LESSONS LEARNED FROM THE HEALTH AND WELLBEING SURVEY OF AUSTRALIANS LIVING WITH MYALGIC ENCEPHALOMYELITIS /CHRONIC FATIGUE SYNDROME (ME/CFS) 2019:

A Summary of Findings for Medical Practitioners

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Thanks

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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

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Foreword

In 2019, Emerge Australia conducted a survey of Australians living with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) to understand their experiences of living with this complex, poorly understood condition. In addition to our main report, *Lifelong Lockdown: Lessons Learned from the Health and Wellbeing Survey of Australians Living with ME/CFS 2019*, this companion document has been compiled specifically to support medical practitioners who wish to increase their knowledge of the lived experience of people with ME/CFS and consequently provide improved care to their patients. We would also draw practitioners' attention to the ThinkGP continuing professional development module *Busting the myths and redefining myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)*, which has up-to-date information on how to accurately diagnose and manage the disease.

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. Of the 250,000 Australians living with ME/CFS, approximately 25 per cent are housebound or bedbound as a result of their symptoms.

For too long, the experiences of people living with ME/CFS have been overlooked and misunderstood by the medical sector and the broader Australian community, with devastating results. When asked about the challenges they faced in accessing appropriate health services, our more than 1,000 survey respondents identified a lack of practitioner knowledge about ME/CFS among GPs, specialists and allied health practitioners as their greatest barrier. Sadly, people with ME/CFS continue to experience stigma and misunderstanding of their symptoms when presenting at healthcare appointments.

It is unsurprising that this is the case. We know that medical practitioners in Australia face significant 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. At present, GPs working with patients with ME/CFS are directed to consult the Royal Australasian College of Practitioners (RACP) clinical guidelines which were last updated in 2002. These guidelines do not reflect the current biomedical understanding of ME/CFS and contain advice regarding treatments which are controversial at best and may cause significant harm. This creates a confusing environment for practitioners to operate in.

Consequently, many people living with ME/CFS reported that they were unable to access the support and information they need from healthcare practitioners. Only 31 per cent of survey respondents regarded health professionals as a key source of information about ME/CFS.

People living with ME/CFS around Australia are eager to find medical practitioners they can trust – and the great news is that we are seeing an increased desire by practitioners to find ways to improve their understanding of ME/CFS and to better support their patients. For individual practitioners seeking to broaden their knowledge about ME/CFS today, we hope that this report will provide additional insights to assist you in your everyday practice.

In this publication for medical practitioners, we present findings most relevant to providing healthcare services. In particular, we present information regarding symptom onset and diagnosis, experience of primary and additional symptoms, experiences with healthcare practitioners, and opportunities to improve healthcare services. You will find a list of recommendations relevant to both individual medical practitioners and medical bodies at page 44.

If you are interested in understanding the broader experience of people living with ME/CFS, we recommend that you read the complete report, Lifelong Lockdown, available on the Emerge Australia website.

We're so grateful that you have taken the time to consider the findings of our survey. We know that there are many GPs, specialists and allied health professionals around Australia who are invested in improving outcomes for people living with ME/CFS and other chronic illnesses. Thank you for joining with us on this journey to learn more about ME/CFS and how we can all begin to improve the support provided to people living with this 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 patients face significant barriers accessing appropriate support. This includes financial support – an unacceptable number of survey respondents live in financial insecurity and poverty. The greatest barrier to accessing services was service providers' lack of knowledge about ME/CFS, with respondents stating that better-informed specialists, allied health professionals and GPs would most directly improve their health and wellbeing.

Diagnosis and onset

- 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.

Severity and experience of symptoms

- When asked which primary ME/CFS symptoms they experienced, 100 per cent of respondents experienced fatigue, 99 per cent experienced post-exertional malaise (PEM), 97 per cent experienced sleep disturbance and 93 per cent experienced pain. Ninety per cent experienced all four symptoms.
- Our survey showed that the experience of PEM – the defining symptom of ME/CFS – varied between respondents in regard to time elapsed after an activity before PEM occurs and recovery time. Forty per cent of people said recovering from PEM usually took days (i.e. 24 hours or longer), 10 per cent stated it could take weeks, while only 3 per cent indicated that they recovered in a matter of hours.
- It is important for practitioners to understand that ME/CFS is a heterogeneous condition associated with a range of additional neurological, autonomic, neuroendocrine and immune symptoms. The experience and presentation of these symptoms can vary but, among our respondents, some of the most common additional symptoms experienced were: concentration impairment (94 per cent), worsening of symptoms with stress (93 per cent), word retrieval (89 per cent), muscle weakness (88 per cent), intolerance of heat and cold (87 per cent), lightheadedness (83 per cent), recurrent flu-like symptoms (73 per cent) and hypersensitivity to noise (82 per cent).

Practitioner knowledge

- 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.

- When asked to indicate how well informed a range of 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.
- 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

- 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) (1).

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 (2).
- Up to 70 per cent of patients are too ill to work (2).
- 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 (3).
- Up to four times more women than men are affected (4-6).

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. Further information about the characteristics of survey respondents (including location, age, gender) can be found in the full report *Lifelong Lockdown*.

Analysis was undertaken by Emerge Australia and Dench Analytics.

SECTION 1:

DIAGNOSIS & ONSET

DIAGNOSIS

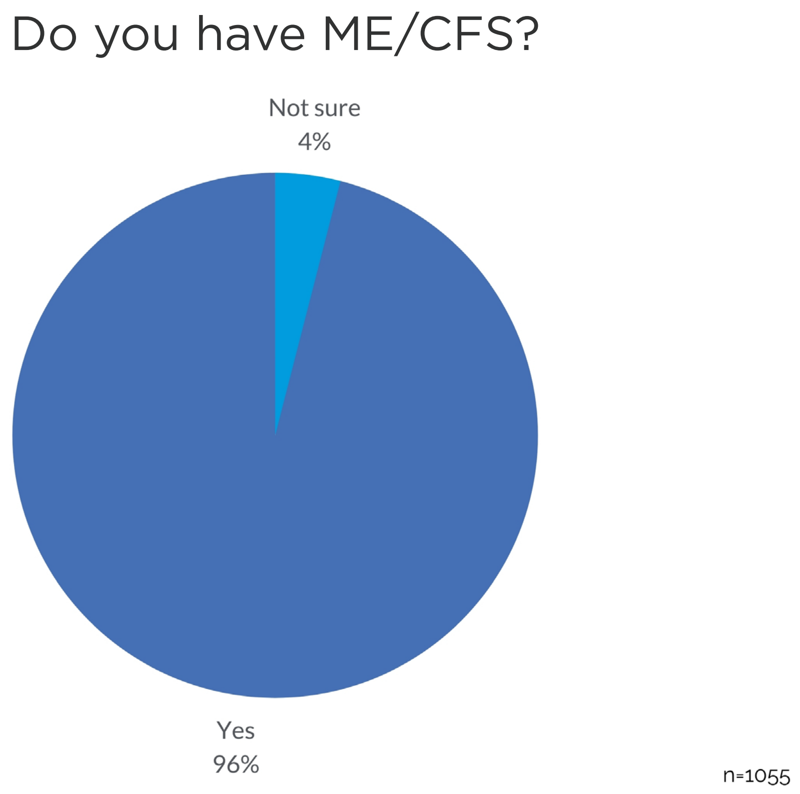


Figure 1.1: Do you have ME/CFS?

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?

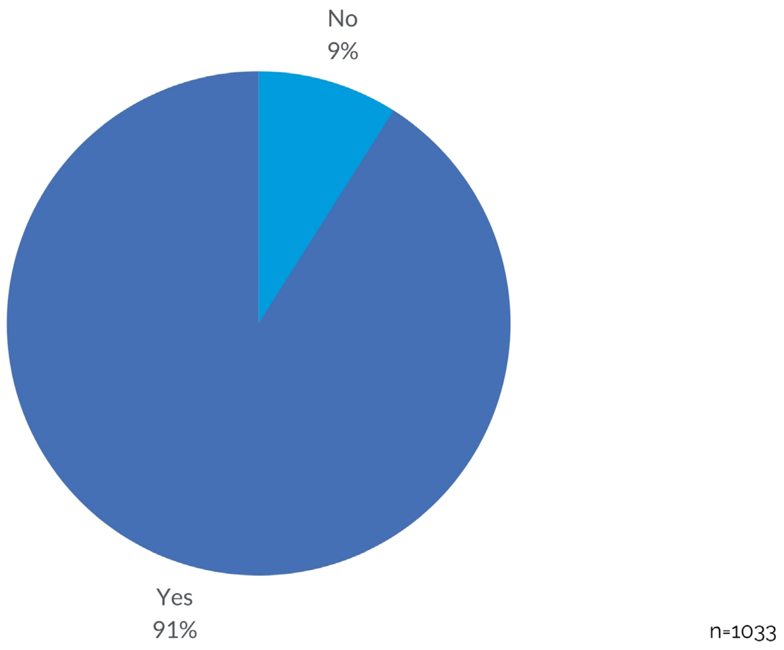


Figure 1.2: Have you received a formal diagnosis of ME/CFS?

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 Three: Medical Costs Associated with Living with ME/CFS and Section Five: Opportunities to Improve the Healthcare Experience.

