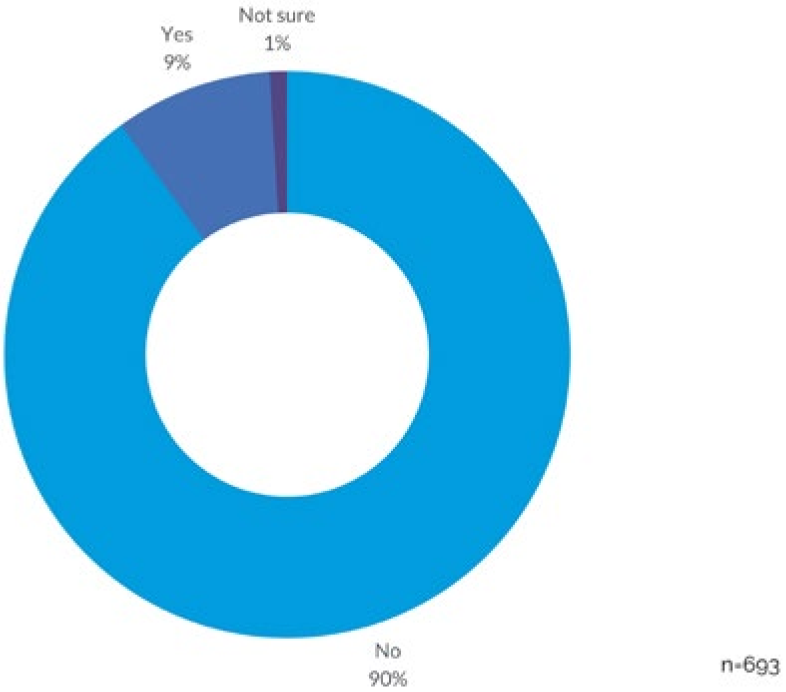


Figure 6.6: Does anyone in your family or any of your friends who help you receive Carer Allowance?

While 56 per cent of respondents reported that they receive support from family and 13 per cent from friends (Figure 6.2), just 9 per cent indicated that their carer/s received Carer Allowance to assist with this (Figure 6.6). Our survey found that 90 per cent of carers were financially unsupported in this role. This causes an inter-generational financial burden in the case of parents, and compounds financial stress for domestic partners.

More research should be undertaken to understand the barriers experienced by carers of people with ME/CFS that prevent them from accessing financial support.

> ***90 per cent of carers were financially unsupported in this role. This causes an inter-generational financial burden in the case of parents, and compounds financial stress for domestic partners.***

DISABILITY SUPPORT PENSION AND SICKNESS ALLOWANCE

Participants were asked if they had applied for the Disability Support Pension (DSP) or Sickness Allowance (SA) and if their application/s had been successful.

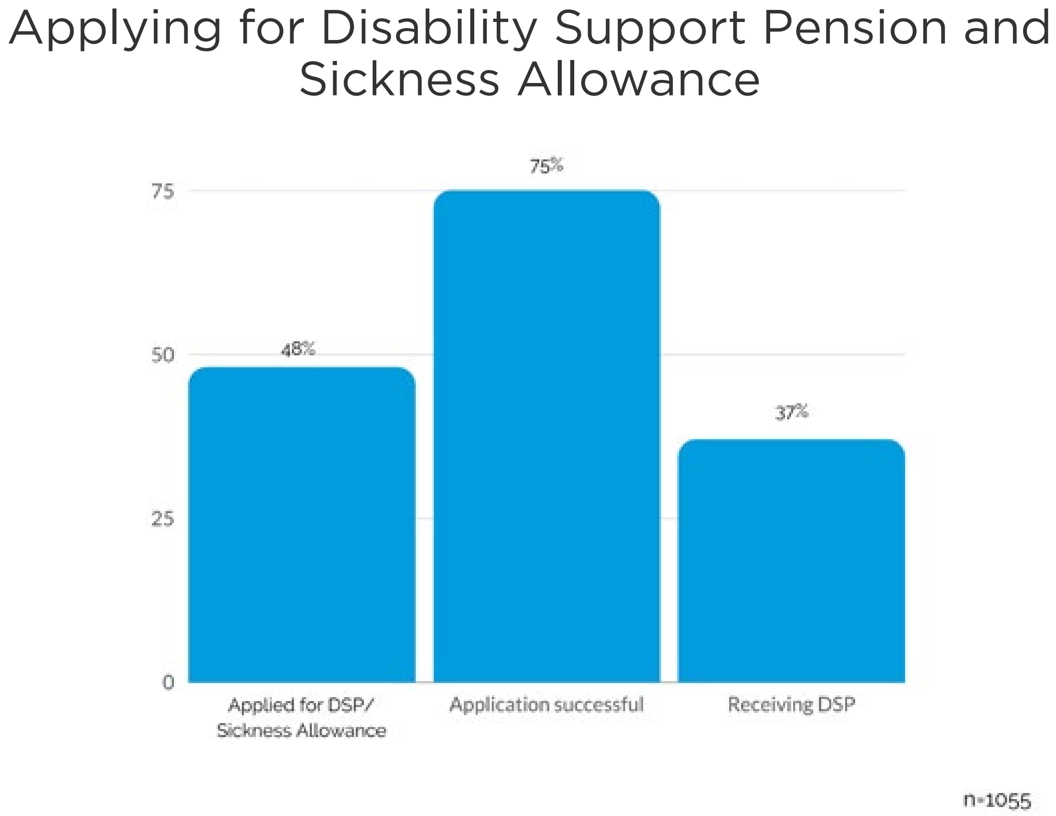


Figure 6.7: Applying for Disability Support Pension and Sickness Allowance

Just under 50 per cent of participants had applied for DSP or SA, with a reported success rate of 75 per cent. People with severe or very severe symptoms were more likely to have applied (62 per cent). Their applications were also somewhat more likely to be successful, at a rate of 77 per cent. It is pleasing to see a success rate of 75 per cent; however, the fact that 23 per cent of people with severe symptoms (who find tasks such as showering, cooking and cleaning particularly difficult and a major source of PEM) said they were not successful is of concern.

Were you able to find useful advice to help you apply for the benefit?

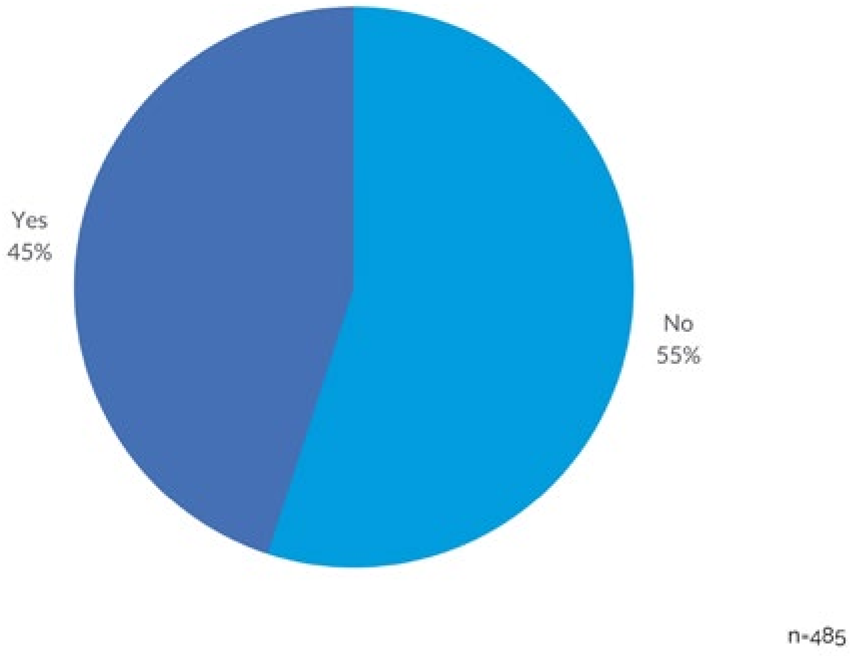


Figure 6.8: Were you able to find useful advice to help you apply for the benefit?

