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Emerge Australia
Health and Wellbeing Survey
of Australians with ME/CFS

Report of key findings

September 2018

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KEY FINDINGS

In 2015, 610 Australian residents who identify as having ME/CFS (Myalgic Encephalomyelitis / Chronic Fatigue Syndrome) completed a comprehensive survey to help provide a greater understanding of their lived experiences with the condition. In terms of demographic composition, there was a fairly even distribution across the age ranges, and the sample reflects known patient characteristics in terms of gender, with a high representation of females responding to the questionnaire (80% sample; 79% in other studies[1]). A large percentage of the sample (62%) indicated that they were long-term sufferers of the condition (more than 10 years).

Whilst there are no notable variations by demographics when considering the severity of symptoms, there are some groups who encounter unique challenges as a result of living with the condition, specifically:

- Those who live regionally who face challenges accessing services due to a lack of local availability; and
- Those with severe symptoms who face significant constraints in terms of the activities in which they can participate.

The following section summarises the key findings from this comprehensive piece of research, including observations specific to those in regional areas and those with severe/very severe symptoms.

Diagnosis

There is an even split in the source of diagnosis between GPs (40%) and ME/CFS specialists or clinics (41%). GPs are critical for early diagnosis, being responsible for 53% of diagnoses which occurred within the first year of symptom onset. Most of those who were diagnosed by an ME/CFS specialist didn't receive their diagnosis until more than a year after the onset of symptoms (87%). Findings show that it is relatively common for people to encounter GPs who are poorly informed on the topic (35%); and those who rate their GP as poorly informed more often receive a diagnosis from a specialist (45%) than a GP (33%).

The majority of respondents were diagnosed with 'CFS' (49%), while 36% were diagnosed using the combined 'ME/CFS' terminology. The diagnosis of 'ME' is more common when the diagnosis is received from an ME/CFS specialist (46%, compared to 39% GPs) and was more commonly used amongst those with severe/very severe symptoms (50%, compared to 37% of those with mild/moderate symptoms).

Symptoms

Over half (56%) of all respondents specified a fatigue-related symptom to have the greatest impact on their life. The second most commonly cited symptom was brain fog (13%), which was particularly prominent amongst males (19%).

There was a relatively even split in the sample amongst those reporting their symptoms as severe/very severe (46%) and mild/moderate (54%). These symptom levels are often fairly consistent over time, with 63% reporting they had been at the specified level for more than a year.

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[1] Jason, L. A., Porter, N., Hunnell, J., Rademaker, A., & Richman, J. A. (2011). CFS prevalence and risk factors over time. *Journal of health psychology*, *16*(3), 445-456.

Healthcare professionals

Findings suggest that there is a need for further education of GPs on the topic of ME/CFS. A quarter (24%) of those who answered the rating questions regarding GPs rated them poorly across all three measures: being informed, being sympathetic and service provided. Specifically, **44% rated their GP's level of being informed as poor/very poor**, 29% rated their GP as unsympathetic/very unsympathetic, and 42% rated the service provided by their GP as poor/very poor.

Those who received a diagnosis through their GP were more often happy with their service, although around a third still rated them poorly across one or more measures. Those who ended up being diagnosed through an ME/CFS specialist, or had another method of diagnosis were particularly cynical about the performance of their GP (presumably because the GP was unable to diagnose, resulting in needing to consult with an alternative health professional for diagnosis).

Other than a GP, the most common health professionals people go to for their ME/CFS are clinical psychologists (24%) and physiotherapists (17%). The service providers which received the highest ratings for being well informed about the condition were osteopaths (49%), clinical psychologists (47%) and physiotherapists (44%); these three were also the most commonly rated as providing good service (69%, 59% and 62% respectively). The service providers with the highest incidences of being rated as poorly informed and/or providing poor service were neurologists (65% poorly informed, 59% poor service), gastroenterologists (61% poorly informed, 51% poor service) and cardiologists (59% poorly informed, 46% poor service). There is a clear correlation between the level of being informed and service rating (more informed = better service rating), with the exception of immunologists who were rated by 43% of users as well informed but with only 27% rated as providing a good service.

Findings show that there are clear areas of focus which would make a real difference to healthcare experiences for people with ME/CFS. These are access to better informed GPs (73%) and access to more effective medication (64%). For those in regional areas and those with severe/very severe symptoms, tele/e-consults (with Medicare rebates) and home visits would also be of particular help.

The primary barriers to accessing ME/CFS health services are lack of specialists close to home (63%, and particularly for those in regional areas at 83%), and subsequently distance/travel time (61%). Other key barriers were: cost of services (58%), lack of knowledge by service provider (56%) and/or too ill (54%).

Impact on life

Three quarters of those who completed the survey indicated that their ME/CFS has had a strong impact on, or stopped their participation in paid work (74%). There was a notably high proportion of people who were working prior to onset of symptoms who indicated that they were no longer in paid employment at the time of interview: 60% of those who worked part time prior to onset and 57% of those who worked full time prior to onset indicated that they were unemployed at the time of interview. When people have to cease working this usually occurs around a year after the onset of symptoms. This shift away from working (or a reduction in work) has a significant impact on income. At the time of survey, 34% of respondents indicated that they had no income, which is significantly higher than the average for the Australian adult population (9%). The mean income dropped from $41,448 prior to onset of symptoms to $17,572 at the time of survey. Males were particularly impacted by this shift in employment, going from 71% in full-time employment prior to onset and a mean income of $54,698, to just 9% in full time employment and a mean income of $20,974 at the time of the survey. Some (39%) indicated they were receiving government assistance (mostly the Disability Support Pension, 20%), however, only 45% of those with no income and 37% of those earning $1-$10,399 per annum indicated that they were on government support.

Other activities which were strongly impacted or stopped completely due to ME/CFS were:

- Participation in sports and hobbies (74%);
- Career choices / development (66%); and
- Participation in voluntary roles (56%).

Treatment

The findings clearly show that increased activity/exercise makes most people feel worse. A total of 89% reported feeling worse after increasing their level of exercise/activity, comprised of 54% reporting they feel worse straight away and 35% reporting that they initially feel better, but then feel worse later. Only 5% report that exercise/activity makes them feel better. For those with severe symptoms, the incidence of gaining any benefit from increased activity/exercise is much lower (26% better at first then worse, 3% better), the majority just feel worse (68%).

Of those who said they feel worse after increased activity/exercise, for a quarter of people it is immediate (28%), with around a third (37%) saying it takes a few days. Recovery from feeling worse after increased activity/exercise mostly takes some time, with 69% reporting the recovery period as days, and 27% saying it can take weeks.

Most had tried a range of treatments, primarily revolving around rest, supplements, diet and pain medication. There are varying levels of success with tried treatments; the most commonly reported as very helpful are:

- Rest, including bed rest (60%);
- Pacing (58%); and
- Medication to aid sleep (40%).

Four of the top seven most helpful treatments were primarily self-prescribed. Only 17% of ME/CFS specialists had prescribed rest (56% self-prescribed) and 27% had prescribed pacing (28% self-prescribed). Medication to aid sleep was most commonly prescribed by GPs (46%, 36% specialists).

The treatments most often reported as making people feel worse were:

- Graded exercise therapy (47%);
- Graded activity therapy (38%); and
- Hydrotherapy (28%).

Specialists were the most common referrer for all three of these treatments.

There is some variation in the type of treatment suggested by different practitioners:

- GPs – common treatments are medication (to ease pain, aid sleep, and help mood), antibiotics and vitamin/mineral supplements. Antibiotics are far more often prescribed by GPs than any other service provider.
- Specialists – common treatments are medication (to aid sleep and ease pain), dietary changes, vitamin/mineral supplements and pacing. Specialists more often prescribe oxygen therapy, graded exercise therapy and graded activity therapy than other providers.
- Self – people are commonly self-prescribing rest, meditation, massage, pacing and dietary changes. It is more common for people to self-prescribe aromatherapy, rest, and massage than for these to be suggested by health providers.
- Alternative therapists – common treatments include herbal medicine, vitamin/mineral supplements, naturopathy, dietary changes and acupuncture. Alternative therapists are the main source for people being prescribed herbal medicine, homeopathy, naturopathy, kinesiology and The Perrin Technique.

Support

The most common areas where ME/CFS sufferers need support are with domestic and household tasks (cleaning, shopping, meal preparation). This need for assistance often arises around a year after the onset of symptoms, and is understandably more common amongst those with more severe symptoms.

Two thirds (68%) of respondents indicated that they had received care at some time for their ME/CFS. Carers are most commonly family members, specifically partners. Only 13% receive a carer's allowance.

Just over one in ten (13%) indicated that they have accessed the Disability Support Pension, however almost half had applied at some time (49%, increasing to 63% of those with severe/very severe symptoms).