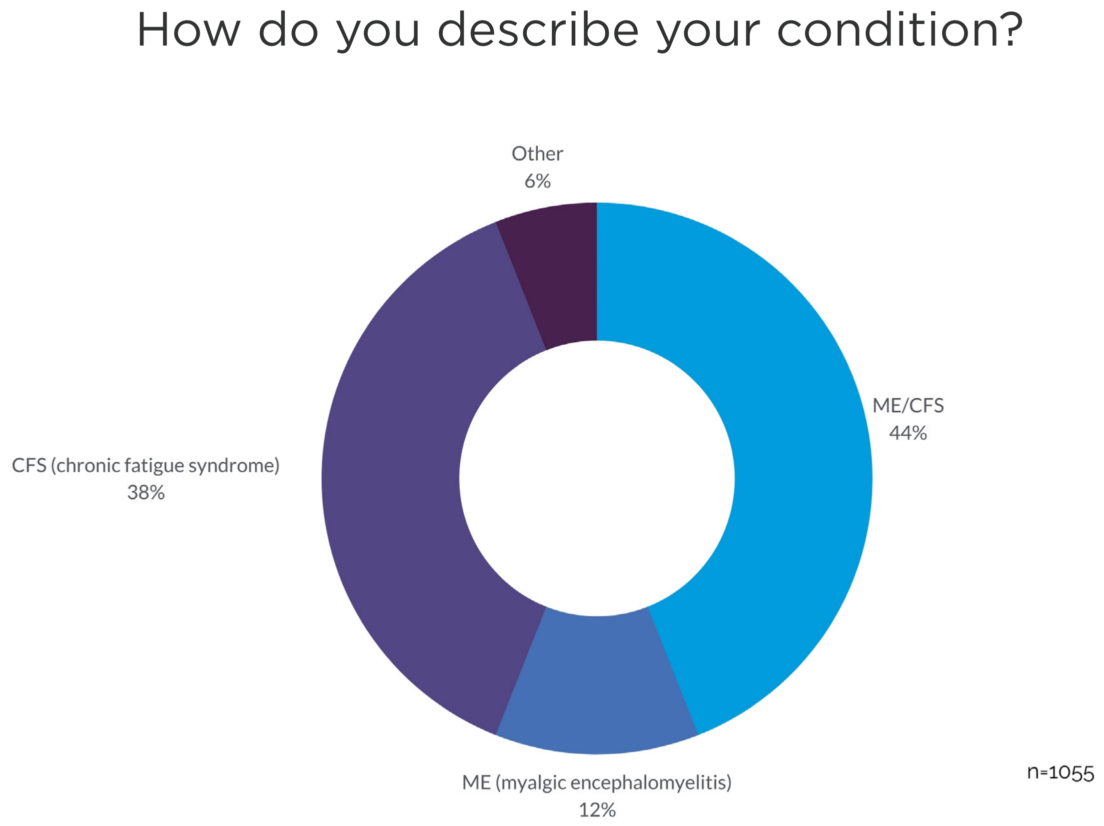


Figure 1.3: How do you describe your condition?

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.

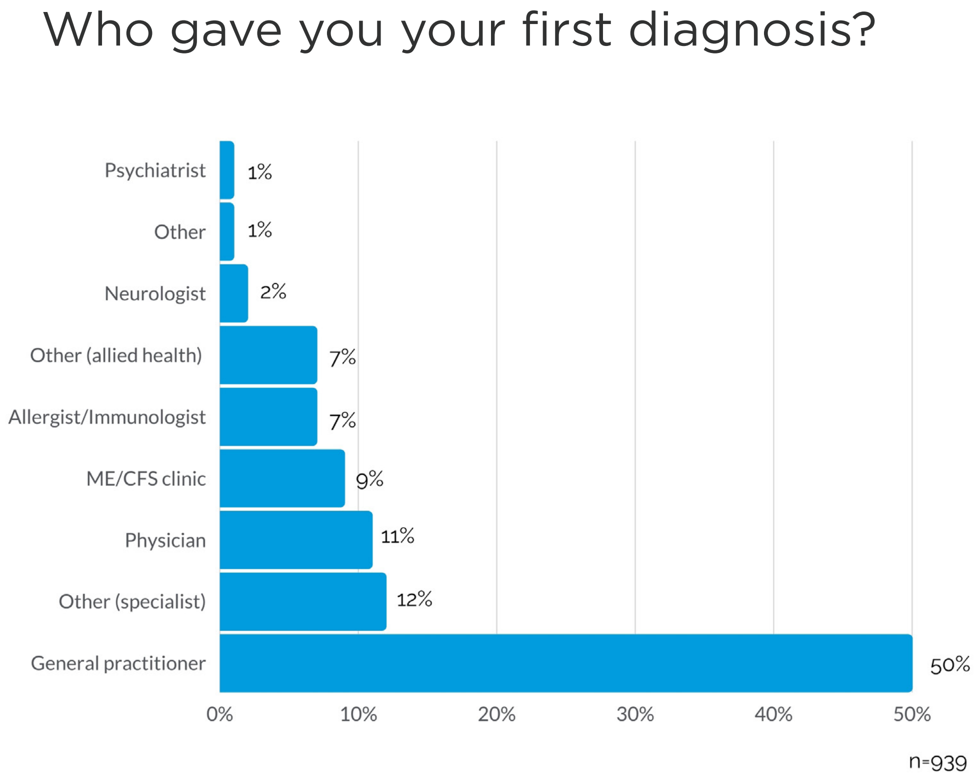


Figure 1.4: Who gave you your first diagnosis?

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 Four: 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

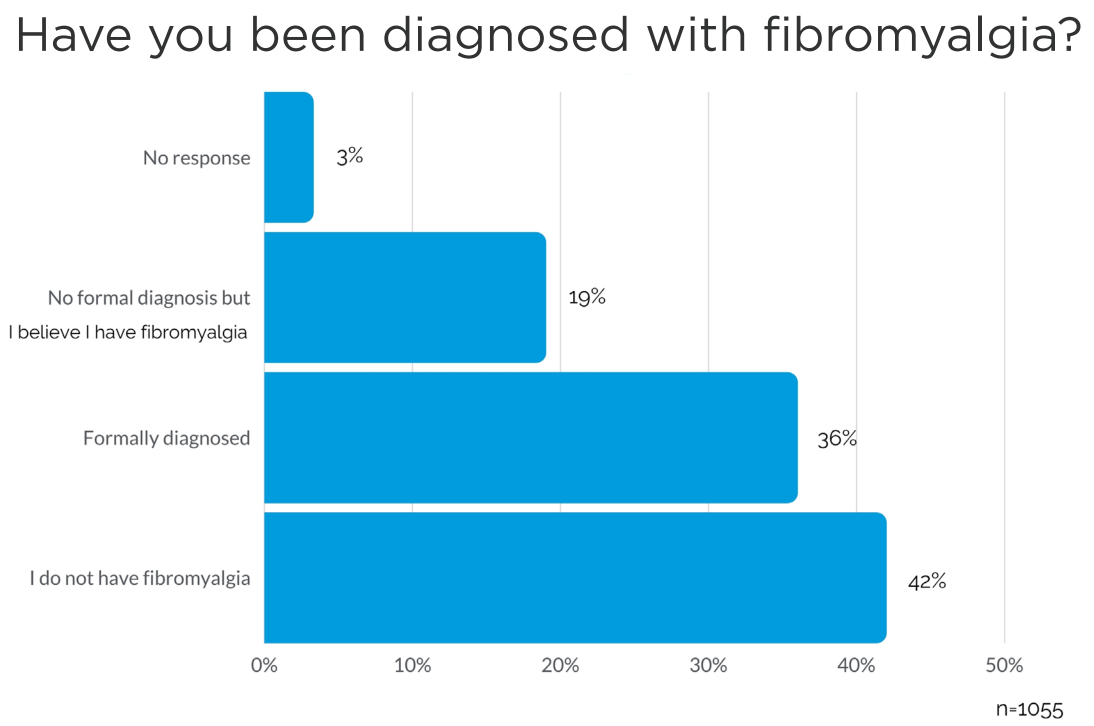


Figure 1.5: Have you been diagnosed with fibromyalgia?

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?

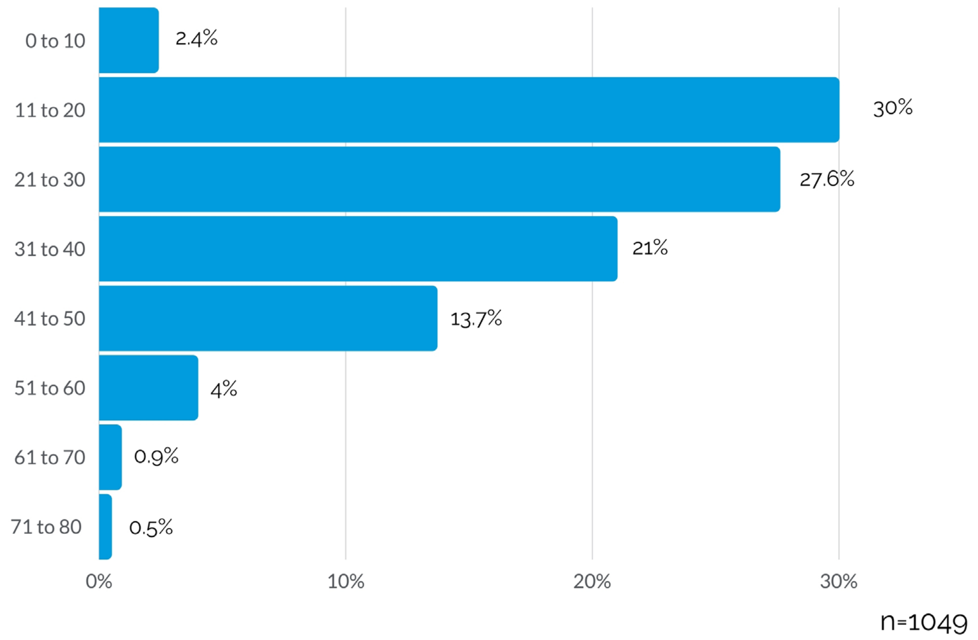


Figure 1.6: At what age did you first notice symptoms of ME/CFS?

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.

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.