More than half of respondents to this question reported that they could not find useful advice about applying for DSP or SA. This survey was completed before the launch of Emerge Australia's new website, which provides limited, although detailed, information about applying for financial support. While Emerge Australia can provide general guidance for the application process, we continue to lobby for adequate one-on-one support for people seeking to access financial help.

DISABILITY SUPPORT SERVICES

The survey asked what types of disability support services participants were accessing (if they had access to this support). Forty-five per cent of participants accessed government-funded services (federal, state and local), while 25 per cent accessed non-government or community-based disability supports. The proportion of severely and very severely unwell patients accessing supports was slightly higher. However, given the extreme limitations on activities of daily living that people with severe/very symptoms experience, this survey indicates that many are not receiving the level of support that they need or ought to be entitled to.

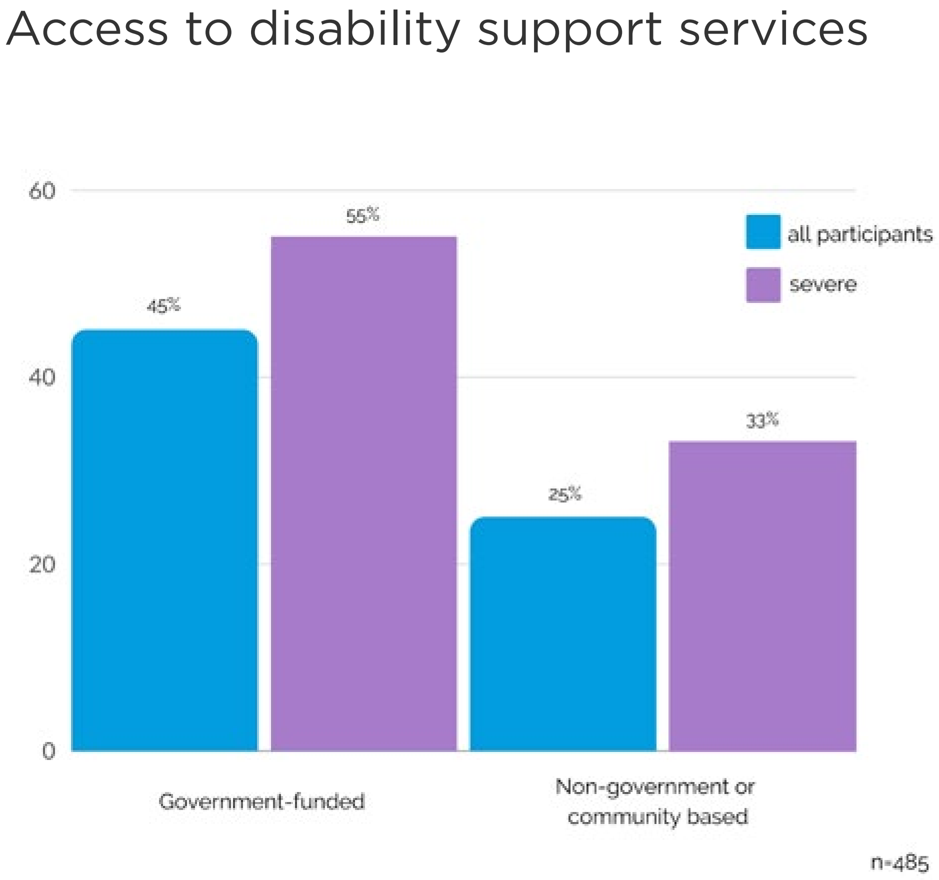
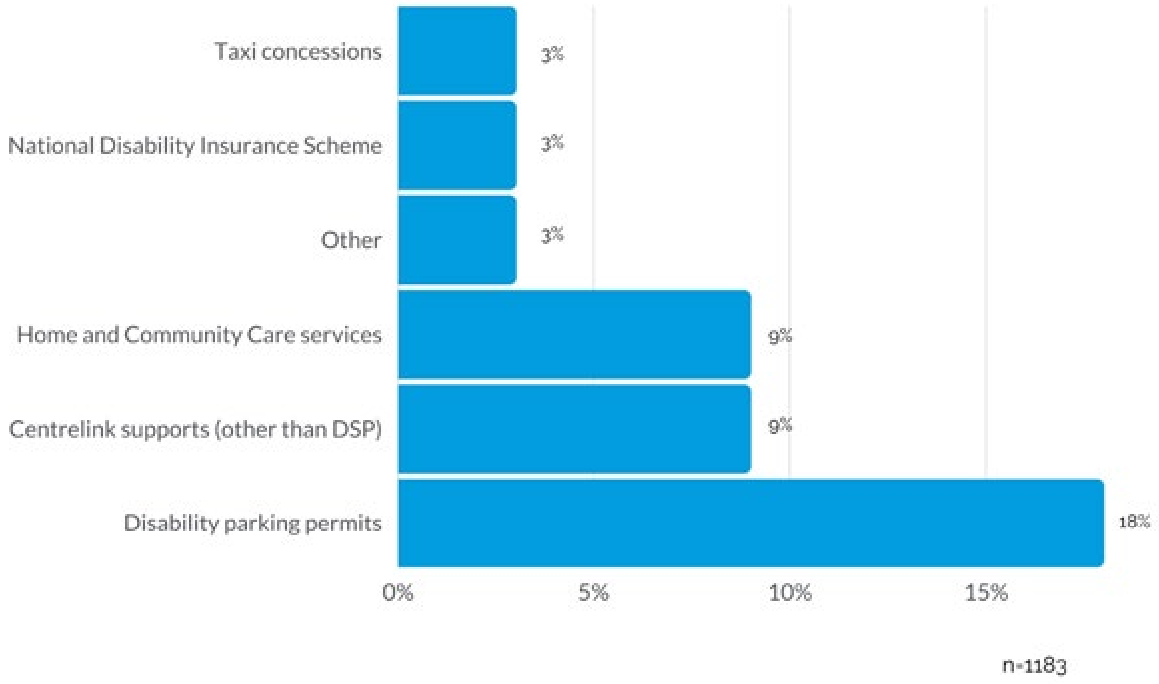


Figure 6.9: Access to disability support services

Three-quarters of respondents had not accessed non-government or community-based disability support services, while less than half had accessed government-funded services including those from local councils. Given the limitations that people with ME/CFS face each day, we would expect that they would be accessing support at higher rates.

Government-funded disability supports accessed



Other includes assistance with shopping, counselling, help with gardening and home maintenance.

Figure 6.10: Government-funded disability supports accessed

A relatively high proportion of respondents (18 per cent) had a disability parking permit, yet just 3 per cent had a taxi concession card. This may inhibit independence for those people with ME/CFS who are unable to drive due to autonomic and cognitive difficulties.

Just 3 per cent of participants had accessed the National Disability Insurance Scheme (NDIS). Given the substantial physical and cognitive disabilities caused by ME/CFS, and the high proportion of patients who are housebound or bedbound, we would expect this participation rate to be much higher. A 2019 petition developed by Emerge Australia about improving access to the NDIS for people with ME/CFS received more than 10,000 signatures – clearly indicating that this community feels unjustly excluded from the scheme (or felt so at the time of the petition).

Emerge Australia will be interested to see how acceptance into the NDIS changes over time as the scheme matures. Advocating for greater transparency in the NDIS application process and success rate by disease, along with improving access, will continue to be a core focus for advocacy.