Of those who had applied for government disability support, almost half (46%) said that **they didn't seek out any support or advice to a**ssist them with their application. The most common sources for those who did seek advice were health care practitioners and GPs. Emerge Australia provided support to just over one in ten (13%) through fact sheets, the info-line and/or other general support. Those who sought assistance from their GP mostly found their GP to be helpful (84%).

When seeking out general information and support relating to ME/CFS, the most common sources are online groups (35%), Emerge Australia (27%) and health professionals (23%).

Regional areas

The findings suggest that those living in regional areas of Australia face unique challenges with regards to diagnosis and treatment and have varying levels of support:

- It can take longer to be diagnosed (9% said it took 6-9 years to be diagnosed, compared to 5% in major cities).
- Higher instance of receiving government support (45%, compared to 36% of those living in major cities).
- Higher instances of wanting telephone/online health services (49%, compared to 36% of major city residents) and/or Medicare rebates for these phone/online consults (48%, compared to 38% of major city residents).
- More likely to experience barriers to accessing services, particularly finding specialists in their area (83% cited this as a barrier, compared to 51% of those who live in metropolitan areas) and distance/travel time (77% cited this as a barrier, compared to 50% of those who live in metropolitan areas).

Severe/very severe symptoms

Those with severe/very severe symptoms more commonly have a need for support services.

- A higher proportion report that they are receiving the Disability Support Pension (31%, compared to 11% of those with moderate/mild symptoms).
- Higher instances of the condition impacting on activities, with almost all saying it has had a strong impact or stopped them from participating in paid work, career development, participation in sports and hobbies and/or participation in voluntary roles.
- Higher instances of wanting home visits by healthcare professionals (53%, compared to 27% of those with moderate/mild symptoms), telephone/internet health services (51%, compared to 33% of those with moderate/mild symptoms), and Medicare rebate for phone/net health consults (51%, compared to 35% of those with moderate/mild symptoms).
- Being too ill is much more commonly cited as a barrier to accessing services (72%, compared to 38% of those with moderate/mild symptoms).
- High proportions need assistance with domestic cleaning (66%), shopping (62%), transport outside the home (58%) and meal preparation (56%).
- Higher instance of receiving care from a home and community carer (16%, compared to 5% of those with moderate/mild symptoms).
- 31% of those with severe/very severe symptoms said they are receiving some kind of government funded disability support (compared to 20% of those with moderate/mild symptoms).

INTRODUCTION

Research Purpose

The Emerge Australia Health and Wellbeing Survey aims to develop an understanding of the health and welfare of people affected by Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) in Australia. This research seeks to investigate the impact of ME/CFS on the education, employment and interpersonal interactions of people with the condition. The project also explores how people access healthcare and support services, and what helps, or gets in the way of, accessing those services.

The results from this project will be **used to guide Emerge Australia's advocacy for the** needs of people with ME/CFS, and for the development of educational programs and resources for people who care for, and work with, people who are living with the illness.

Background

The survey was conducted in 2015 as a joint project between Emerge Australia and Federation University School of Health Sciences and Psychology. Due to staff changes within the Federation University School of Health Sciences and Psychology, the opportunity for the University to conduct an analysis of the data did not eventuate. In 2018 Emerge Australia received permission to use the data to produce an analysis report so that the findings can be used to inform planning, education and communications.

Emerge Australia educates about and provides information on Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS). The organisation provides information about ways that people with the condition can access various social and financial supports as well as advocating for improved recognition, more effective treatments, and research into the biological causes of the illness. Emerge Australia has been working with people affected by ME/CFS since it was established in 1980.

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

- 25% of patients are classed as severe and are housebound or bedbound[2].
- Up to 70% of patients are too ill to work[2]
- Patients with ME score more poorly on quality-of-life surveys than patients with multiple sclerosis, stroke, diabetes, renal failure, lung disease and various cancers[3].
- ME/CFS affects between 0.4 and 1% of the population[4] and it is therefore estimated that up to 240,000 Australians have the condition.
- The condition affects people of all ages, nationalities and socio-economic backgrounds[2].

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[2] National Academy of Medicine. (2015). Beyond myalgic encephalomyelitis/chronic fatigue syndrome: Redefining an illness, from http://www.nationalacademies.org/hmd/Reports/2015/ME-CFS.aspx (accessed July 2018)
[3] Hvidberg, M. F et al. (2015). The health-related quality of life for patients with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). PloS one, 10(7), e0132421.
[4] Carruthers, B. M. et al. (2012). *Myalgic Encephalomyelitis – Adult & Paediatric: International Consensus Primer for Medical Practitioners.*

- Up to 4x more women than men are affected[5].

Methodology

The survey was conducted from February to May 2015 using a combination of online survey (through SurveyMonkey) and paper completion forms (which were later entered into the SurveyMonkey online system). The majority of surveys were completed online but it is not known whether any data quality processes were employed for the data entry of paper forms. Participants were invited to complete the survey over several sittings if they wished, and no questions were compulsory.

The survey was advertised to members, and the broader community, through the Emerge Australia quarterly journal, the Emerge Australia Facebook page, the Emerge Australia e-newsletter, as well as other social media groups for people with ME/CFS. Other ME/CFS groups around Australia were encouraged to help with distribution. Paper copies were sent to people with limited access to the internet or with issues with reading electronic media.

A total of 774 responses were recorded. This data file was then cleaned using the parameters outlined in Appendix 1, resulting in a total sample of 610 for analysis.

[5] Jason, L. A. et al. (1999). A community-based study of chronic fatigue syndrome. Archives of internal medicine, 159(18), 2129-2137. *and* Reyes, M. et al. (2003). Prevalence and incidence of chronic fatigue syndrome in Wichita, Kansas. Archives of internal medicine, 163(13), 1530-1536 *and* Jason, L. A., et al (2011). CFS prevalence and risk factors over time. Journal of health psychology, 16(3), 445-456

Sample size: n=610

Location

The sample is heavily skewed towards residents of Victoria, with more than half (55%) from this state. This **perhaps reflects Emerge Australia's origins as a** Victorian based organisation.

Figure 1 - State

State

State	%
Victoria	55%
New South Wales	16%
Queensland	13%
South Australia	5%
Tasmania	5%
Western Australia	3%
Australian Capital Territory	2%
Northern Territory	1%

The sample is also heavily metropolitan, with 60% indicating they are from a major city (inner or outer). It should be noted that the locality definition was self-assigned by the respondent and therefore is open to subjective, individual interpretation.

Figure 2 – Locality

Locality

Locality	%
Major city (outer)	36%
Regional area	27%
Major city (inner)	24%
Rural area	11%
Remote area	1%

Geographic distribution should not be considered indicative of the distribution of sufferers of CFS, but rather of the reach of the distribution methods used to disseminate the survey.

Demographics

Of those who provided adequate information to calculate their age (n=587), the mean age was 46, with ages ranging from 15 through to 87. Ages have been split into relatively even groupings by decade for ease of analysis.

Age Category
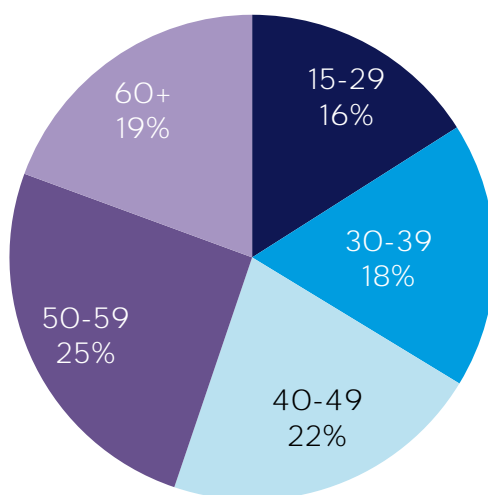
Research conducted in Norway showed age peaks amongst those aged 10-19 years and 30-39 years; this is not reflected in the data for this survey[6].

Whilst the online survey form appears to have an 'other' option for gender, no entries appeared in the data file for 'other'; although there were 4 blank entries for this variable which may represent those who chose 'other', or they may represent those who didn't complete the question.

Of those who selected either 'male' or 'female' for the gender question (n=606), 80% selected female. This finding aligns with the commonly recognised global distribution for the condition, where it is expected that females represent 75-85% of overall ME/CFS sufferers[7].