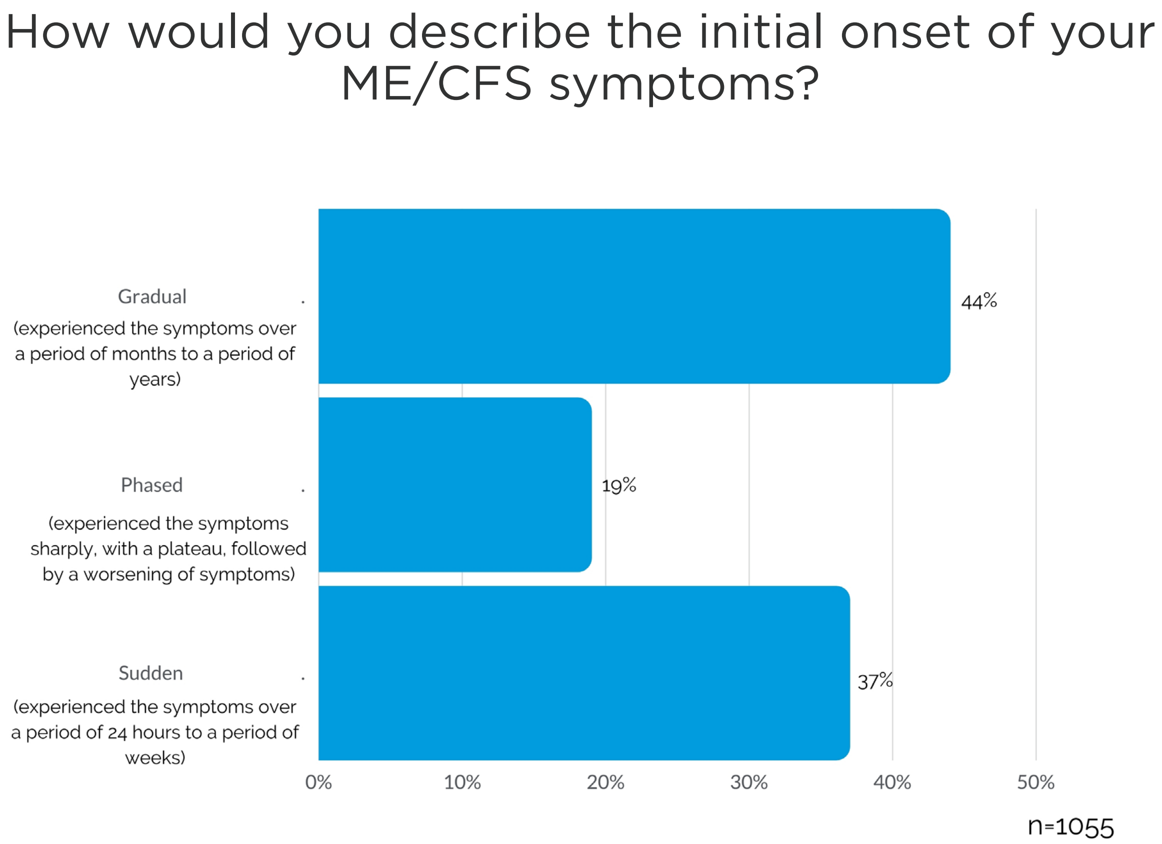


Figure 1.7: How would you describe the initial onset of your ME/CFS symptoms?

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.

> ***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.***

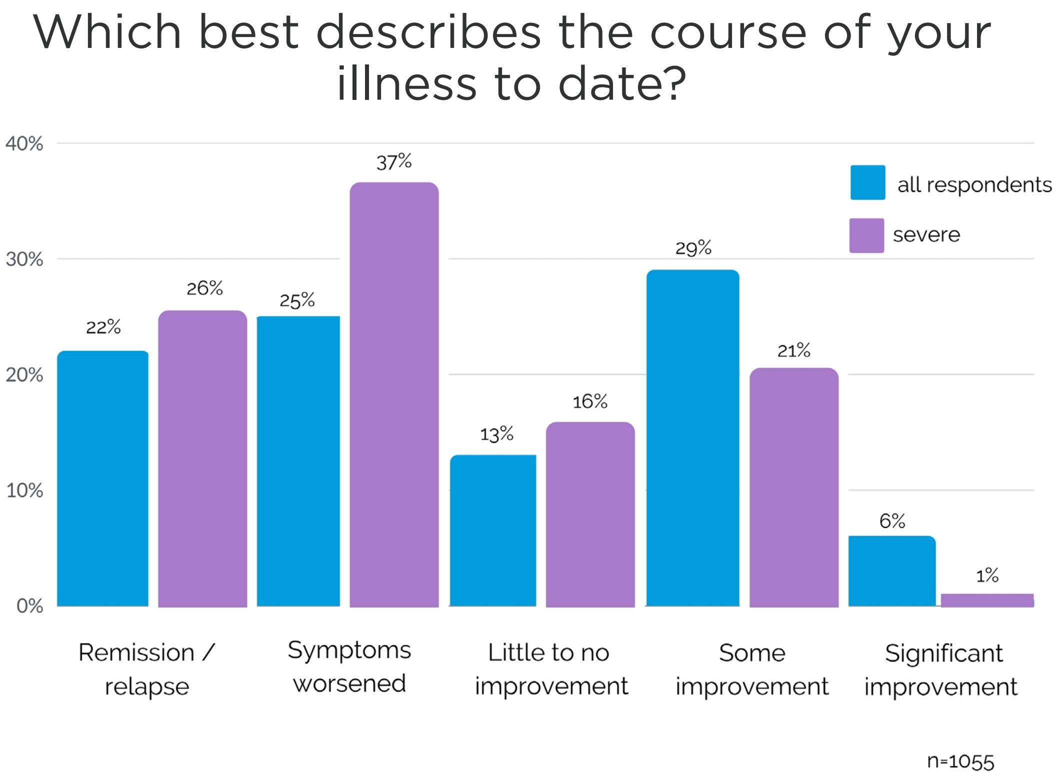


Figure 1.8: Which best describes the course of your illness to date?

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

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 2:

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).

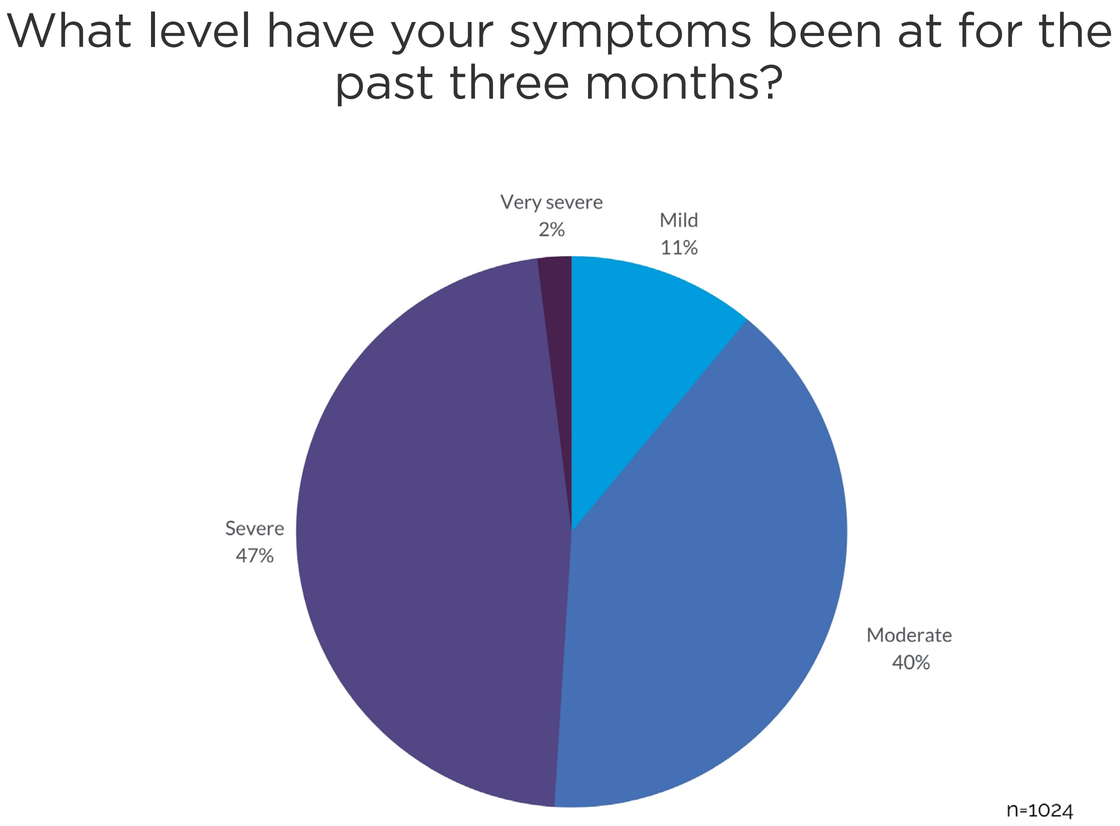


Figure 2.1: What level have your symptoms been at for the past three months?

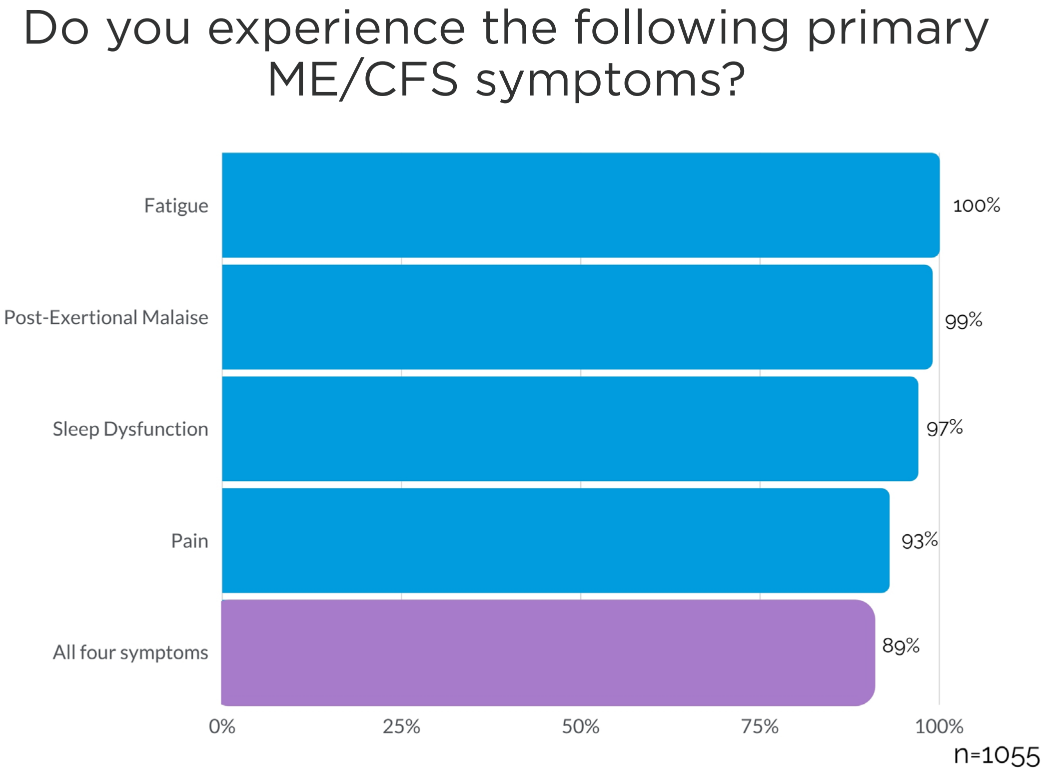
An estimated 25 per cent of people living with ME/CFS are housebound/bedbound (2), indicating that people with severe and very severe ME/CFS are over-represented in this survey at 49 per cent combined.