The ‘lifelong lockdown’ that many people with ME/CFS experience is compounded by the challenges in accessing quality healthcare, and having their needs heard and understood by healthcare practitioners.

Non-government or community-based disability supports accessed

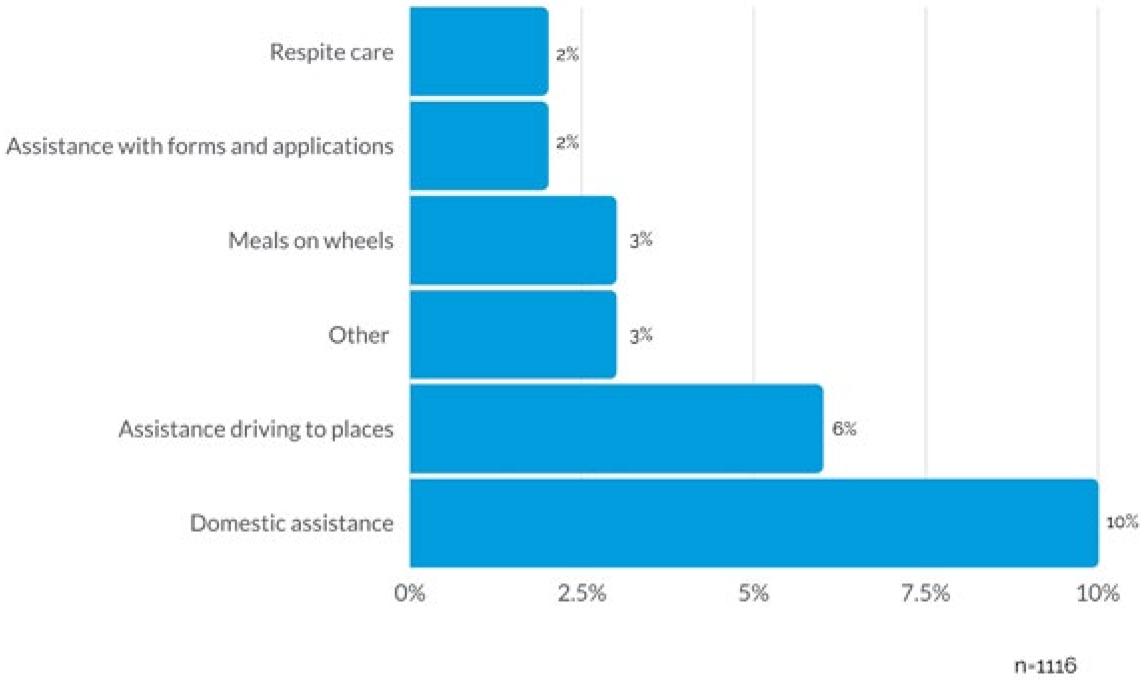


Figure 6.11: Non-government or community-based disability supports accessed

The percentage of participants who were receiving non-government or community-based support was extremely low. A number of respondents noted that they had tried to access support but that services were at capacity or unable to provide the service required. For example, one person was offered shopping assistance – but only if they could leave the home to attend the supermarket with the support worker. The individual was unable to leave their home and was therefore unable to receive the support.

Emerge Australia is trying to improve information and resources for people via our ‘InfoLine’, but it is clear that more help is required to assist people in accessing supports offered within the community to which they ought to be entitled.

SECTION 7:

PRACTITIONER KNOWLEDGE AND PATIENT EXPERIENCE

GENERAL PRACTITIONER KNOWLEDGE

How well-informed do you feel your GP is?

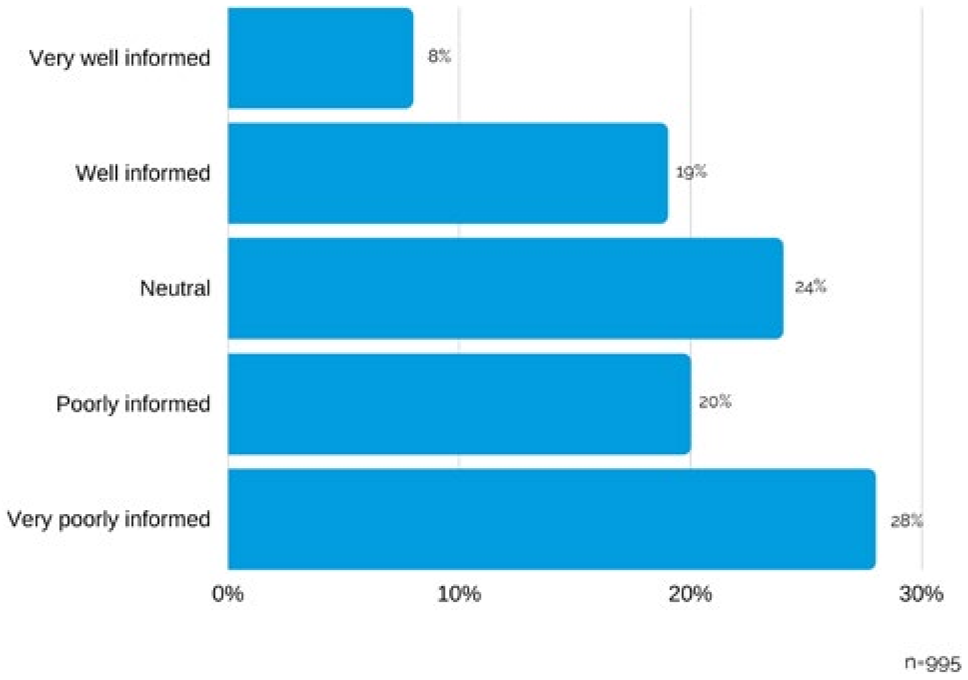


Figure 7.1: How well-informed do you feel your GP is?

Asked to rate their GP's knowledge of ME/CFS, 48 per cent of respondents said they were poorly or very poorly informed and only 27 per cent felt that their GP was well or very well informed. This was a poorer outcome than the 2015 survey, where 44 per cent of respondents stated that their GP was poorly or very poorly informed and 29 per cent stated they were well or very well informed.

This is a major concern. As there is no single medical specialty for the condition, patients often rely on their GP for information and diagnosis. As this survey demonstrates, GPs diagnose at least 50 per cent of cases. GPs must be better informed about the multisystemic and physiological nature of ME/CFS, clinical diagnostic criteria including post-exertional malaise, the potentially harmful effects of graded exercise therapy, and treatments or ways of managing the condition that may help people to deal with their symptoms more effectively and improve their quality of life.

Only 7 per cent of participants stated that their GP was very well informed, demonstrating the strong need for educational support for practitioners. ThinkGP, an Australian online education platform, has recently developed and launched an accredited program aimed at improving GPs' understanding of ME/CFS. Emerge Australia contributed to developing the module and conducted a promotional campaign to ensure GPs Australia-wide know about it. Topics include pathophysiology, diagnosis and management. GPs are able to obtain continuing professional education points upon completion of the module. At the time of publication, more than 500 healthcare professionals had completed the module.

However, with ~27,000 practising GPs around Australia, we need to reach many more (22). ThinkGP is currently developing a second module.

GPs who seek to provide support and guidance to ME/CFS patients in their care face the current challenge of inadequate Australian guidelines. The National Health and Medical Research Council's (NHMRC) recent Advisory Committee Report into ME/CFS recommended that the current Royal Australasian College of Physicians ME/CFS clinical guidelines should be updated (23). The guidelines have not been updated since 2002 and include treatments that are no longer recommended and may cause harm. Emerge Australia is currently advocating for these guidelines to be updated to enable GPs to take a best practice approach to ME/CFS symptom management.

SPECIALIST AND ALLIED HEALTH PRACTITIONER KNOWLEDGE

In addition to GPs, participants in this survey seeking support for their ME/CFS symptoms had seen a wide range of specialists and allied health professionals.