Gender

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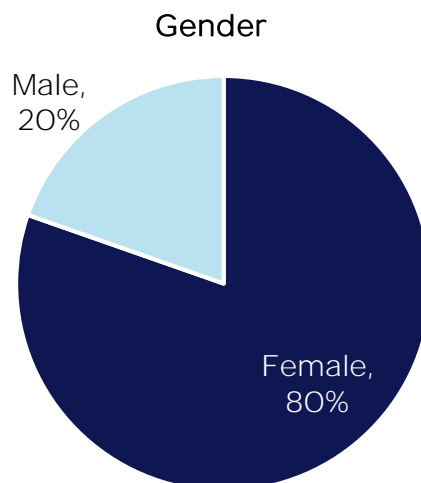
[6] Bakken IJ et al (2014) Two age peaks in the incidence of chronic fatigue syndrome/myalgic encephalomyelitis: a population-based registry study from Norway 2008-2012, *BMC Medicine*, Oct1;12:167

[7] Jason, LA; Richman, JA; Rademaker, AW; Jordan, KM; Plioplys, AV; Taylor, RR; McCready, W; Huang, C; Plioplys, S (1999), "A Community-Based Study of Chronic Fatigue Syndrome", Arch Intern Med, 159 (18): 2129-2137, doi:10.1001/archinte.159.18.2129 *and* Jason, L. A., et al (2011). CFS prevalence and risk factors over time. Journal of health psychology, 16(3), 445-456

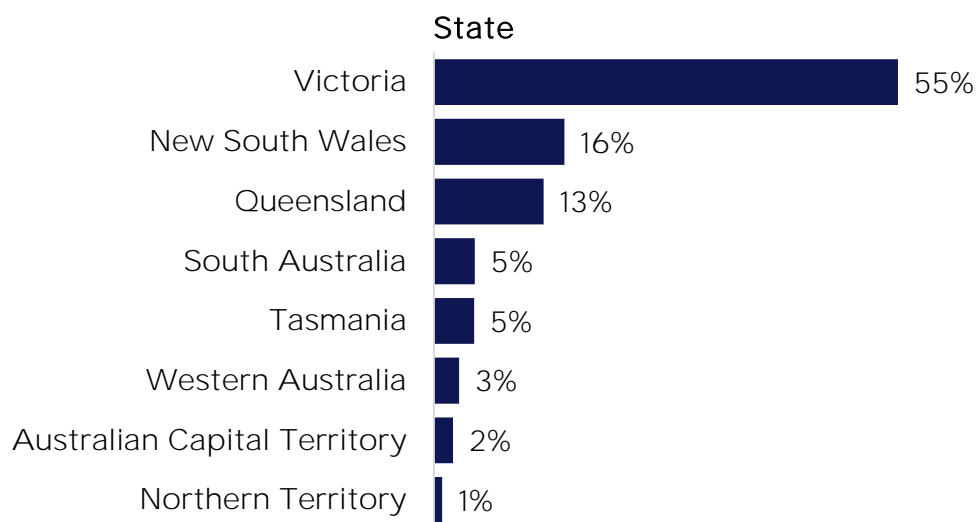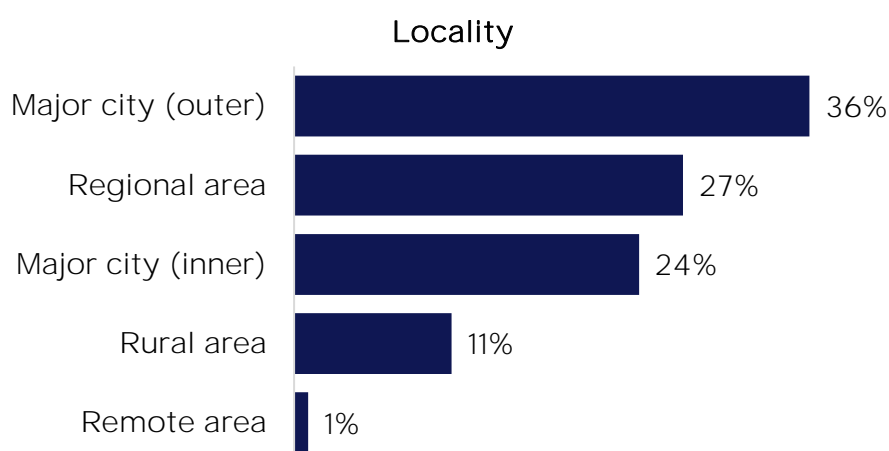Age distribution was relatively similar across both males and females.

Four in ten (43.5%) of the sample indicated that they have children in their household.

Cultural background

The clear majority of the sample were born in Australia (85%).

Figure 5 – Country of birth

Born in Australia

No, 15%

Yes, 85%
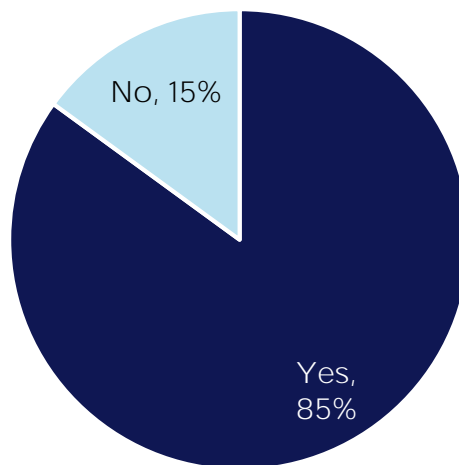
The most common countries of birth outside of Australia were the United Kingdom (6%), New Zealand (5%) and Non-English speaking European countries (2%).

Consistent with most being born in Australia or from English speaking countries, 99.3% indicated that English was the primary language spoken in their household.

One percent of the sample indicated that they identify as Aboriginal or Torres Strait Islander. Due to the small sample size, to protect anonymity no analysis has been conducted by this variable.

Health insurance

Six in ten (59%) of the sample indicated that they have private health insurance. A significantly higher incidence of residents in major cities (63%) have private health insurance (compared to 53% of those from rural, regional, and remote areas).

Notes on analysis

At the start of each section the report lists the question number and text, followed by the number of people who answered each question in brackets (n=). In some cases this is followed by an analysis note that provides important information for consideration when interpreting the findings.

Each question has been cross-examined by a range of variables as follows. Where statistically significant variations in responses are identified[8], these are included at the end of each section.

- Gender
- Age category
- Have children
- Region
- Private health insurance

- Source of diagnosis (Q16)
- Symptom duration (Q17)
- Onset (Q19)
- Symptom severity (Q28)

Occasionally, charts have been included to show differences by these variables. When a variation is statistically significant it is marked with a green ↑ or orange ↓ arrow. It may be that variations look significant, but if there is no arrow next to the figure it means that the sample size is too small to say with certainty that the observed variation is occurring in a real-world scenario.

During the data cleaning process a number of data transformations and alterations were made, which have been outlined in the appendices. The appendices also include recommendations for changes to future iterations of the survey to improve accuracy and usefulness of data.

Where reference has been made to the question text (at the start of each section and in Appendix 1), the exact wording used in the survey script has been presented. We recognise that occasionally this includes grammatical errors.

Glossary of key terms

ABS	Australian Bureau of Statistics
CFS	Chronic Fatigue Syndrome
Codeframe / codes	List of answer categories for a question. These include answer options presented in the survey, as well as options added during the analysis stage to group written responses ('other – specify' or open ended answers)
Coding	Transforming written responses into categories for analysis
GP	General Practitioner
ME	Myalgic Encephalomyelitis
n=	Number of people who answered the question (sample base)
POTS	Postural Orthostatic Tachycardia Syndrome
PVFS	Post Viral Fatigue Syndrome

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[8] Statistical significance is calculated at a 0.05 significance level through SPSS Custom tables using the Bonferroni method to adjust p-values.

RESEARCH FINDINGS

Diagnosis

Incidence and source of diagnosis

Q14 Have you been diagnosed? (n=600)

Q16 Who were you diagnosed by? (n=603)

Analysis notes:	Both of these questions only allowed for a single response option to be selected.

Most (97%) indicated that they had been diagnosed, although of these 2.7% classified their diagnosis as 'self-diagnosed' or 'no formal diagnosis'. It was decided to keep in the sample those 27 people who didn't answer this question or said that they hadn't been diagnosed, as these people generally provided valuable responses in later questions in the survey.

The means of diagnosis is fairly evenly split between ME/CFS clinic or specialist (41%) and GP (40%). One in five indicated their diagnosis was through another type of specialist or alternative medicine practitioner, the most common being rheumatologist / immunologist.