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 (8), 2011 International Consensus Criteria (9) and 2015 Institute of Medicine criteria (2)) 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 2.2: Do you experience the following primary ME/CFS symptoms?

Institute of Medicine (IOM) criteria (2) 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).

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

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.

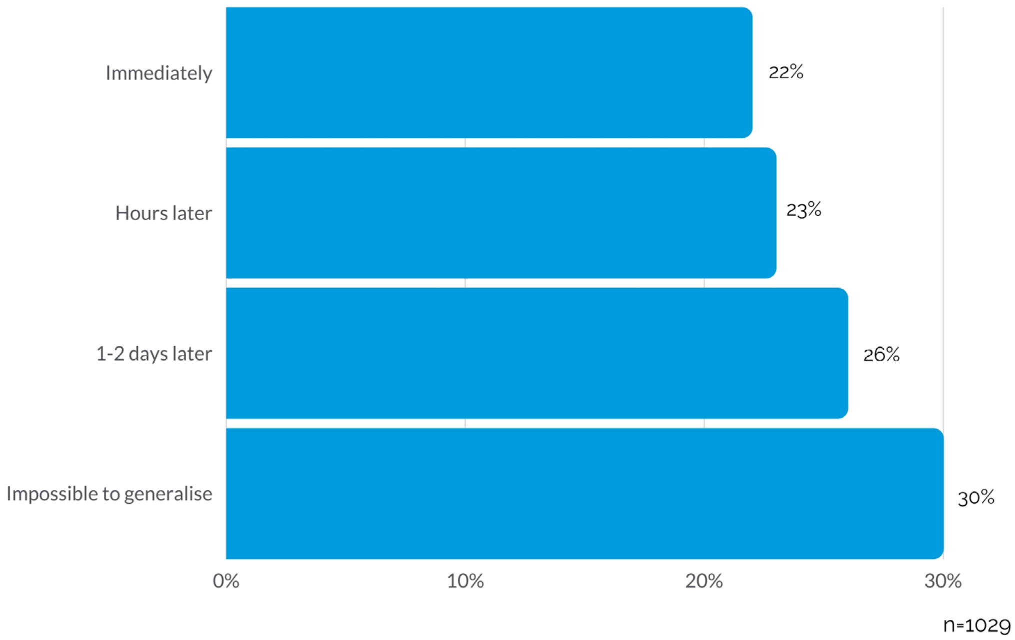

How long after increasing physical activity and/or mental activity do you experience PEM?

Figure 2.3: 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 (10).

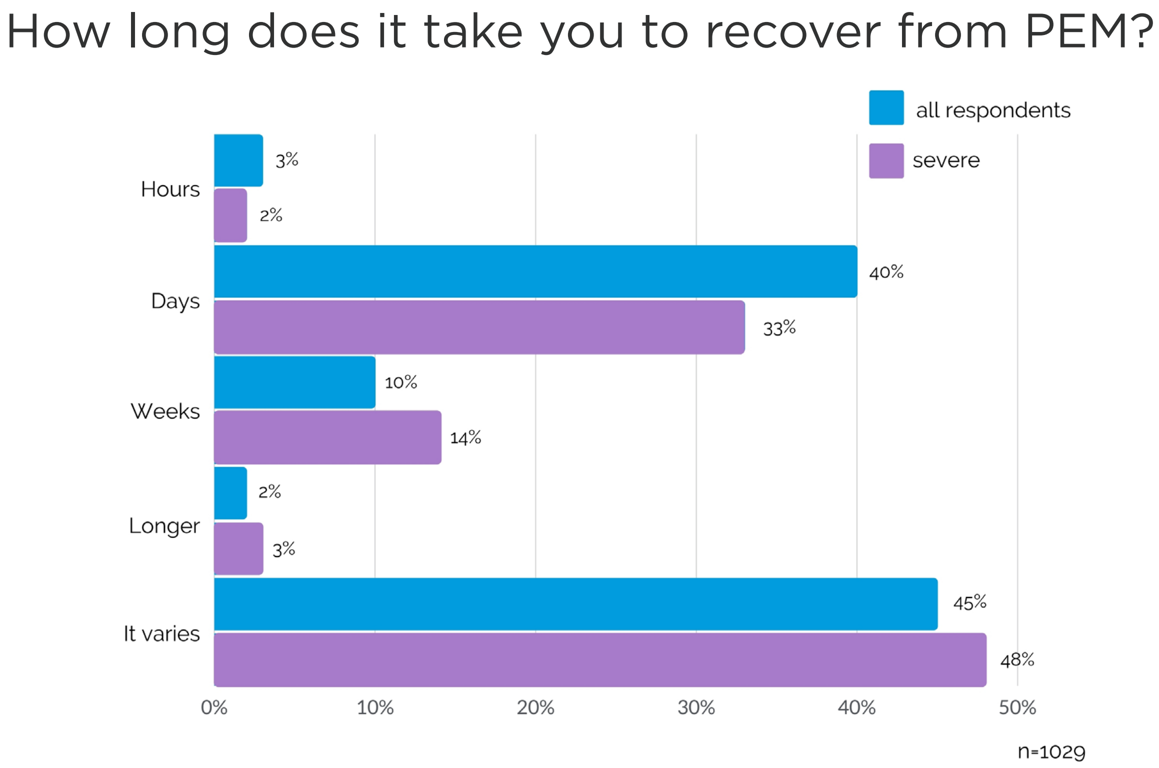


Figure 2.4: How long does it take you to recover from PEM?

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.