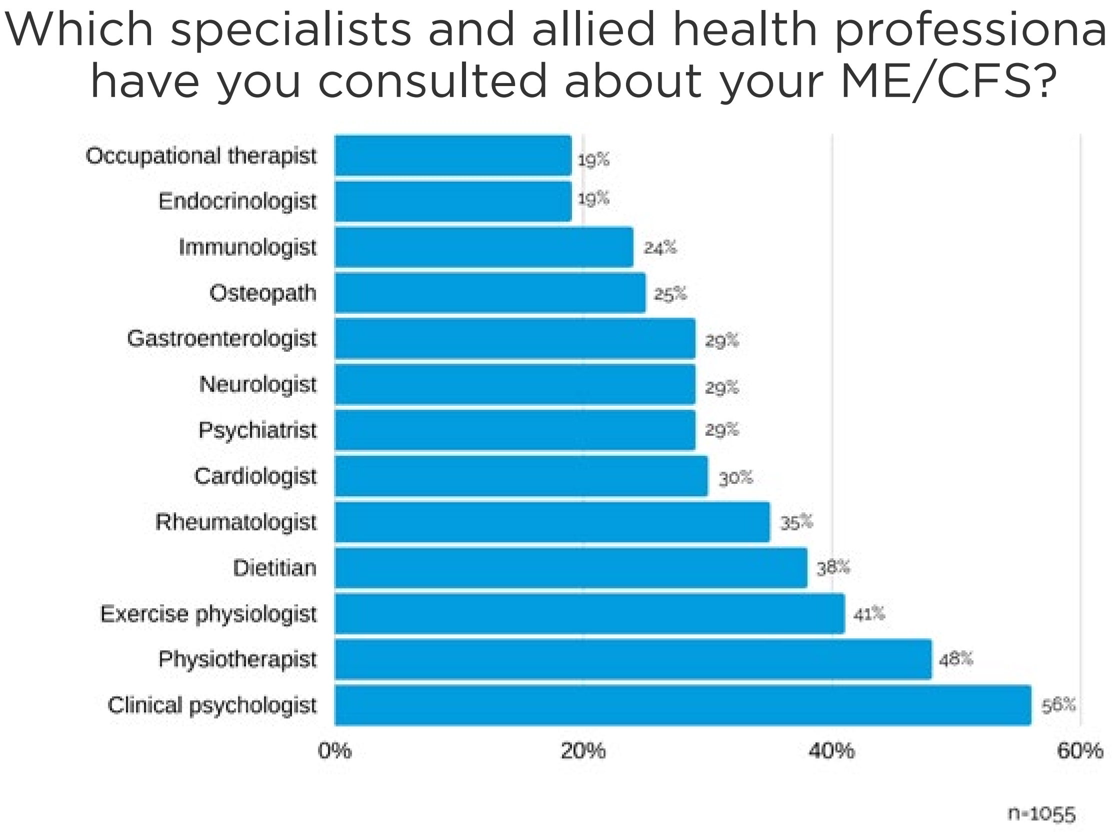

Which specialists and allied health professionals have you consulted about your ME/CFS?

Figure 7.2: Which specialists and allied health professionals have you consulted about your ME/CFS?

People with ME/CFS consulted clinical psychologists more than any other allied health or medical speciality (56 per cent). Physiotherapists (48 per cent) and exercise physiologists (41 per cent) were the next most consulted allied health professionals.

It is important to note that while clinical psychologists and exercise physiologists can be extremely valuable for people living with ME/CFS, Emerge Australia is concerned that some patients are being prescribed inappropriate exercise therapy that could worsen their condition. Australian ME/CFS clinical guidelines still recommend graded exercise therapy (GET; now removed as a recommended treatment by the Center for Disease Control in the US (11)), which compounds poor knowledge and misconceptions about ME/CFS in the allied health professions.

Survey respondents had also seen a large range of other specialist and allied health practitioners. This included, but was not limited to, naturopaths, myotherapists, Chinese medicine practitioners, sleep specialists, kinesiologists, acupuncturists, chiropractors, gynaecologists, pain specialists, integrative GPs, fatigue specialists, audiologists, and POTS and Lyme disease specialists.

How well informed about ME/CFS, out of a score of 5, were the following practitioners?

Specialist	Average rating
Gastroenterologist	2
Cardiologist	2
Endocrinologist	2.1
Neurologist	2.1
Psychiatrist	2.4
Dietitian	2.4
Occupational therapist	2.6
Physiotherapist	2.6
Immunologist	2.7
Osteopath	2.8
Clinical psychologist	2.8
Rheumatologist	2.9
Exercise physiologist	2.9

Figure 7.3: How well informed about ME/CFS, out of a score of 5, were the following practitioners?

When asked to indicate how well informed each of these practitioners were about ME/CFS (when rated 1–5), participants graded each practitioner 2.0–2.9 on average. Exercise physiologists and rheumatologists were given the highest rating overall, at 2.9. This indicates that there is still a significant lack of well-informed specialists and allied health practitioners, which, as well as being problematic in itself, has implications for GPs who want to refer their patients on for specialised testing, advice or treatment.

Having explored the experiences of people living with ME/CFS, the survey sought to identify the major barriers to accessing services and opportunities to improve future experiences. Note that participants were able to select all barriers and opportunities that applied to them when answering questions in this section of the survey.

LOCATION OF PRACTITIONERS

Only 44 per cent of participants said that the majority of practitioners they have seen were located in their local area. When considered against participants' geographical location (urban, regional or remote), this decreased somewhat for those living regionally and more so for those living remotely. Only 31 per cent of people living remotely were accessing the majority of practitioners for direct care of their condition in their local area.