Figure 6 – Source of diagnosis

Who diagnosed by

ME/CFS clinic or specialist	41%
GP	40%
Rheumatologist/Immunologist	5%
Self Diagnosed	3%
Physician	3%
No formal diagnosis	2%
Paediatrician	1%
Neurologist	1%
Naturopath	1%
Psychologist/Psychiatrist	1%
Allied Health	0%
Other	3%
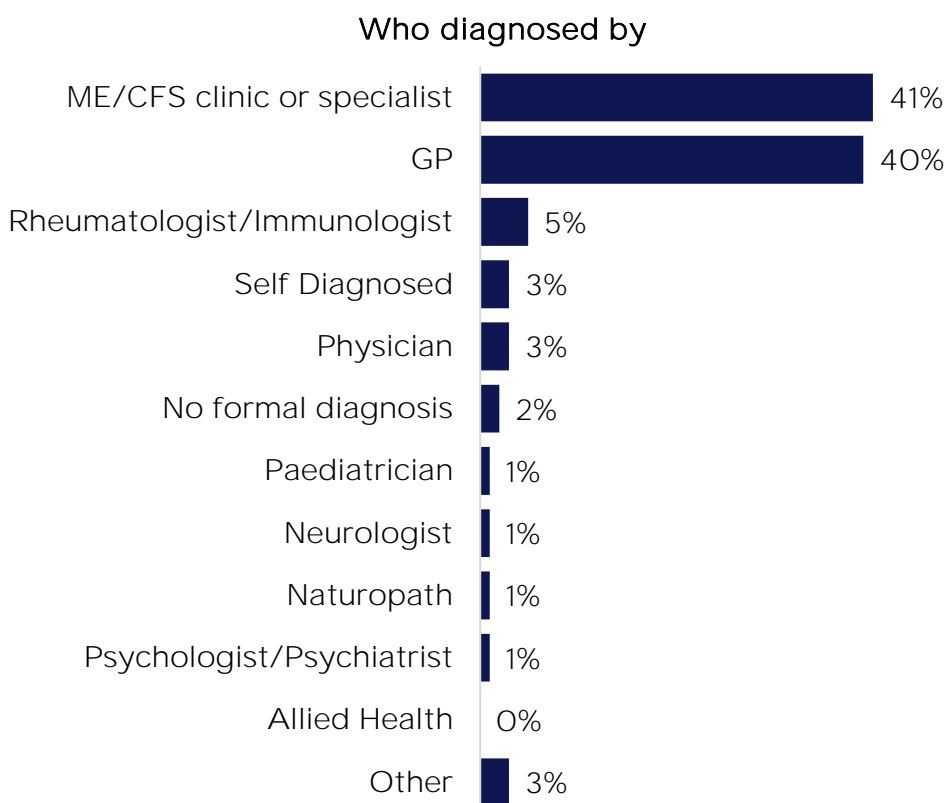
A higher proportion of those without private health cover were diagnosed by a GP (45%) than those with (36%), highlighting the importance of GP diagnosis for those without financial assistance to cover specialist appointments.

Nature of diagnosis

Q15 What is your diagnosis? (n=599)

Analysis notes:	This question allowed for multiple responses to be selected.
	In the questionnaire, the only options available were ME, CFS and PVFS (Post Viral Fatigue Syndrome). However, respondents were provided with an 'other' text box to type in any other diagnosis. The responses in this 'other' box were later coded for ease of analysis (including fibromyalgia, Postural Orthostatic Tachycardia Syndrome (POTS) and Lyme disease). The percentages for these additional coded answers show the proportion of people who took the time to type in additional information, rather than the proportion of people diagnosed with the condition. Had these options been included in the survey list, it is possible that the percentages would be higher.

CFS is the most common diagnosis which Australian patients receive, followed by ME/CFS.

Figure 7 – Diagnosis
Includes multiple responses
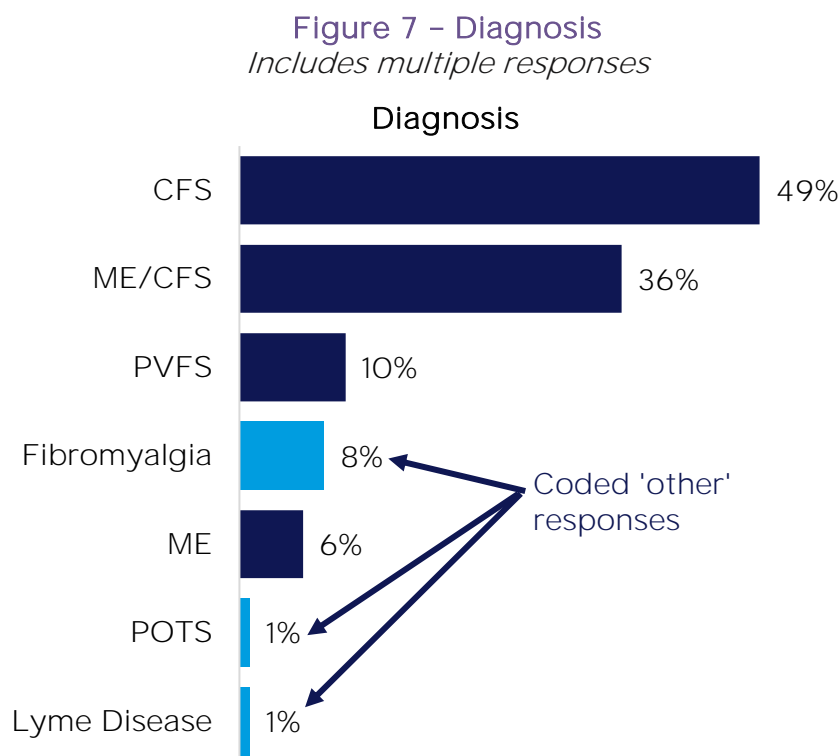
ME is more commonly diagnosed by specialists (46%, compared to 39% GPs), while over a third (36%) of Fibromyalgia cases were diagnosed by practitioners other than GPs or ME/CFS specialists.

These findings demonstrate that there is varied terminology being used by health professionals in Australia. Data suggests that a diagnosis of ME tends to correlate with more severe symptoms and lack of effectiveness of exercise therapy.

Most of those who specified a diagnosis other than ME/CFS also said they had been diagnosed with ME/CFS. This is to be expected given that the topic of the survey is ME/CFS.

Figure 8 – Incidence of non-ME/CFS diagnosis being diagnosed in conjunction with ME/CFS

Incidence of being diagnosed with ME/CFS as well

Diagnosis	Percentage
PVFS (n=57)	51%
Fibromyalgia (n=45)	66%
POTS (n=7)	72%
Lyme Disease (n=7)	85%
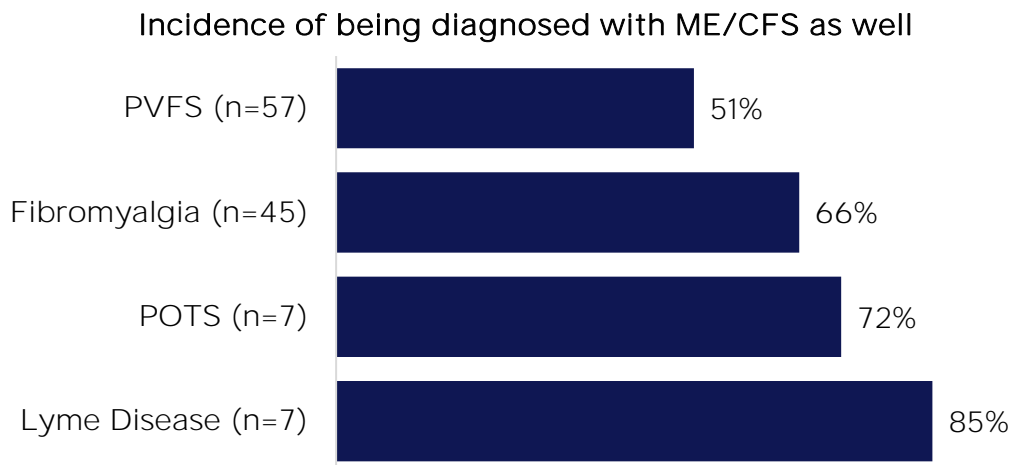
Those with severe/very severe symptoms show a higher incidence of being diagnosed with ME (ME/CFS + ME, 50%, compared to 37% of those with mild/moderate symptoms). Those with mild/moderate symptoms are more commonly diagnosed with just CFS and/or POTS. The variation in diagnosis of ME/CFS between the two severity categories is not statistically significant.