OTHER COMMONLY EXPERIENCED SYMPTOMS

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

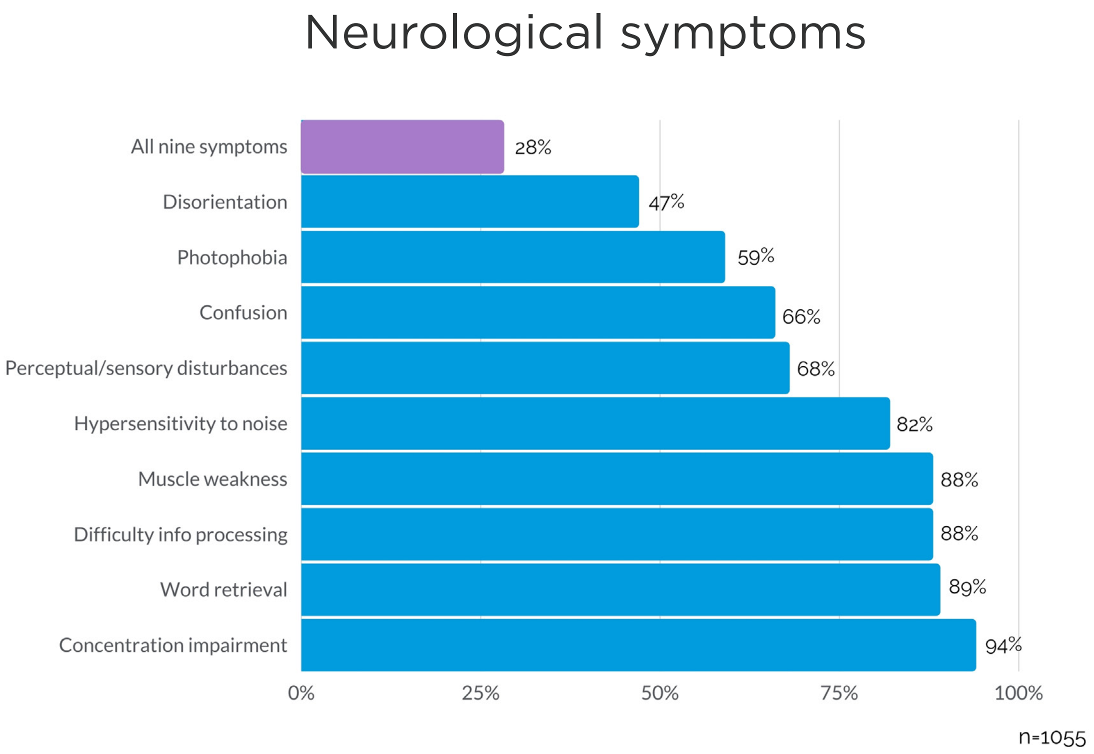


Figure 2.5: Neurological symptoms

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.***

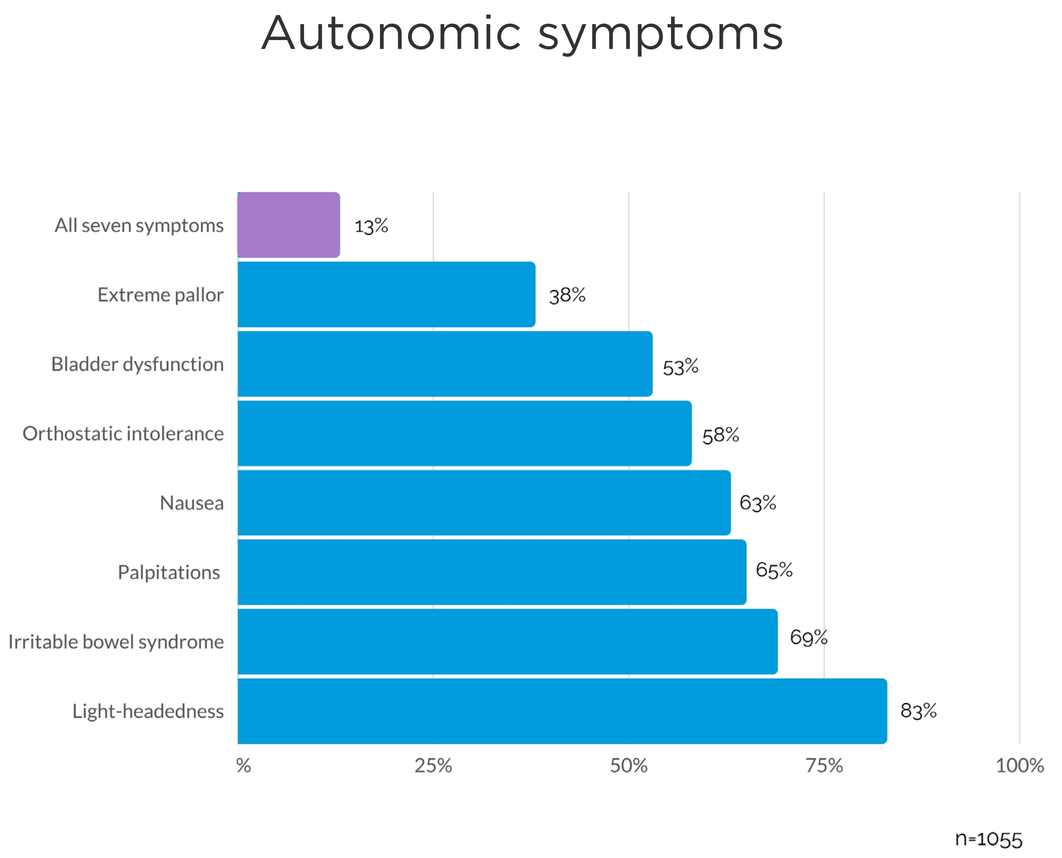


Figure 2.6: Autonomic symptoms

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

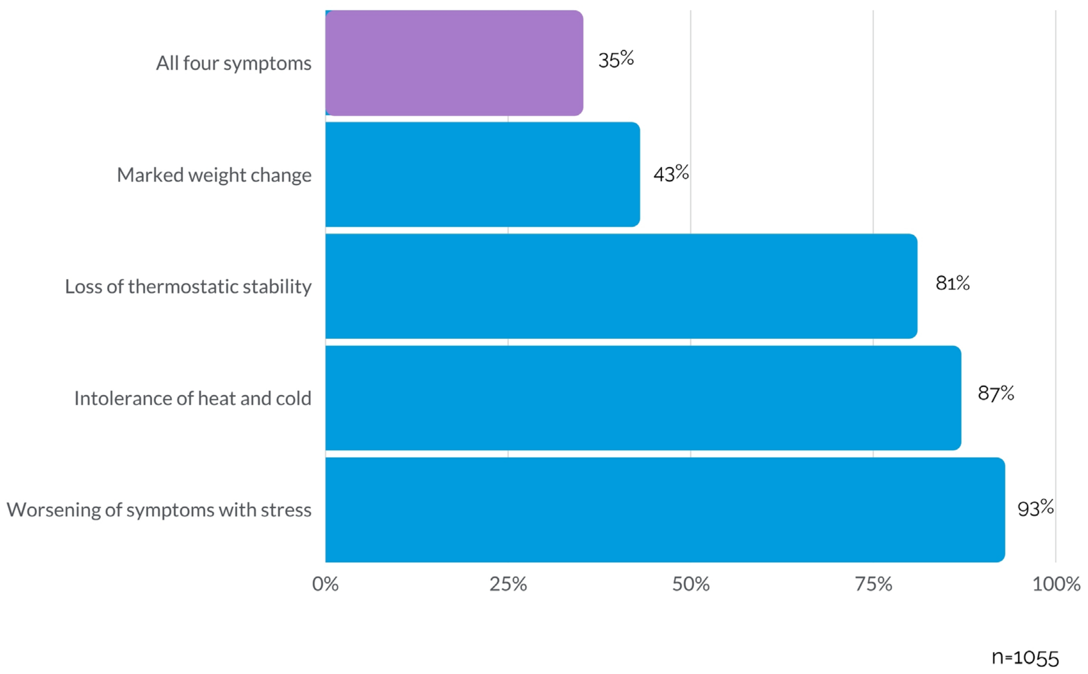


Figure 2.7: Neuroendocrine symptoms

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.

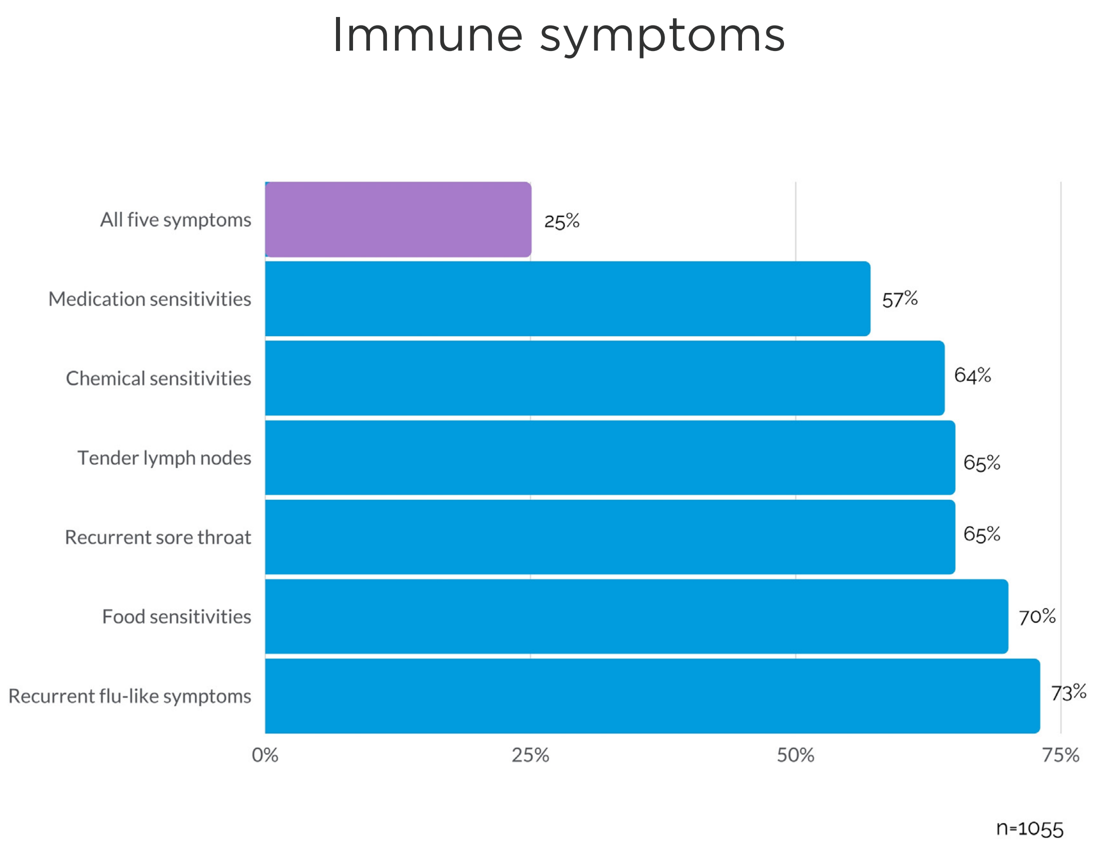


Figure 2.8: Immune symptoms

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 (11).

SECTION 3:

MEDICAL COSTS ASSOCIATED WITH LIVING WITH 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.

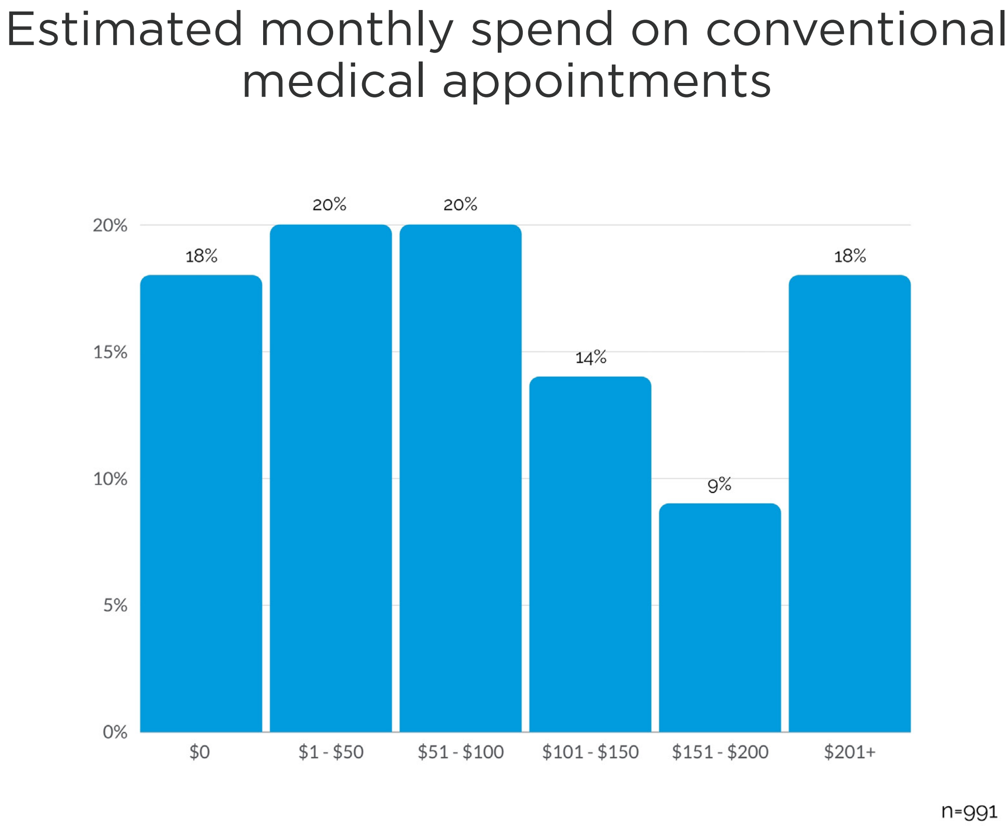


Figure 3.1: Estimated monthly spend on conventionally prescribed medication

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.