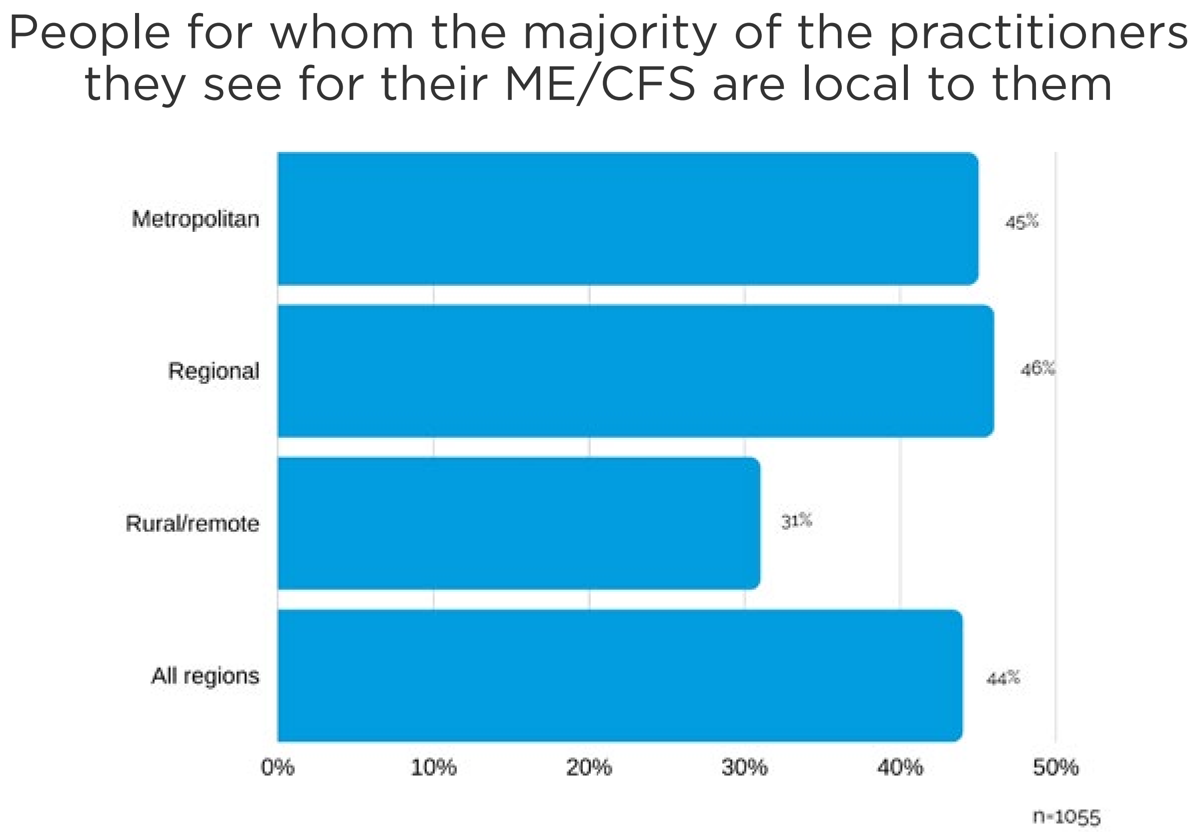


Figure 7.4: People for whom the majority of the practitioners they see for their ME/CFS are local to them

Travelling more than a short distance, particularly if the travel is followed by a lengthy wait, can bring on, or exacerbate, post-exertional malaise. The consultation itself and the travel back home can make symptoms even worse. Many patients take days or longer to recover from appointments with their healthcare team.

This is far from optimal and emphasises the need for more flexible and appropriate consultation options, including funded telehealth with any appropriate healthcare practitioner.

SECTION 8:

OPPORTUNITIES TO IMPROVE THE HEALTHCARE EXPERIENCE

BARRIERS TO ACCESSING SERVICES

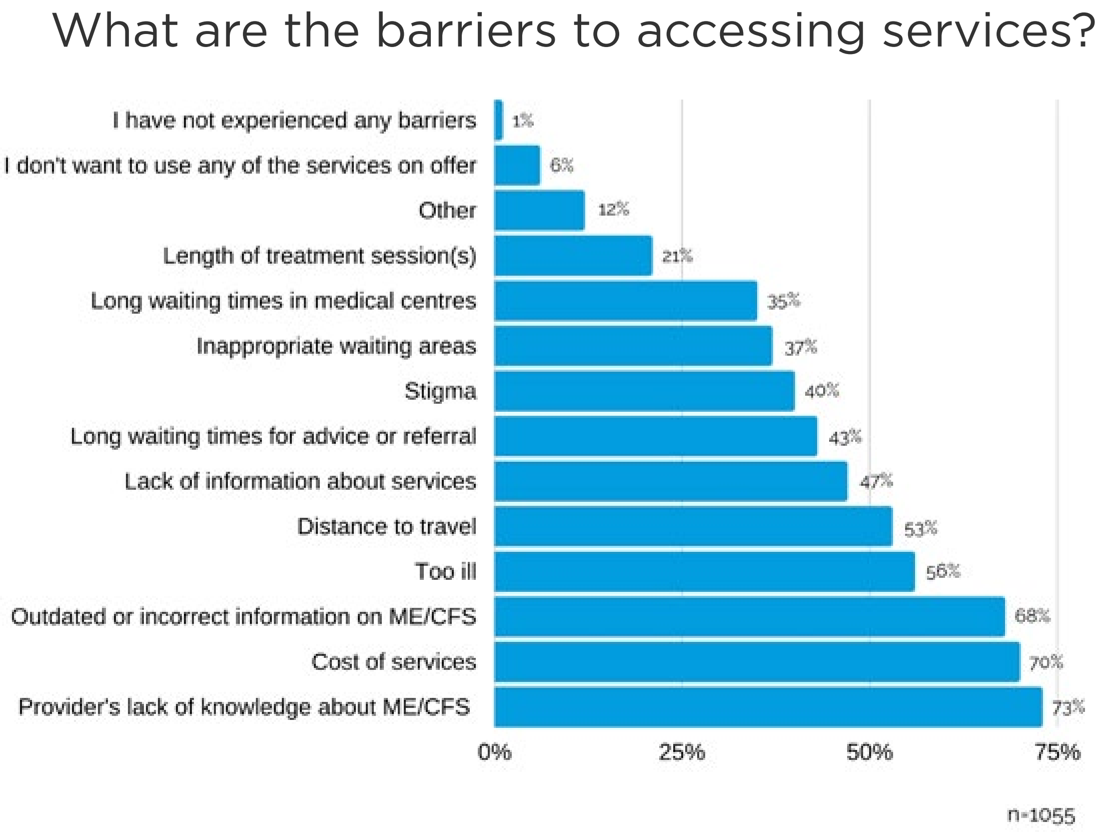


Figure 8.1: What are the barriers to accessing services?

Section Seven highlighted patients' experience with healthcare practitioners, finding that most respondents felt that their GPs and specialists have a poor knowledge of ME/CFS. Accordingly, our survey found that a lack of service-provider knowledge was the greatest barrier to accessing services. Seventy-three per cent of participants selected this option, while 68 per cent identified outdated or incorrect information about ME/CFS as a barrier. These findings further reinforce the importance of providing greater support and education to medical practitioners, including updated RACP clinical practice guidelines.

Cost was the second largest barrier, with 70 per cent of participants identifying it as an issue. As detailed in Section Five, the onset of ME/CFS has a significant effect on income due to the difficulties that people with the condition face remaining in full-time work. We know that many people with ME/CFS have no access to financial support and that more than two-thirds of survey participants have an annual income below the poverty line. Given this, it is not surprising that cost is seen as a significant barrier. Despite the low income level of the ME/CFS population represented by this survey, we know that 40 per cent of people reported costs for medical care of $101+ per month for appointments, 41 per cent reported spending $51+ per month on conventionally prescribed medications and 41 per cent reported spending more than $100 per month on alternative health management options. The high cost associated with managing ME/CFS combined with the low income experienced by most people with the condition is of great concern.

People who selected ‘other’ as a barrier (and specified the reason) detailed experiences of providers not believing that ME/CFS existed, negative attitudes towards ME/CFS and an inability to get a diagnosis. A lack of specialists in ME/CFS, and a lack of interest from medical practitioners in becoming ME/CFS specialists, were also significant concerns. This reflects the barrier of ‘stigma’ which was identified by 40 per cent of participants.

Have you ever made a formal complaint about treatment you have received for your ME/CFS?