Figure 9 – Severity of symptoms by diagnosis

Severity of symptoms by diagnosis

Diagnosis	Severe / very severe (n=267)	Mild / moderate (n=307)
CFS	43%	53%
ME/CFS	40%	33%
PVFS	7%	12%
Fibromyalgia	8%	7%
ME	10%	4%
Lyme Disease	1%	1%
POTS	2%	1%
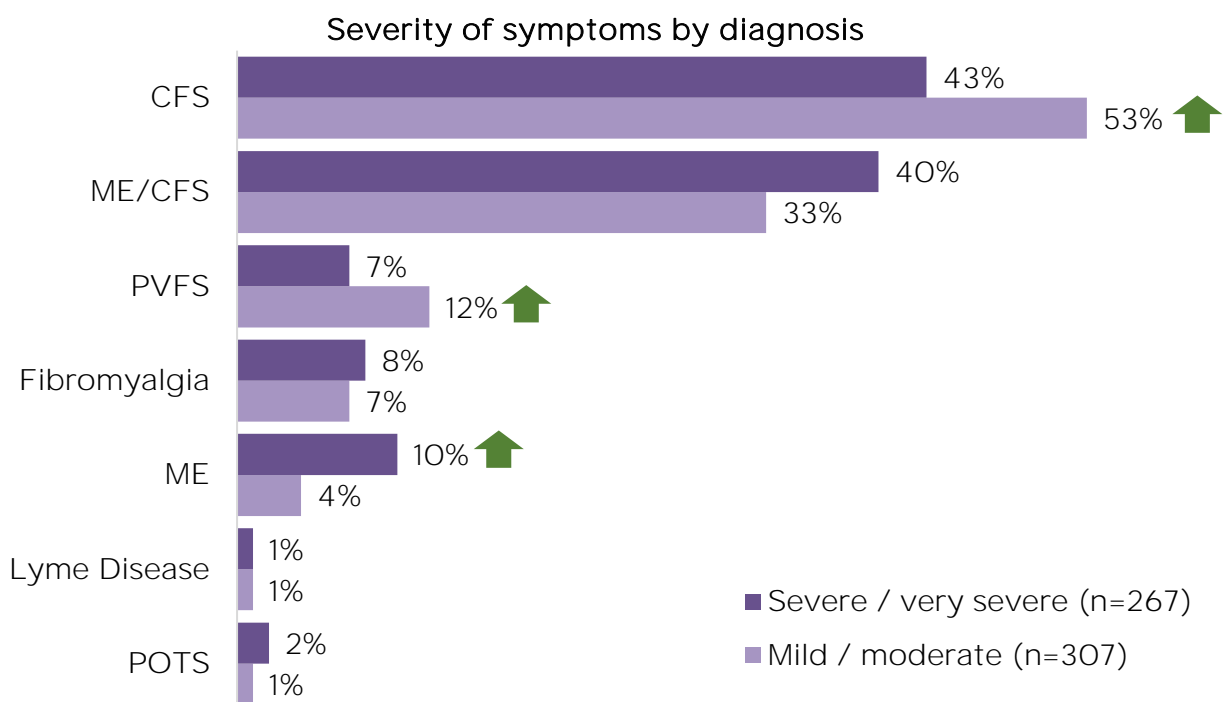
Time taken to diagnose

Q17 **When did you obtain your diagnosis?** (n=586)
Q18 **When did you first notice the symptoms of ME/CFS?** (n=591)
Q19 **Did you have a gradual or sudden onset?** (n=597)

One in five (20%) indicated that they were diagnosed in the same year as they experienced their first symptoms. A further 40% indicated that diagnosis was within 1-2 years of first symptoms.

Figure 10 – Time between first symptoms and diagnosis

Time between onset and diagnosis
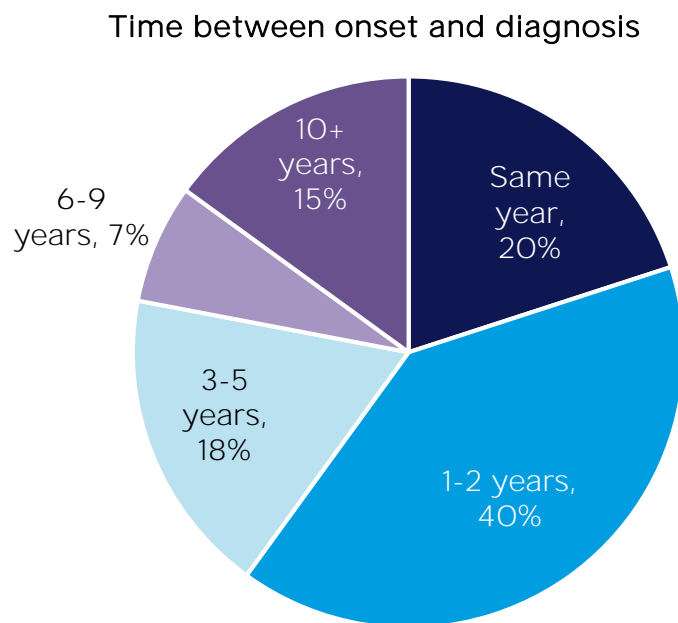
Those who were diagnosed by a GP were more often diagnosed faster (27% within the same year) than those diagnosed by an ME/CFS clinic or specialist (14% in the same year as symptoms arose).

Duration of symptoms

Half (51%) of those surveyed indicated that they were diagnosed 10 or more years prior to undertaking the survey, and 62% said that their symptoms began more than 10 years prior to participating in the survey.

Onset

Half of the sample defined the onset as gradual (51%), whilst the other half defined it as sudden (49%).

Those in regional areas show a higher incidence of it taking 6-9 years to be diagnosed (9%, compared to 5% in major cities).

Those with private health cover show a higher instance of being diagnosed quickly (25% within a year of symptoms, compared to 15% of those without private health cover).

Symptoms

Symptom level

Q28 Please tell us what level your symptoms have been at for the past three months. (n=585)

Around half of respondents self-reported their symptoms as mild or moderate, with the other half reporting them as severe or very severe. Definitions were provided in the survey script for each of these levels of severity as follows:

Answer option	Definition as listed on survey form
Mild	you have a significant reduction in activity levels compared to pre-illness
Moderate	you have an approximately 50% reduction in activity levels compared to pre-illness
Severe	you are mostly housebound
Very severe	you are mostly bedbound and require assistance with daily functions

Figure 11 – Symptom level

Symptom Level - 3 months prior to interview
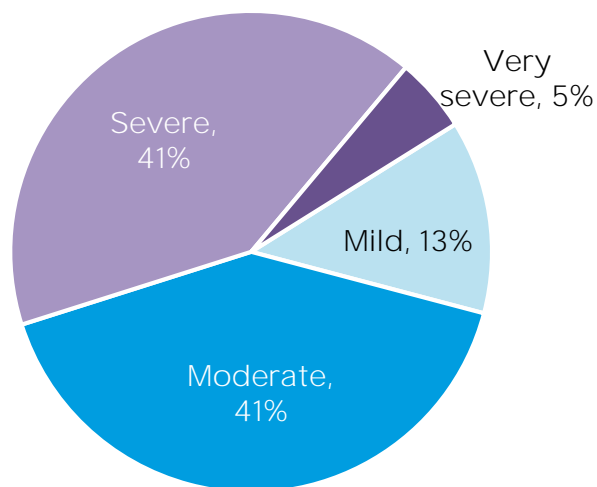
Of the 552 respondents who specified how long they had been experiencing this level of symptom, results are fairly similar when comparing those who self-reported severe/very severe and mild/moderate symptoms. Most (63%) indicate their symptoms to have been at the specified level for more than a year.

50-59 year olds register a higher incidence of rating their symptoms as severe (49%) when compared to those in the older category (30% 60+ year olds).

The green and orange arrows in Figure 12 show statistically significant variations when comparing severity of symptoms to diagnosis terminology. Those with a CFS diagnosis show a higher incidence of stating their symptoms to be mild (13%, compared to 9% others). The data suggests that there is a correlation between being diagnosed with ME

and having severe symptoms; 8% of those diagnosed with ME rated it as very severe (compared to 5% diagnosed with CFS and 3% diagnosed with PVFS / Fibromyalgia).

Figure 12 – Severity of symptoms by diagnosis
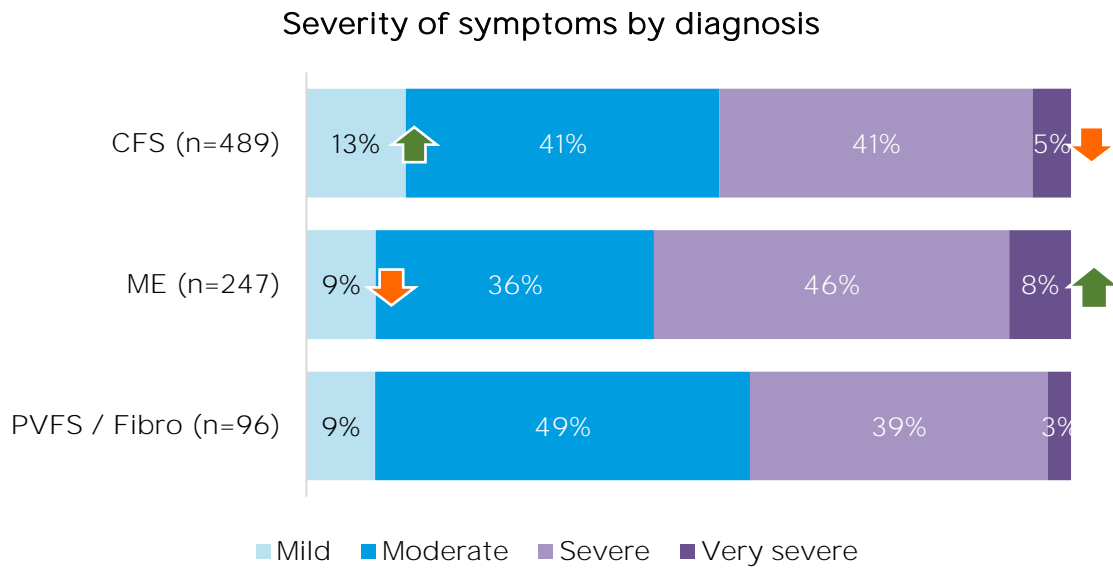
Severity of symptoms by diagnosis

Diagnosis	Mild	Moderate	Severe	Very severe
CFS (n=489)	13%	41%	41%	5%
ME (n=247)	9%	36%	46%	8%
PVFS / Fibro (n=96)	9%	49%	39%	3%

■ Mild ■ Moderate ■ Severe ■ Very severe

Key symptom

By far the most common primary symptom reported was fatigue (40%), followed by brain fog (13%).