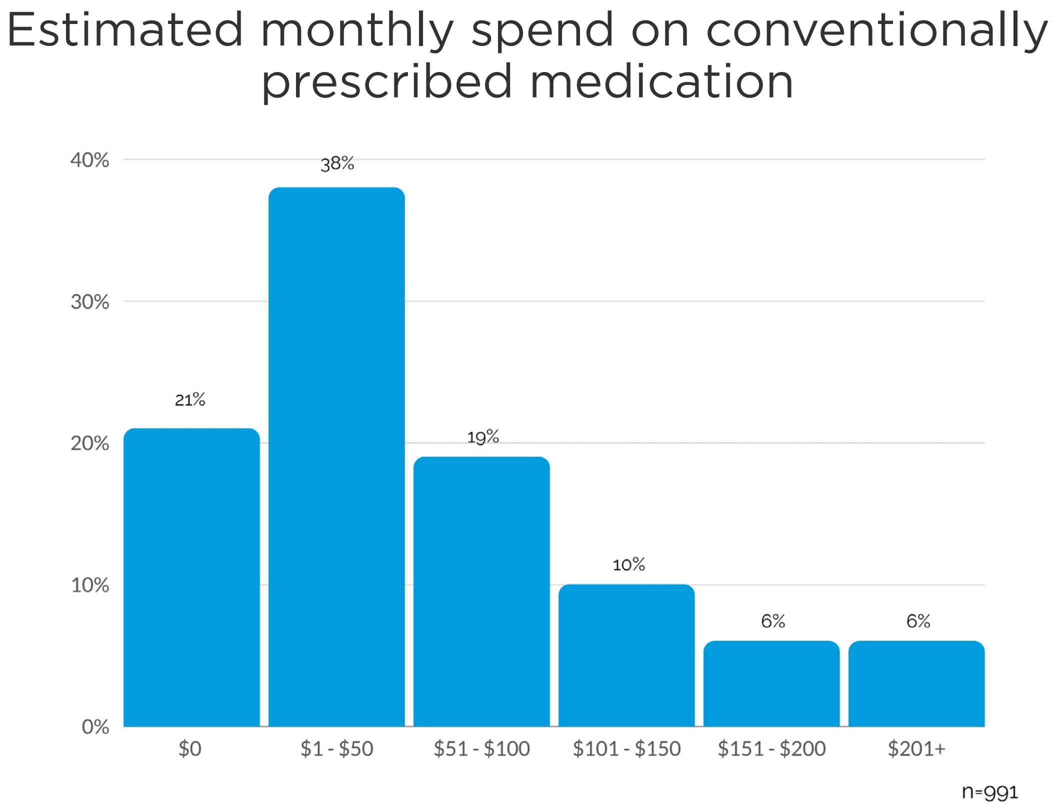


Figure 3.2: Estimated monthly spend on conventionally prescribed medication

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.

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

Estimated monthly spend on alternative therapy and supplements

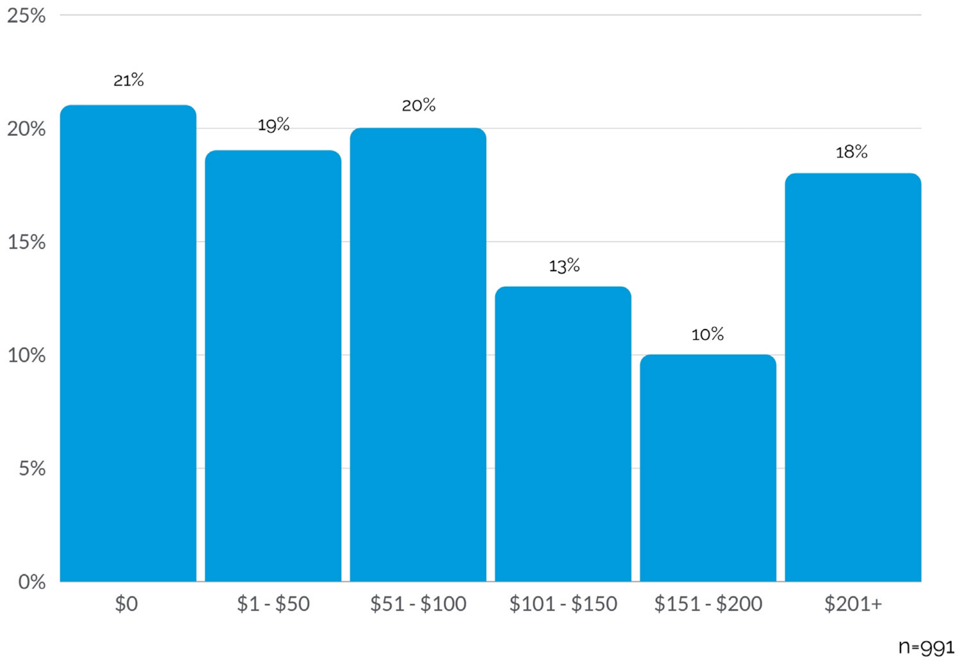


Figure 3.3: Estimated monthly spend on alternative therapy and supplements

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 (12), costs associated with medical appointments, conventional medicines and supplements are likely to be a significant financial burden on people with ME/CFS. Further insight into the impact of ME/CFS onset on income and financial security can be found in our full survey report, Lifelong Lockdown.

SECTION 4:

PRACTITIONER KNOWLEDGE AND PATIENT EXPERIENCE

GENERAL PRACTITIONER KNOWLEDGE

How well-informed do you feel your GP is?

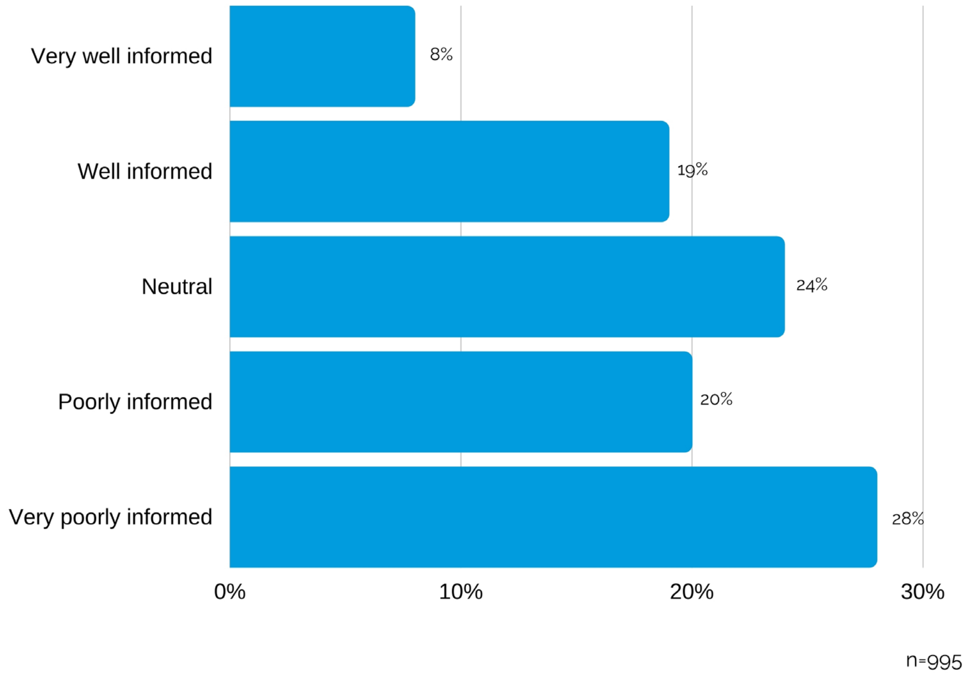


Figure 4.1: How well-informed do you feel your GP is?

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 (13). 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 (14). 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.

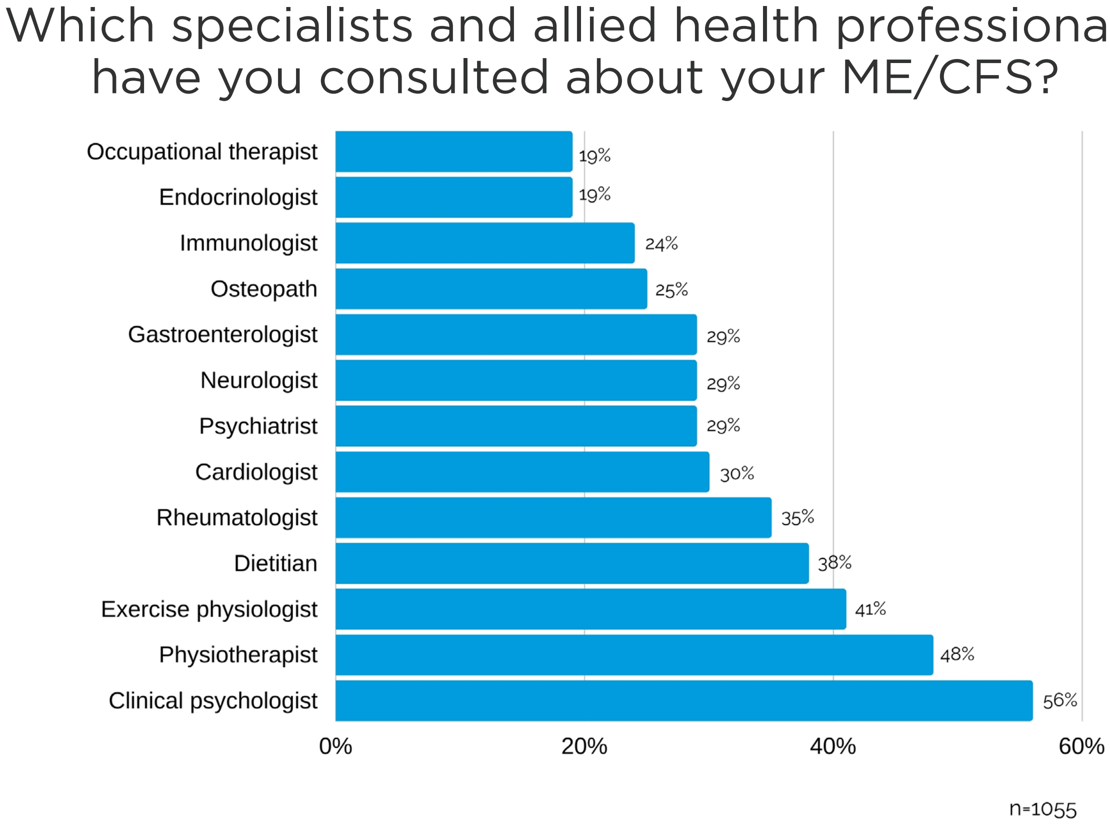

Which specialists and allied health professionals have you consulted about your ME/CFS?

Figure 4.2: 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 (15)), 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 4.3: 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.

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.