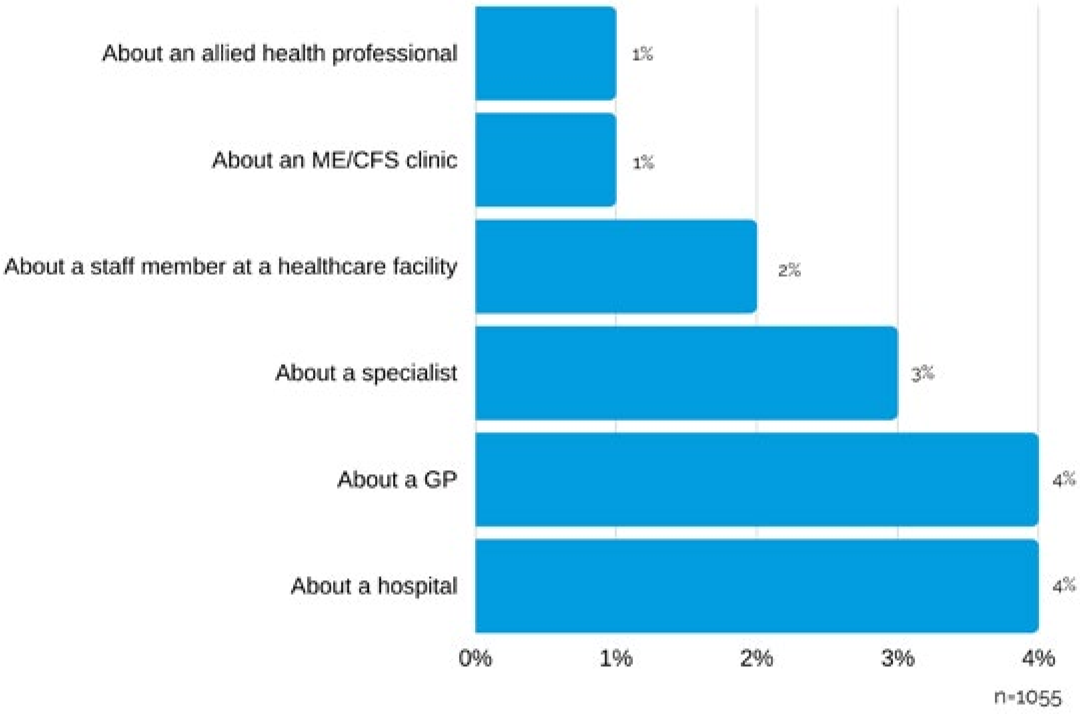


Figure 8.2: Have you ever made a formal complaint about treatment you have received for your ME/CFS?

Despite a multitude of barriers in accessing services – including stigma and the effects of not being believed by healthcare professionals – very few participants reported ever having made a formal complaint about medical treatment. Emerge Australia recently distributed a survey seeking insight into experiences of violence, abuse and neglect of people living with ME/CFS, which will be collated and published as a submission to the Royal Commission into Disability in late 2020. This report will detail these experiences in much more detail and has uncovered areas of significant concern.

Our survey found that a lack of service-provider knowledge was the greatest barrier to accessing services.

OPPORTUNITIES TO IMPROVE SERVICES

Respondents were given nine options including ‘none of the above’ to outline what would make a real difference to their healthcare. Responses were co-designed with patient participants during the development of the survey.

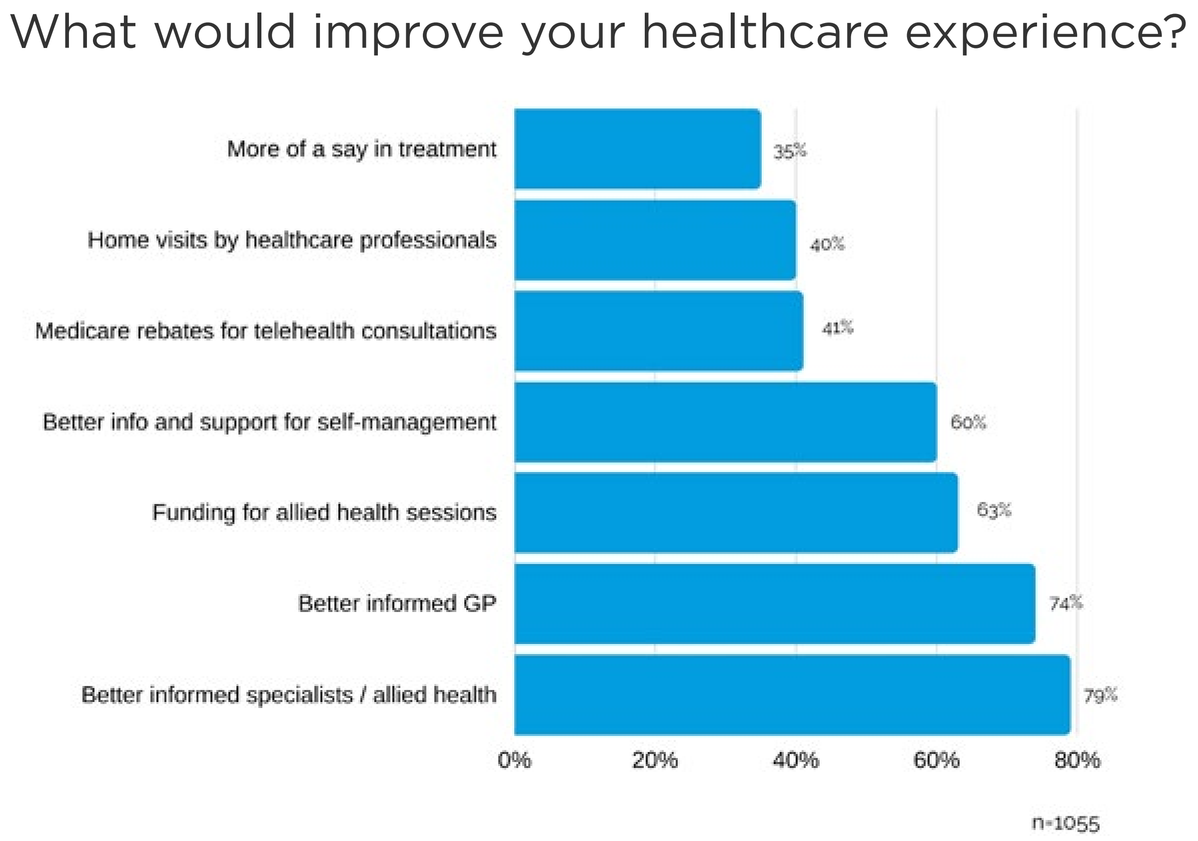
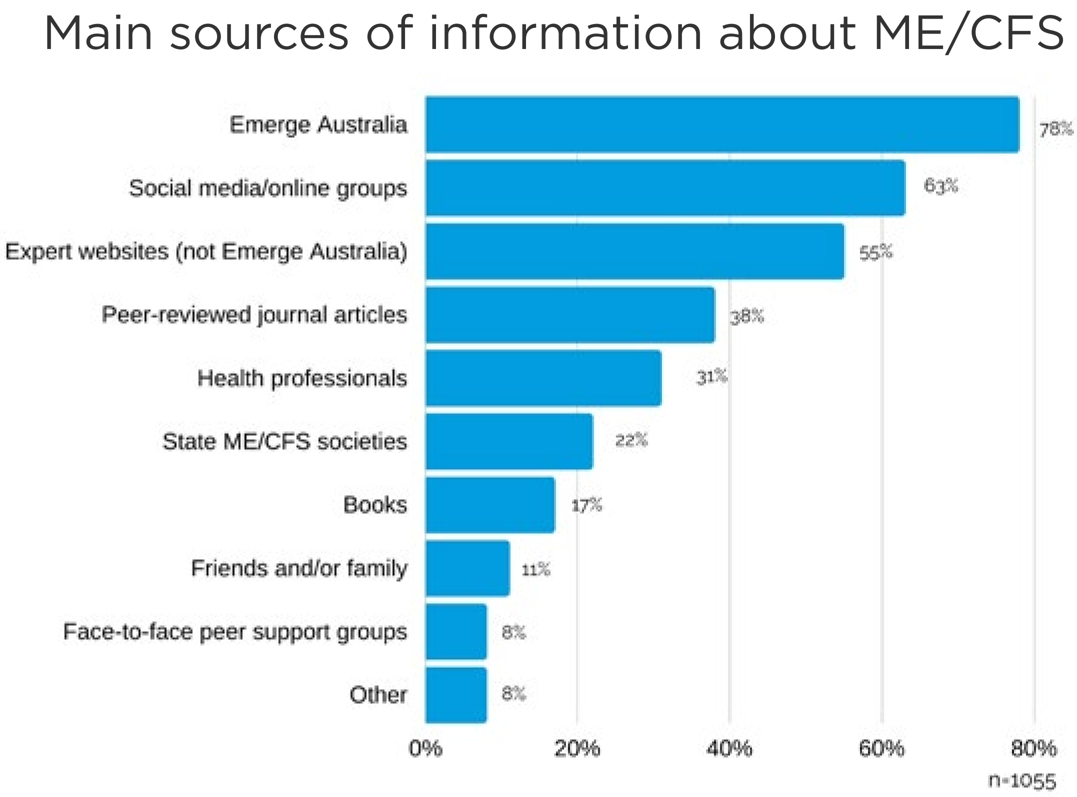


Figure 8.3: What would improve your healthcare experience?