Figure 13 – Primary symptom

Symptom that impacts the most strongly on life

Symptom	Percentage
Fatigue	40%
Brain fog - cognitive impairment	13%
Pain	8%
Exhaustion	7%
Lack of energy - stamina	6%
Post exertional malaise - PEM	5%
Orthostatic intolerance - dysautonomia - POTS	5%
Tiredness	3%
Other	13%
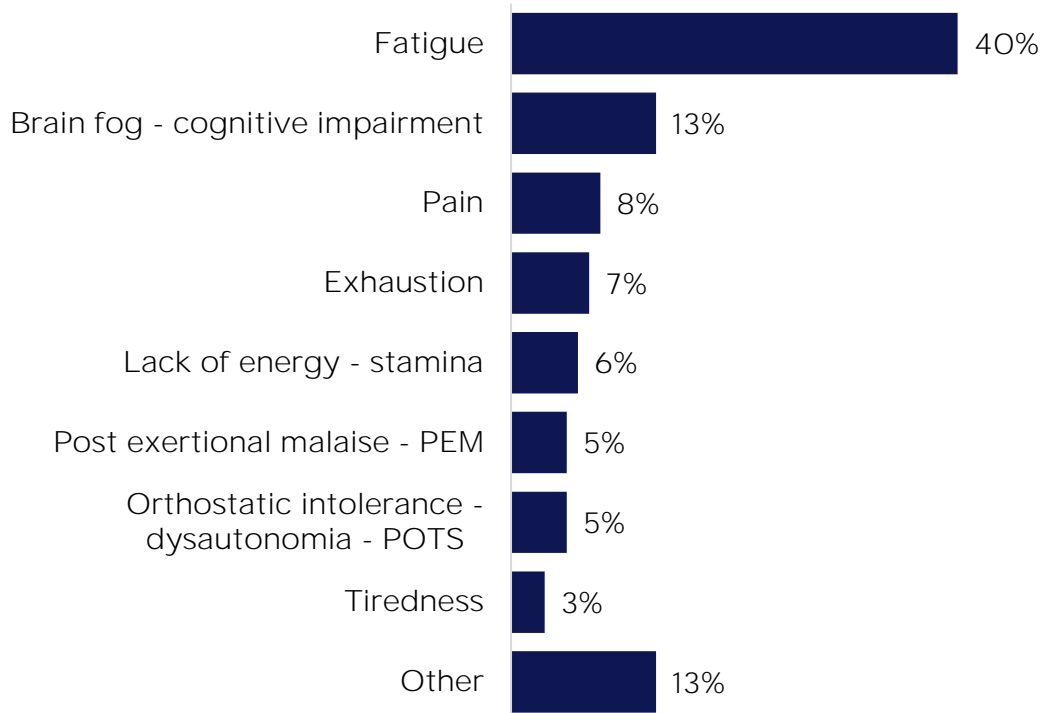
When combining the different symptoms relating to fatigue: fatigue, exhaustion, lack of energy and tiredness, 56% of respondents nominated this as the symptom that most affected their life.

A range of other symptoms were specified as the main symptom by less than 10 respondents each (as included in the 'other' category in the previous chart):

- Headaches / migraines (7 mentions);
- Muscle weakness (4 mentions);
- Sleep issues / insomnia (4 mentions);
- Immune / Flu like symptoms (4 mentions)
- Gastro intestinal issues (2 mentions);
- Sensory sensitivity (2 mentions);
- Isolation (2 mentions); and
- Multiple Chemical Sensitivity (MCS) (2 mentions).

A further 12 responses couldn't be categorised into a specific answer.

A range of notable variations occurred when analysing the data by demographics and symptom related information:

- Those reporting a mild/moderate symptom level show higher instances of specifying their primary symptom as fatigue (45%, compared to 35% of those with severe/very severe symptoms).
- Those experiencing severe/very severe symptoms show higher instances of stating their main symptom to be POTS (7%, compared to 3% of those with mild/moderate symptoms).
- Those with PVFS/Fibromyalgia show higher incidences of reporting exhaustion (13%, compared to 4% ME) or pain (15%, compared to 8% CFS/ME) as their one primary symptom.
- Brain fog is more commonly reported as the key symptom by males (19%) than females (11%).

Healthcare professionals

GP ratings

Q48 - On a scale of 1 to 5, where 1 is very poor and 5 is very well, how well-informed do you feel your GP is about ME/CFS? (n=537)

Q49 - On a scale of 1 to 5, where 1 is very poor and 5 is very well, how sympathetic is do you feel your GP is to ME/CFS? (n=534)

Q50 - On a scale of 1 to 5, where 1 is very poor and 5 is very good, how do you rate the service your GP provides to you regarding your ME/CFS? (n=531)

Around a quarter (29%) of respondents indicated that they felt their GP was very well/well informed, however a larger proportion (44%) rated their GP's level of being informed as poor/very poor. The average rating out of 5 was 2.73. This finding suggests that there is room for improvement in GP education on the topic.

Figure 14 – How well informed is GP about ME/CFS

How well informed is GP about ME/CFS
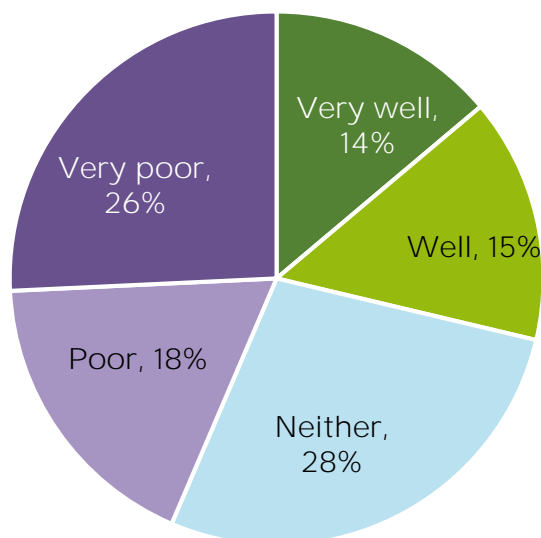
Most (55%) perceived their GP to be sympathetic towards ME/CFS, although findings suggest that there are still some GPs (29%) who do not sympathise with the condition. The average rating out of 5 was 3.47.

Figure 15 – How sympathetic is GP to ME/CFS

How sympathetic is GP to ME/CFS
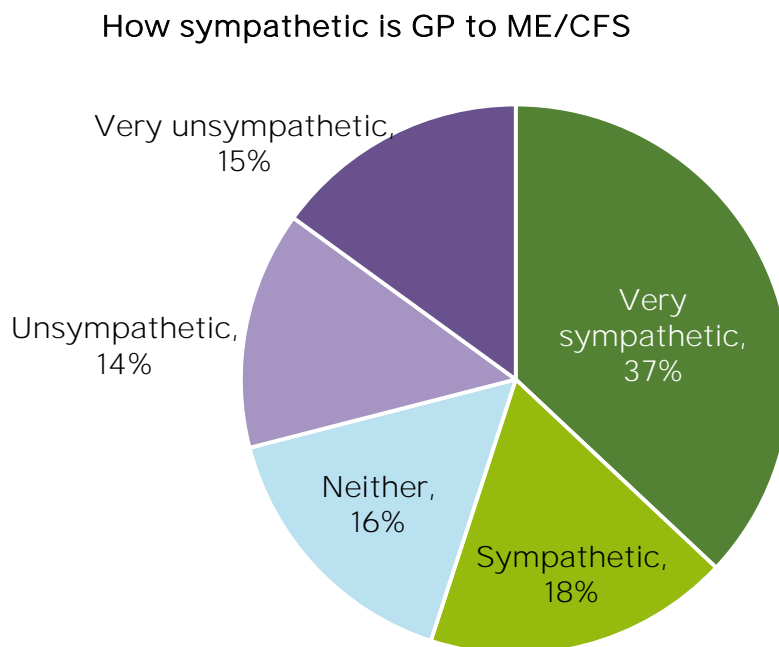
Those living in major cities show a much higher incidence of rating their GP as very sympathetic (41%, compared to 30% of those in regional areas).