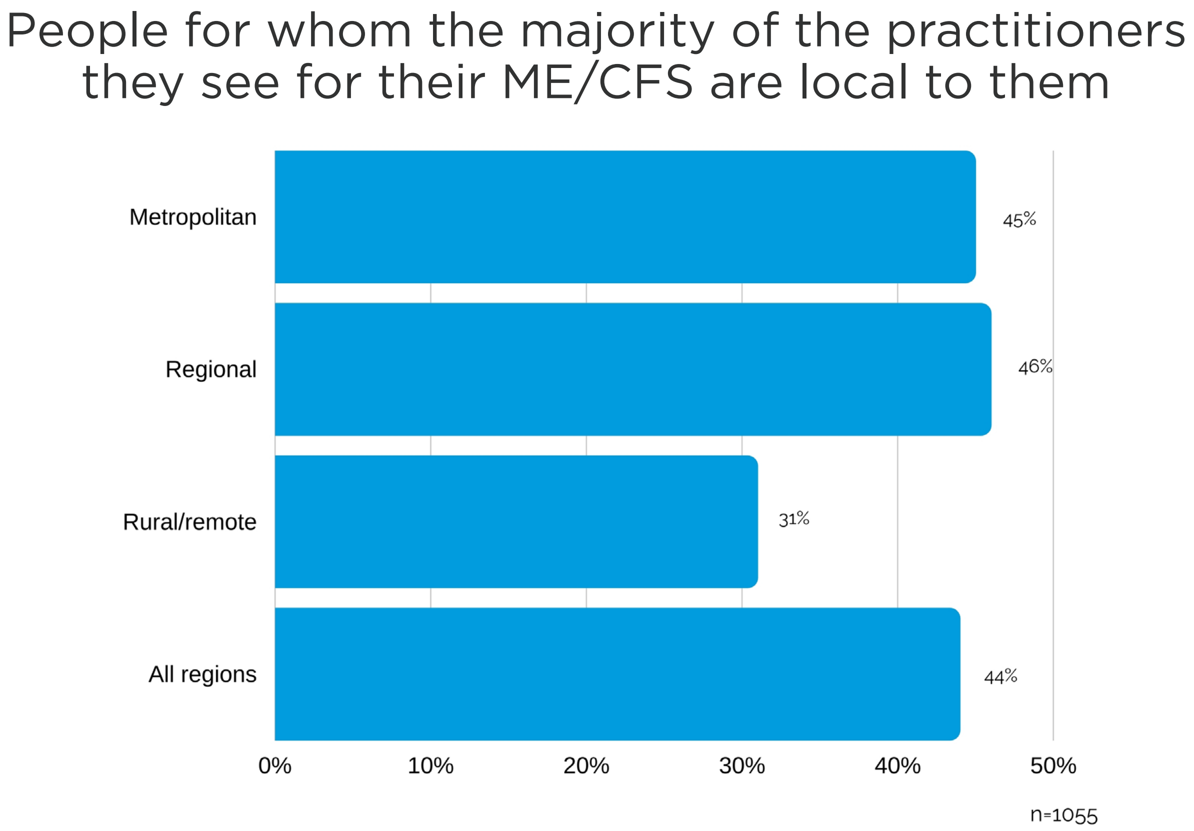


Figure 4.4: People for whom the majority of the practitioners they see for their ME/CFS are local to them

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 5:

OPPORTUNITIES TO IMPROVE THE HEALTHCARE EXPERIENCE

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.

BARRIERS TO ACCESSING SERVICES

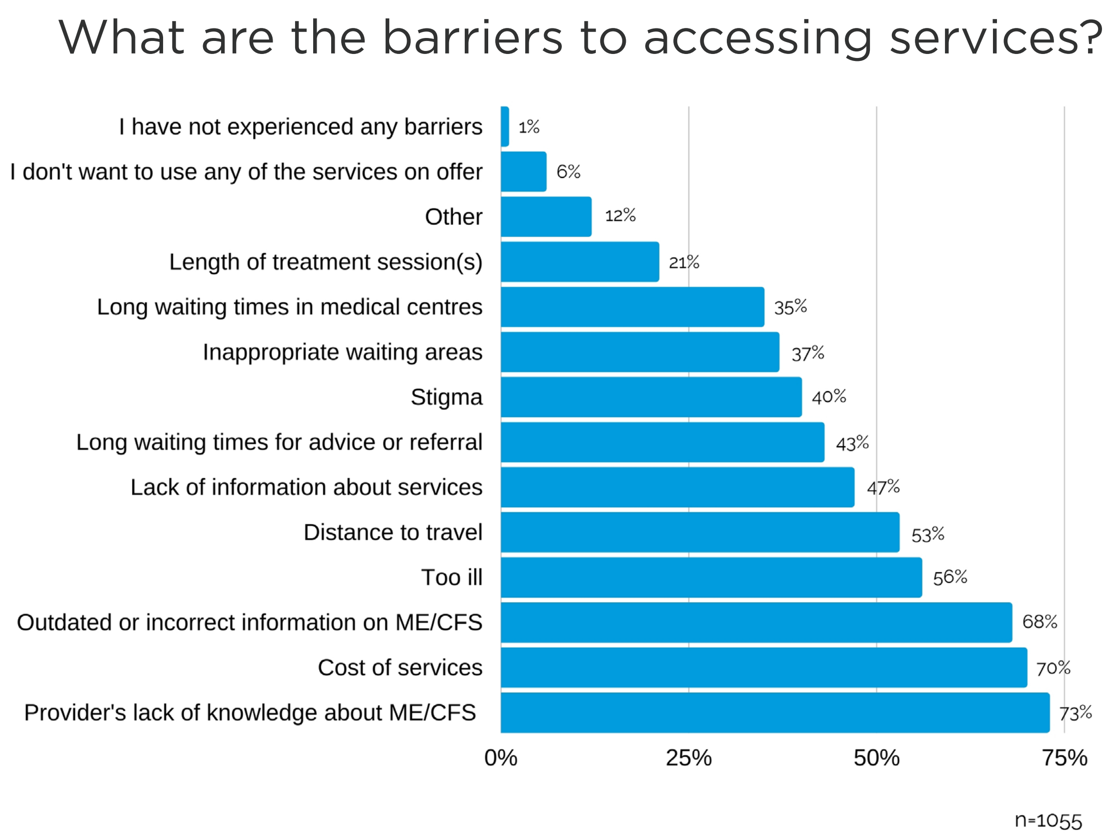


Figure 5.1: What are the barriers to accessing services?

Section Four 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.

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

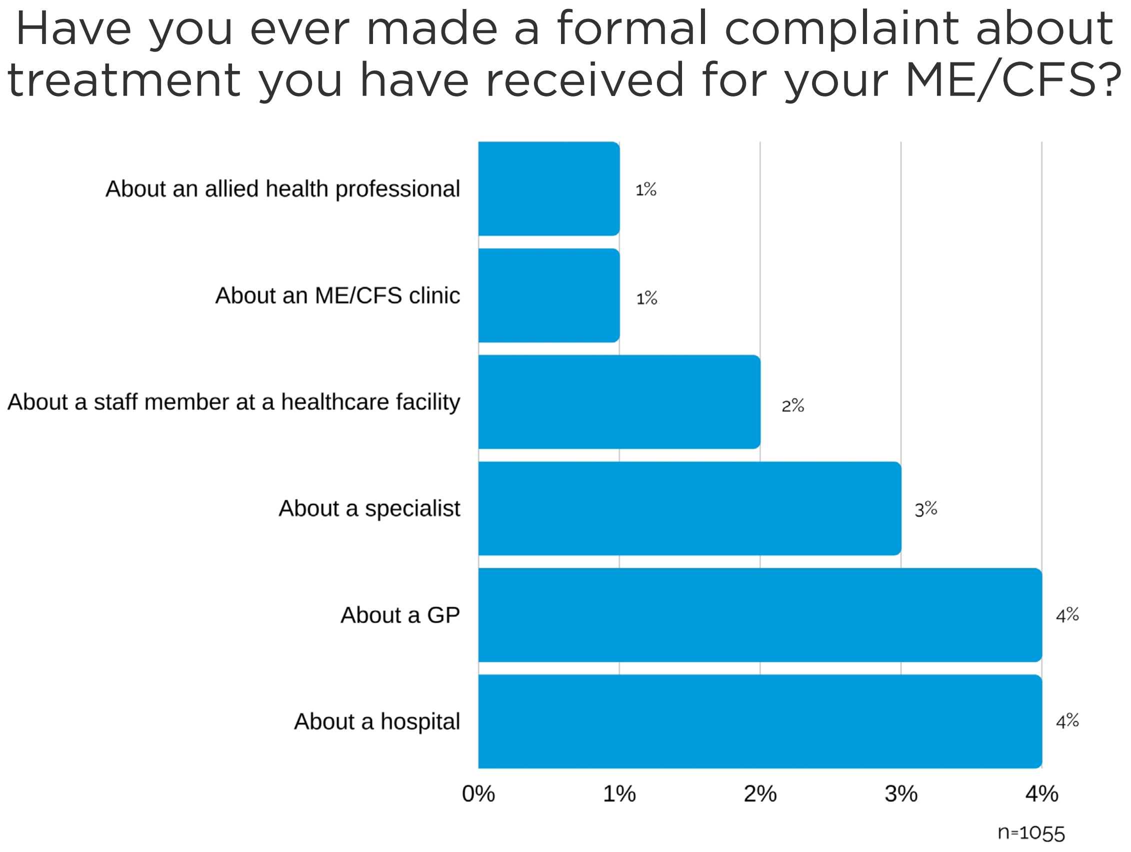


Figure 5.2: Have you ever made a formal complaint about treatment you have received for your ME/CFS?

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.

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.