When asked what would make a real difference to their healthcare, the top choices were better informed specialists and allied health professionals (79 per cent), better informed GPs (74 per cent), followed by funding for allied health sessions (63 per cent), and better information and support for self-management (60 per cent).

SEEKING INFORMATION ABOUT ME/CFS



'Other' includes people with ME/CFS, internet browsing, online peer support and forums, twitter, podcasts, self-experience.

Figure 8.4: Main sources of information about ME/CFS

Seventy-eight per cent of participants who answered this question (multiple choices allowed) reported that Emerge Australia was their greatest source of information about ME/CFS. While we were pleased to learn that participants saw Emerge Australia as a key source of information, everyone undertaking the survey is already engaged with us as an organisation. People living with ME/CFS and not aware of the organisation would not have taken part in this survey and therefore may be missing out on accessing a key supporter of their interests and health.

Only 31 per cent of respondents saw health professionals as a main source of information. It is concerning that people more commonly sought information online, through social media, through organisations (including Emerge Australia) and through peer-reviewed journals than via health professionals. We are keen to work in partnership with relevant agencies and medical and professional colleges to help to improve the reliability and support available to people with ME/CFS through traditional healthcare services.

Only 31 per cent of respondents saw health professionals as a main source of information.

Further analysis revealed differences across age groups regarding sourcing information online. Older participants were less likely to use social media and online groups (44 per cent of 61–70 year-olds, 22 per cent of 71–80 year-olds, and no-one in the 81–90 age group). In contrast, more than 50 per cent of people aged under 60 who participated in this survey used social media and online groups. This could indicate that older people living with ME/CFS are excluded from receiving information when it is delivered online, and from connecting with online communities.

Additionally, people living with 'very severe' ME/CFS were most likely to use Emerge Australia as a source of information (88 per cent) and social media and online groups (84 per cent). This indicates that Emerge Australia has a committed cohort of people who classify themselves as living with very severe ME/CFS. This group was also the least likely to view health professionals as a major source of information (28 per cent). This indicates difficulties in accessing the kind of health care appropriate for people who are bedbound and reliant on others for most daily needs.

RECOMMENDATIONS

A range of opportunities to improve the quality of life and the health and wellbeing outcomes of people living with ME/CFS have been identified, informed by our survey findings.

The following recommendations should be considered by policy makers, service providers and healthcare practitioners to enable delivery of more equitable and outcome-focused health and social care support for the 250,000 Australians living with ME/CFS. While these recommendations are geared toward improving outcomes for people living with ME/CFS, we suggest that they will apply to improving health and wellbeing outcomes for people with other chronic illnesses and disabilities.

ACCESS TO EDUCATION AND EMPLOYMENT

Recommendation one: That employers and educators working with employees and students with ME/CFS familiarise themselves with the range of symptoms associated with living with this condition (see page 29-35). ME/CFS is a complex condition impacting multiple systems in the body, and the experience of symptoms can vary widely between individuals. ME/CFS is sometimes labelled an 'invisible disability' in recognition of the fact that people with the condition can look physically healthy. This can make it difficult to understand what a person with ME/CFS might be experiencing, to empathise with their experience, and to make appropriate and reasonable adjustments for that person. Workplace disability action plans should include information around how to support people living with ME/CFS and other chronic illnesses.

Recommendation two: Education departments and providers including schools, TAFEs and universities should improve access to education for people living with ME/CFS, including through online learning and flexible learning approaches such as via study from home. Eighty-eight per cent of survey respondents told us that they had stopped or significantly reduced time spent on education and training after they were diagnosed with ME/CFS. Thirty per cent of respondents experienced their first symptoms between the ages of 11–20, highlighting the importance of appropriate education and early career support for young people with ME/CFS.

Recommendation three: In order to retain and take on employees with ME/CFS who are well enough to work, employers should consider how they can better support these employees. Just 19 per cent of survey respondents who are still in the workplace reported that their employer provided specialist supports. The most common forms of support were allowing working from home and flexible work hours. With 89 per cent of respondents reporting that they had stopped or significantly reduced their paid working hours after symptom onset, there is significant room for improvement to support people to stay in work.

Since this survey was undertaken, the COVID-19 pandemic has demonstrated the flexibility and adaptability of many workplaces in Australia in enabling people to work from home. We urge employers to continue to offer working-from-home options once the pandemic has ended in order to maintain mutually beneficial relationships with employees living with ME/CFS.

CARE SUPPORT

Recommendation four: Improve access to Carer Allowance for carers of people living with ME/CFS. The needs of carers of people living with ME/CFS and other chronic illnesses and disabilities are often overlooked, and adequate provision for their support and requirements, including for financial help, needs to be more thoughtfully considered by policy makers and service providers. Our survey respondents told us that 90 per cent of people performing a caring role for them did not receive Carer Allowance. This indicates that there are substantial barriers to accessing adequate support for people providing care to those living with ME/CFS.

Recommendation five: Increase awareness of and accessibility to government and non-government support services, including through better understanding of the needs of people living with ME/CFS and altering eligibility criteria accordingly to include them. While more than two-thirds of respondents to the survey live below the poverty line and between 65–70 per cent of respondents reported that they require support to undertake a range of daily tasks (such as leaving the house and self-care), only 45 per cent of survey respondents told us that they were accessing government support and only 25 per cent were accessing non-government and community-based supports. A number of respondents explained that they had been ineligible for some services as a direct result of their symptoms – for example, they were only able to access social supports provided through their council if they could leave their home, resulting in housebound/bedbound people being excluded from social support activities.

Emerge Australia would welcome working with government and non-government support services to assist in making their programs more accessible and appropriate for people living with ME/CFS.

Recommendation six: Boost the capacity of the NDIA to efficiently and accurately assess people living with ME/CFS. Only 3 per cent of respondents reported that they had access to the NDIS, despite the debilitating and often permanent nature of the condition (less than 10 per cent of patients recover to pre-illness functioning and 20 per cent of patients may worsen with time) (3). Opportunities include funding Emerge Australia to establish a new NDIS assessment position to support the NDIA in this work. This aligns with the National Health and Medical Research Council's (NHMRC) recent ME/CFS Advisory Committee Report recommendation that NDIA assessment guidelines should be developed in collaboration with ME/CFS experts and community (23).

Recommendation seven: That the NDIA improve their reporting and evaluation around application processes by disabling disease. At present ME/CFS sits across a number of reportable categories within the NDIS and there is no transparency around how many applications are submitted by people living with ME/CFS and the success rate of these applications. This information would enable organisations such as Emerge Australia to evaluate and improve support services provided to people living with ME/CFS seeking to access support to which they ought to be entitled.

PRACTITIONER KNOWLEDGE

A lack of practitioner knowledge about ME/CFS was identified as the greatest barrier to accessing appropriate services. Accordingly, better informed allied health practitioners and GPs were the most commonly selected options that survey respondents told us would improve their experience of the healthcare system. Only 31 per cent of respondents regarded health professionals as a key source of information about ME/CFS. Medical professionals must be provided with up-to-date, accurate information about ME/CFS and supported to deliver appropriate care to people living with ME/CFS.