Around 22% of GPs whose level of being informed was rated as poor/very poor were considered to at least be sympathetic.

Four in ten (40%) rate the service of their GP as good/very good, whilst a similar proportion rate the service as poor/very poor (42%). The average rating out of 5 was 2.92.

Rating - service of GP
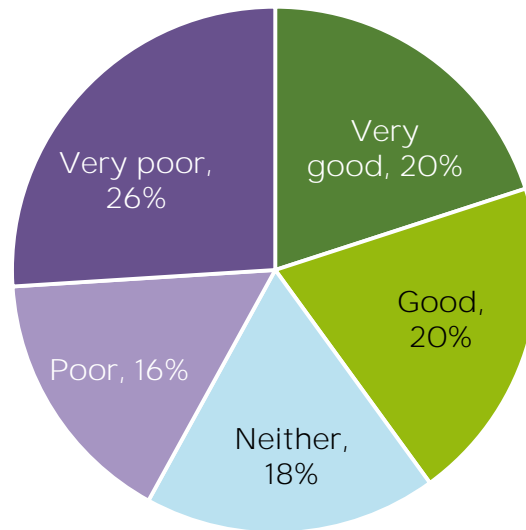
Only 6% of those who rated their GP's level of being informed as poor/very poor provided a good/very good overall rating to the service of their GP.

A quarter (24%) who answered these questions about their GP (n=539) rated them poorly across all three measures.

Ratings for GPs were notably lower across all three measures for those who were diagnosed by ME/CFS specialists or someone else other than a GP. Generally, those who were diagnosed by a GP provide their GP with higher ratings.

Visits to health professionals other than a GP

Q64 The table below offers a list of specialists you may have seen about your ME/CFS. (n=610) Please tell us:

a. how many times in the past 12 months you have seen them

b. how well-informed you feel they were about ME/CFS (1 = very poor, 5 = very good)

c. how you rate the service they provided regarding ME/CFS (1 = very poor, 5 = very good)

Analysis notes:	Given that there was an instruction in the survey script to leave the cells blank if they had not used a specialist, the findings for this question have been calculated from a base of all respondents, not just those who answered the question. Given it is not possible to identify from those who skipped this question as to who may have indeed visited specialists on the list, versus those who didn't visit specialists, it is possible that these figures are under-reported.

In the 12 months prior to interview clinical psychologists and physiotherapists were the most commonly visited specialists for ME/CFS.

Figure 17 – Visitation of health professionals other than a GP

Incidence of appointment in 12 months prior to interview

Clinical psychologist	24%
Physiotherapist	17%
Dietitian	11%
Osteopath	11%
Cardiologist	11%
Psychiatrist	11%
Gastroenterologist	9%
Neurologist	9%
Endocrinologist	8%
Immunologist	6%
Occupational therapist	4%
Paediatrician	2%

Legend: ■ Allied health ■ Medical specialist
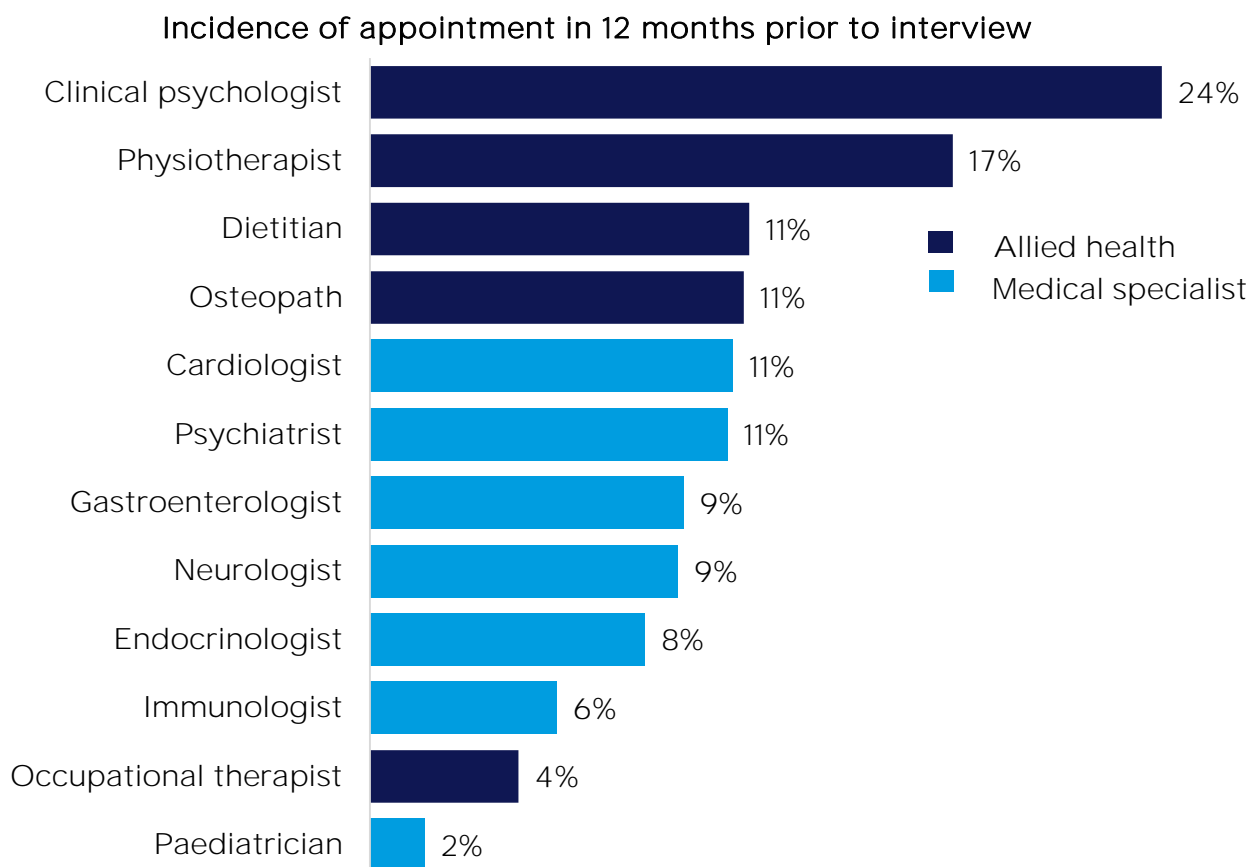
Those who self-rate their symptom severity as severe or very severe show a higher incidence of having visited a neurologist (14%, compared to 6% of those with mild/moderate symptoms), cardiologist (15%, compared to 8% of those with

mild/moderate symptoms) and/or occupational therapist (8%, compared to 2% of those with mild/moderate symptoms) in the 12 months prior to interview.

There is a correlation between age and incidence of visiting a clinical psychologist in the year prior to interview, starting at 38% amongst 15-29 year olds, then dropping to 28% amongst 30-49 year olds, 18% amongst 50-59 year olds, and down to 11% amongst 60+ year olds.

Males show a higher incidence of having visited an immunologist in the 12 months prior to interview (12%) compared to females (4%), whilst females show higher instances of having visited a physiotherapist (19%, compared to 12% males).

Osteopaths, clinical psychologists and physiotherapists were more commonly rated as well informed and providing good service.

Figure 18 – Positive ratings of health professionals

Positive ratings of health professionals

Health professional	Well informed / Allied health	Good service / Medical specialist
Osteopath (n=70)	49%	69%
Clinical psychologist (n=146)	47%	59%
Physiotherapist (n=99)	44%	62%
Immunologist (n=40)	43%	27%
Paediatrician (n=10)	40%	55%
Psychiatrist (n=67)	37%	49%
Endocrinologist (n=59)	33%	39%
Dietitian (n=77)	30%	37%
Cardiologist (n=75)	27%	34%
Occupational therapist (n=27)	26%	31%
Gastroenterologist (n=61)	15%	30%
Neurologist (n=62)	12%	21%

Legend:
■■ Well informed
■■ Good service
■■ Allied health
■■ Medical specialist

In most cases there were people who considered the service to be good, despite the practitioner not being well informed about ME/CFS, with the exception of immunologists, where almost half (49%) of patients rated the service as poor despite only 36% indicating they were poorly informed.

Figure 19 – Poor ratings of health professionals

Poor ratings of health professionals

Professional	Poorly informed	Poor service
Neurologist (n=62)	65%	59%
Gastroenterologist (n=61)	61%	51%
Endocrinologist (n=59)	54%	50%
Immunologist (n=40)	36%	49%
Cardiologist (n=75)	59%	46%
Dietitian (n=77)	47%	43%
Psychiatrist (n=67)	43%	37%
Occupational therapist (n=27)	52%	35%
Paediatrician (n=10)	50%	33%
Clinical psychologist (n=146)	33%	24%
Physiotherapist (n=99)	34%	20%
Osteopath (n=70)	31%	17%

Legend: Poorly informed, Poor service, Allied health, Medical specialist

Healthcare support opportunities

Q65 What would make a real difference to your healthcare? (n=517)

Analysis notes:	Statistics include multiple responses to the question.
	Groupings from 'other specify' cannot be directly compared with options provided in the survey as respondents may have been more likely to consider the 'other' options if they were listed as a pre-defined answer code.