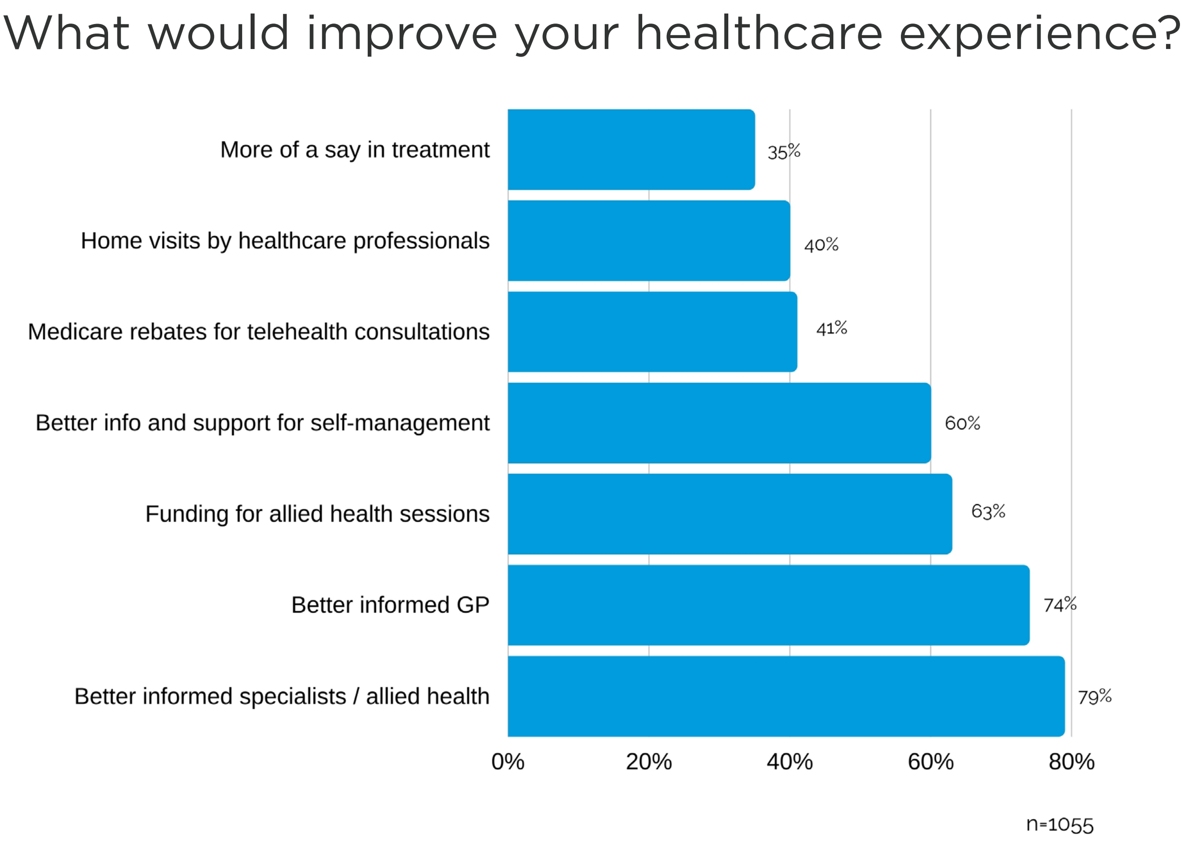
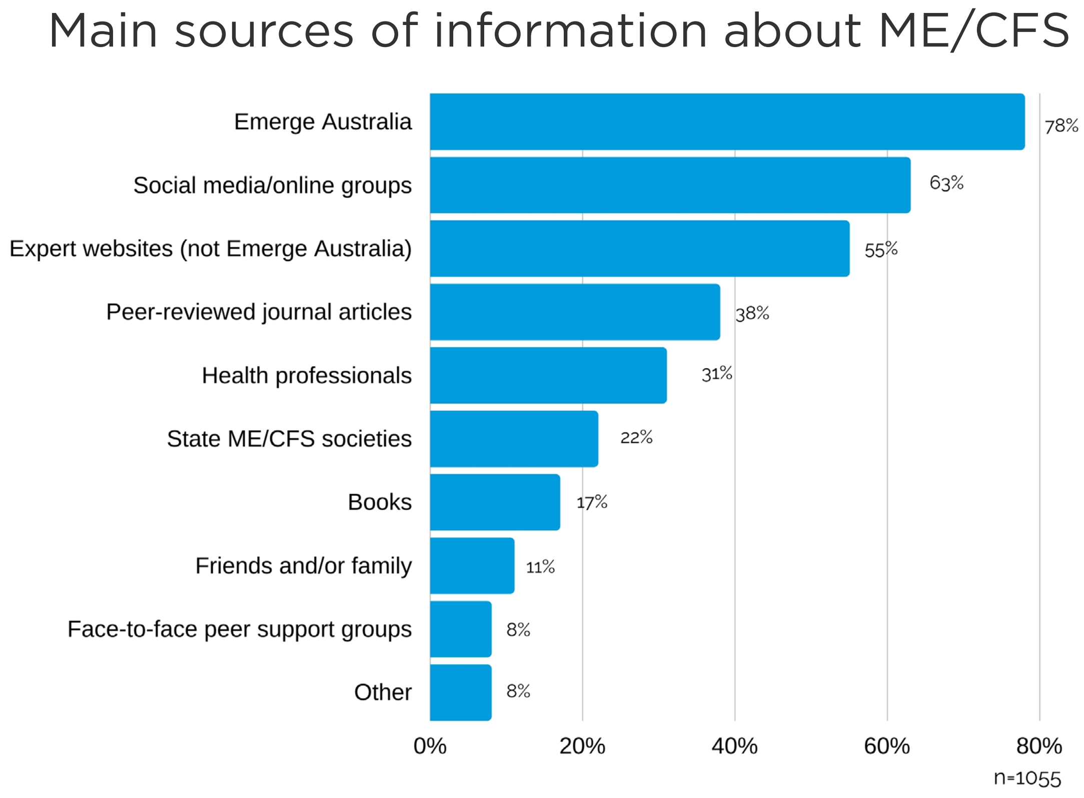


Figure 5.3: What would improve your healthcare experience?

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).

> ***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).***

SEEKING INFORMATION ABOUT ME/CFS



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

Figure 5.4: 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 health and wellbeing outcomes of people living with ME/CFS have been identified, informed by our survey findings.

The following recommendations are focused on improving practitioner knowledge and increasing access to healthcare services. They 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.

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 one: 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 (14). 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 two: 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 three: 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 four: 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 five: 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 six: 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 seven: 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

We hope that *Lessons Learned from the Health and Wellbeing Survey of Australians Living with ME/CFS 2019: A Summary of Findings for Medical Practitioners* has provided insight into the lived experience of people with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and has offered practical recommendations to improve everyday practice and broader health services delivery.

Our findings show that many people living with ME/CFS feel unheard and unsupported by their healthcare providers. When asked to rate a range of practitioners about their knowledge of ME/CFS, on average each practitioner (including GPs, psychologists, neurologists, endocrinologists and cardiologists) scored only 2.0 – 2.9 out of 5.

This perceived poor level of practitioner knowledge about ME/CFS, and a lack of up-to-date information and training about ME/CFS, were reported by survey respondents as their greatest barriers to accessing healthcare (alongside healthcare costs). While this finding is troubling, it also presents an opportunity for patient organisations such as Emerge Australia, people with ME/CFS, medical practitioners and researchers to work together to improve the quality of care available. While there are currently no known treatments for ME/CFS, practitioners with a greater understanding of ME/CFS are better equipped to support patients to develop symptom management strategies and to build trust and understanding.

Affecting 250,000 Australians, ME/CFS is far from a rare condition. It is likely that most, if not all, medical practitioners will be sought out to provide support and advice to a person living with this highly complex, disabling condition during their career. Given this, we believe that medical practitioners have a responsibility to increase their understanding of ME/CFS. With greater understanding, practitioners and medical bodies will not only provide more appropriate one-on-one advice – they will be better placed to advocate for system-wide change on behalf of their patients and to oversee improvements to service delivery models. For example, GPs or hospital administration staff empowered with a full understanding and awareness of ME/CFS may choose to place patients in a quieter waiting room or prioritise their position in a waiting line, thus reducing the extent of PEM experienced when attending an appointment.

As the national patient organisation for ME/CFS in Australia, Emerge Australia is committed to working with medical practitioners and service providers to improve the quality of care available to people living with ME/CFS. We recognise that individual medical practitioners face barriers outside of their control in providing high-quality care. We are therefore eager to work more closely with medical bodies to advocate for structural and policy change to facilitate best practice in support provided to the ME/CFS community.

We will continue to advocate for the RACP 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 – a delivery model which has been embraced during the pandemic – to be made permanently available for people with chronic illnesses as COVID-19 recedes.

We welcome the opportunity to collaborate with practitioners and support service providers seeking out information about ME/CFS. We encourage you to contact us with any questions that may have been prompted by the findings of this report.

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.

REFERENCES

1. Carruthers BM, van de Sande MI. Myalgic Encephalomyelitis Adult & Paediatric: International Consensus Primer for Medical Practitioners. Canada: Carruthers & van de Sande; 2012.

2. Institute of Medicine. Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness. Washington, DC: The National Academies Press (US). 2015. Available from: https://doi.org/10.17226/19012

3. Hvidberg MF, Brinth LS, Olesen AV, Petersen KD, Ehlers L. 2015. The Health-Related Quality of Life for Patients with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS). PLOS ONE. July 2015. 10(7): e0132421.

4. Jason LA, Richman JA, Rademaker AW, Jordan KM, Plioplys AV, Taylor RR, et al. A community-based study of chronic fatigue syndrome. Arch Intern Med. 1999;159(18):2129–37.

5. Jason LA, Porter N, Hunnell J, Rademaker A, Richman JA. CFS prevalence and risk factors over time. J Health Psychol. 2011 Apr 1;16(3):445–56.

6. Reyes M, Nisenbaum R, Hoaglin DC, Unger ER, Emmons C, Randall B, et al. Prevalence and Incidence of Chronic Fatigue Syndrome in Wichita, Kansas. Arch Intern Med. 2003 Jul 14;163(13):1530–6.

7. Cairns R, Hotopf M. A systematic review describing the prognosis of chronic fatigue syndrome. Occup Med. 2005 Jan;55(1):20–31.

8. Carruthers BM, Jain AK, De Meirleir KL, Peterson DL, Klimas NG, Lerner AM, et al. Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols. J Chronic Fatigue Syndr. 2003 Jan;11(1):7–115.

9. Carruthers BM, Sande MI van de, Meirleir KLD, Klimas NG, Broderick G, Mitchell T, et al. Myalgic encephalomyelitis: International Consensus Criteria. J Intern Med. 2011;270(4):327–38.

10. Holtzman CS, Bhatia S, Cotler J, Jason LA. Assessment of Post-Exertional Malaise (PEM) in Patients with Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS): A Patient-Driven Survey. Diagnostics. 2019 Mar;9(1):26.

11. Komaroff AL. Advances in Understanding the Pathophysiology of Chronic Fatigue Syndrome. JAMA. 2019 Aug 13;322(6):499.

12. Australian Council of Social Services, UNSW. Poverty in Australia 2020: Part 1 Overview. Sydney: ACOSS; 2020.

13. Medical Board of Australia Registrant Data, Reporting period 01 January – 31 March 2020.

14. ME/CFS Advisory Committee. ME/CFS Advisory Committee Report to NHMRC Chief Executive Officer. Canberra: National Health and Medical Research Council (NHMRC); 2019 Apr.

15. Centers for Disease Control and Prevention. Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Treatment of ME/CFS (Nov 19, 2019). https://www.cdc.gov/me-cfs/treatment/index.html

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