Recommendation eight: That the Royal Australasian College of Physicians ME/CFS clinical guidelines be replaced with up-to-date, fit-for-purpose guidance, as recommended by NHMRC's 2019 ME/CFS Advisory Committee Report (23). The Australian clinical guidelines for ME/CFS were last updated in 2002, do not reflect the current biomedical understanding of the condition and contain advice regarding treatments which are controversial at best and may cause significant harm. Medical practitioners must be enabled to access accurate information as a priority.

Recommendation nine: That health practitioners have access to education on the aetiology, diagnosis and treatment of ME/CFS based on the current understanding of the condition. ME/CFS should be covered at both undergraduate and postgraduate levels, and included in professional development recommended by RACGP to ensure that newly trained and existing healthcare practitioners have accurate information about the condition from the beginning of their careers. Educational content should be developed in conjunction with the ME/CFS community to ensure that it reflects both current understanding of the condition and the patient community's needs and concerns.

Recommendation ten: That medical expertise in ME/CFS in Australia be fostered through the establishment of Centres of Excellence (CoE). There are vanishingly few healthcare practitioners in Australia who could be considered experts in ME/CFS, making it difficult for Australian ME/CFS patients to access high-quality care. Centres of Excellence provide an opportunity for patients to receive the best multidisciplinary medical care available, and would also serve as training centres for healthcare practitioners to develop expertise in ME/CFS, as well as hubs for research projects and clinical trials. The establishment of one or more Centres of Excellence would enhance both ME/CFS clinical care and research in Australia.

Emerge Australia welcomes the opportunity to work with healthcare professionals to improve the quality of care provided.

ACCESS TO HEALTHCARE

In addition to better informed healthcare practitioners, our survey identified a range of other opportunities to improve access to appropriate healthcare services for people living with ME/CFS.

Recommendation eleven: Improve access to bulk-billed healthcare services for people living with ME/CFS. Cost was reported as a significant barrier to accessing appropriate services. This is unsurprising given the number of respondents living below the poverty line.

Recommendation twelve: Funding for organisations such as Emerge Australia to develop resources to provide more support around self-management. Sixty per cent of respondents called for more information around self-management. As the national organisation supporting people with ME/CFS, Emerge Australia has a medical advisory committee, a patient advisory group, a core staff of trained professionals and is well-placed to develop these resources if funding were available.

Recommendation thirteen: Telehealth services to be made permanently available through Medicare for people with ME/CFS and other chronic illnesses. Telehealth services have been made temporarily available throughout the COVID-19 pandemic and have been warmly welcomed by people living with ME/CFS who have previously struggled to access in-person appointments. Attending in-person appointments can be challenging for people living with ME/CFS, as the process of travelling to an appointment, inappropriate waiting areas and long waits to see a practitioner can trigger post-exertional malaise. This means that people with ME/CFS are often not able to attend GPs or other health services when they are at their most unwell. Attending in-person appointments is particularly challenging for people who are housebound or bedbound as a result of their symptoms.

Recommendation fourteen: Home visits made by healthcare professionals to be made available through Medicare. For the same reasons as described above, home visits can enable people who are housebound or bedbound to access necessary healthcare supports.

CONCLUSION

Lifelong Lockdown: Lessons Learned from the Health and Wellbeing Survey of Australians Living with ME/CFS 2019 demonstrates how living with this complex, disabling disease can profoundly impact all aspects of daily life.

People living with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) – of whom there are approximately 250,000 in Australia – too often find themselves locked out of education and employment opportunities and, along with a lack of access to financial support, are at significant risk of falling into financial insecurity and poverty. The onset of ME/CFS usually leads to a reliance on partners, friends and family to take on care roles. This vital work is rarely officially recognised and our report has uncovered that financial support for carers is lacking. These factors, combined with an almost certain loss of meaningful social connection, means that a diagnosis of ME/CFS can look especially bleak. Challenges faced by patients are further exacerbated by a lack of knowledge about ME/CFS among employers, education providers and medical practitioners, leading to isolation and uncertainty about where to seek support.

Despite our findings portraying a huge range of challenges faced by people living with ME/CFS (and their carers), we also found immense opportunity in what we learned. This report lays out a number of straightforward and sensible recommendations which, if implemented, would make a significant positive impact on the health and wellbeing of people living with ME/CFS and other chronic illnesses.

Throughout the national response to COVID-19, we have been heartened to see a number of our recommendations implemented on a whole-of-population basis. Telehealth and home learning for tertiary education have both been successfully implemented and expanded in 2020. The ability to access high-quality healthcare and education using online technologies is a gamechanger for many people with ME/CFS and other chronic illnesses, particularly for those who are sometimes, or always, housebound by their symptoms. We hope to see both of these service delivery models maintained and refined in Australia once the pandemic is over.

There are also enormous issues in provision of, and access to, high-quality healthcare for people with ME/CFS. The most urgent change required is to increase knowledge and understanding of ME/CFS by medical practitioners. To that end, we have also published a summary of survey findings relevant to the medical community. Emerge Australia understands that medical practitioners face barriers themselves in accessing clear, accurate information about ME/CFS. Historic underfunding for biomedical research into the causes and possible treatments of ME/CFS has led to the dissemination of inaccurate and out-of-date advice to GPs and other practitioners in Australia. Along with the lack of updated guidelines by the RACP, this has created a confusing environment for practitioners to operate in. Despite, or perhaps because of this, we are seeing an increased desire by practitioners to find ways to improve their understanding of ME/CFS and to better support their patients. We hope to work more closely with professional bodies to assist them in this work.

For too long, ME/CFS has been misunderstood, downplayed and overlooked by the medical community and broader society, but we are beginning to see new awareness of the painful reality of life with the condition. We hope that this survey will contribute to a continuing shift in recognition for patients with ME/CFS and will help to further reduce the stigma of this under-researched biomedical disease.

GLOSSARY

Autonomic manifestations: symptoms related to the dysregulation of the autonomic nervous system, which is responsible for managing a range of automatic functions like blood pressure, circulation, heart rate and digestion.

Canadian Consensus Criteria (CCC): diagnostic criteria for ME/CFS published in 2003. According to the CCC, PEM, sleep dysfunction and pain are all required to receive a diagnosis, in addition to two or more neurological manifestations, and at least one symptom from two or more of the following categories: autonomic, neuroendocrine or immune manifestations. Adults are diagnosed at six months and children at three months after symptom onset.

Immune manifestations: symptoms related to dysfunction of the immune system, including abnormalities in functioning of cytokines, natural killer cells and ion channels.

Institute of Medicine criteria: diagnostic criteria for ME/CFS published in 2015. According to these criteria, a diagnosis requires the following three symptoms: substantial reduction in functioning accompanied by fatigue, PEM and unrefreshing sleep; as well as at least one of the following two symptoms: cognitive impairment or orthostatic intolerance.

International Consensus Criteria (ICC): diagnostic criteria published 2011. A patient must experience PEM in addition to one (or more) neurological impairments from three out of four categories (neurocognitive impairment; pain; sleep disturbance; neurosensory, perceptual and motor disturbances). Patients must also have one (or more) immune symptoms and energy metabolism symptoms.

Neuroendocrine manifestations: symptoms related to the functioning of the neuroendocrine system, which makes and releases hormones to control bodily functions.

Neurological manifestations: neurological or cognitive symptoms are related to functioning of the central and peripheral nervous system (brain, spinal cord, nerves).

Post-exertional malaise (PEM): the primary symptom of ME/CFS, PEM can be understood as a worsening of symptoms such as fatigue, pain and cognitive impairment following physical or mental effort.

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LIST OF FIGURES

Section One

Section Two

Section Three

Section Four

Section Five

Section Six

Section Seven

Section Eight

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www.emerge.org.au

Ross House
247 - 251 Flinders Lane
Melbourne VIC 3000