Of the list provided in the survey, the most popular options that respondents felt would make a difference to their healthcare were better informed GPs and more effective medication.

Figure 20 – Healthcare support opportunities
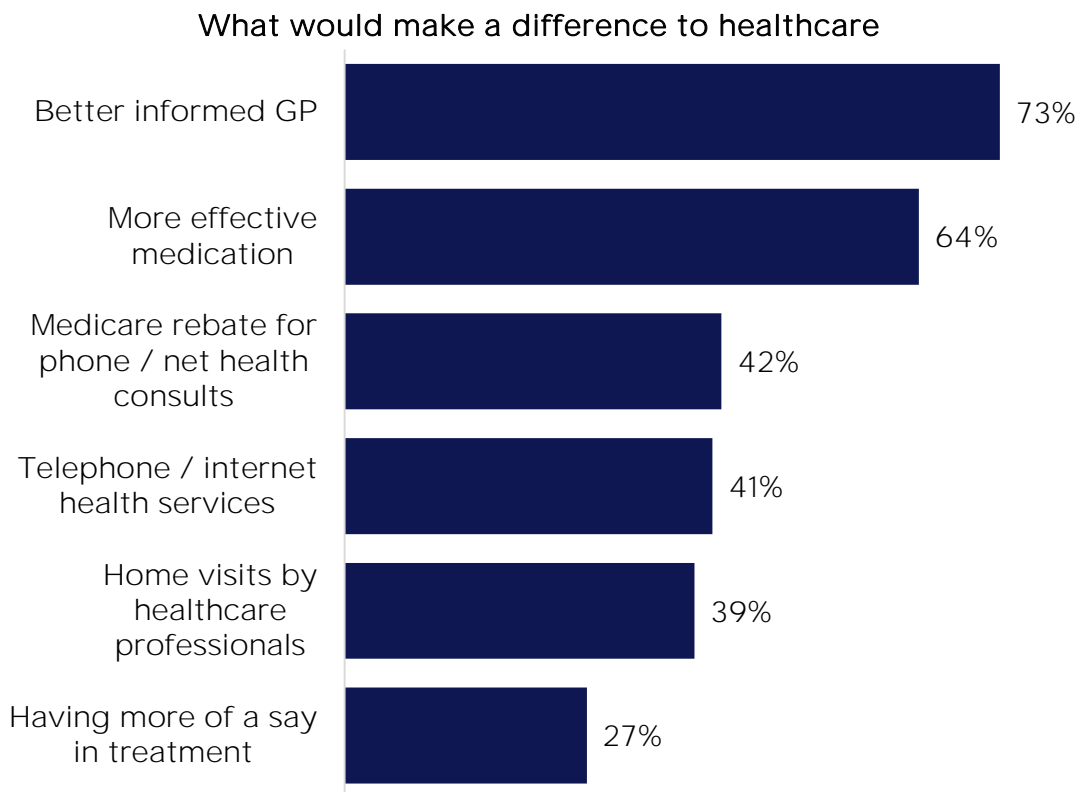
What would make a difference to healthcare

- Better informed GP — 73%
- More effective medication — 64%
- Medicare rebate for phone / net health consults — 42%
- Telephone / internet health services — 41%
- Home visits by healthcare professionals — 39%
- Having more of a say in treatment — 27%

A wide variety of additional suggestions were put forth in the provided text box. These have been grouped for the purpose of analysis, but it should be borne in mind that the likely popularity of these options based on number of mentions alone cannot be directly compared to the popularity of the options in the chart above, as respondents may have been more likely to select these if they were included in the question list.

Figure 21 – Additional suggestions for healthcare support

Theme	mentions
More affordable treatment / rebates	27
Access to / Easier to find a specialist / more specialists	19
Education of medical community / members of	20
Alternative Treatment / recognition / rebates	19
More effective treatment / a cure	12
More research into treatment	11
A local clinic / access to/ local services / professionals	13
Home care	10
Better coverage by Centrelink / Medicare	13
Being believed / having illness recognised	12
Public education / general awareness	9
Better diagnosis	7
Holistic / integrated / cross-discipline healthcare	6

As can be seen in the following figure, those who self-report severe or very severe symptoms show higher instances of indicating that the listed options would make a difference, particularly home visits.

Figure 22 – Healthcare support needs by symptom severity

Things that would make a difference by symptom severity

Severe / very severe
Mild / moderate

Category	Severe / very severe	Mild / moderate
Better informed GP	76%	70%
More effective medication	72%	57%
Home visits by healthcare professionals	53%	27%
Medicare rebate for phone / net health consults	51%	35%
Telephone / internet health services	51%	33%
Having more of a say in treatment	33%	23%
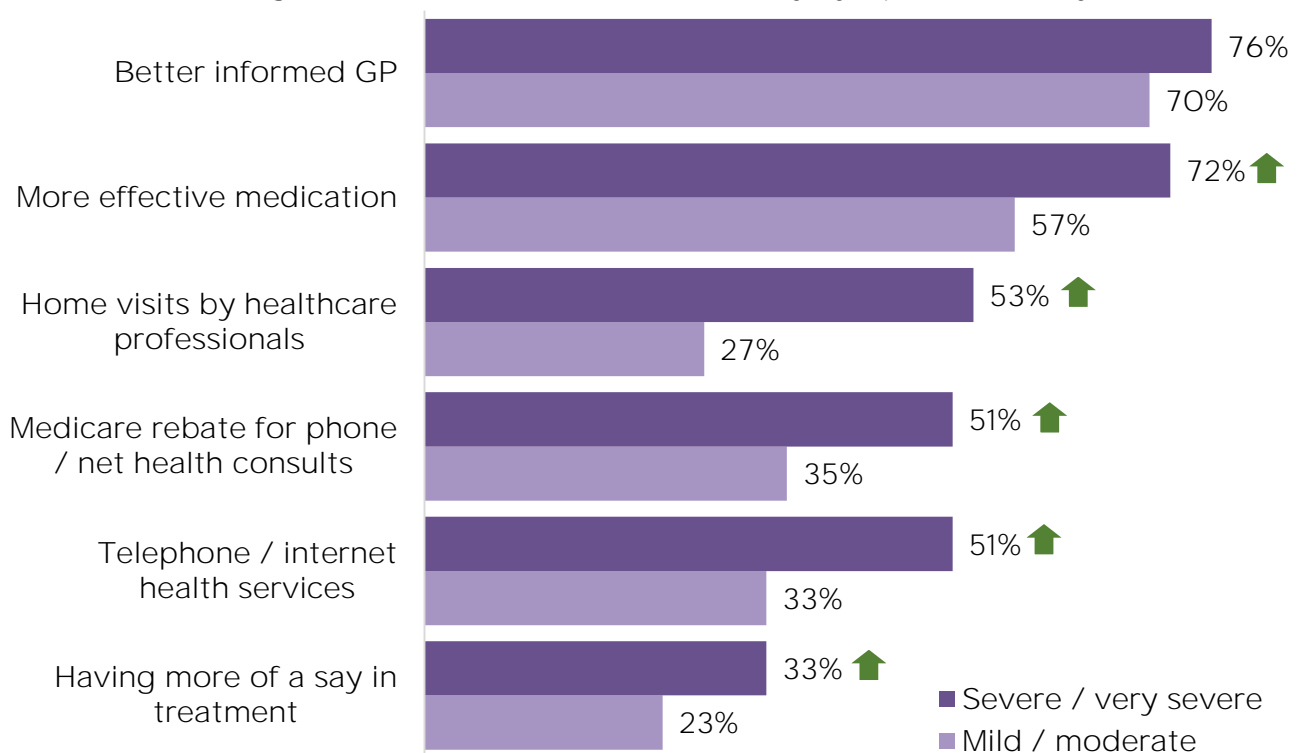
Having more say on treatment is of greater importance for those diagnosed by practitioners other than GPs or ME/CFS specialists (37%, 23% ME/CFS specialists). A higher proportion of females want telephone/internet health services (44%, 32% males), a Medicare rebate for phone/online consults (45%, 29% males) and/or home visits (42%, 27% males).

Having more say into treatment is a more common need amongst those with children (33%, 23% those without children), and those who live in regional areas (32%, 24% major city residents). Regional residents also show higher instances of wanting telephone/online services (49%, compared to 36% of major city residents) and/or medicare rebates for these phone/online consults (48%, compared to 38% of major city residents).
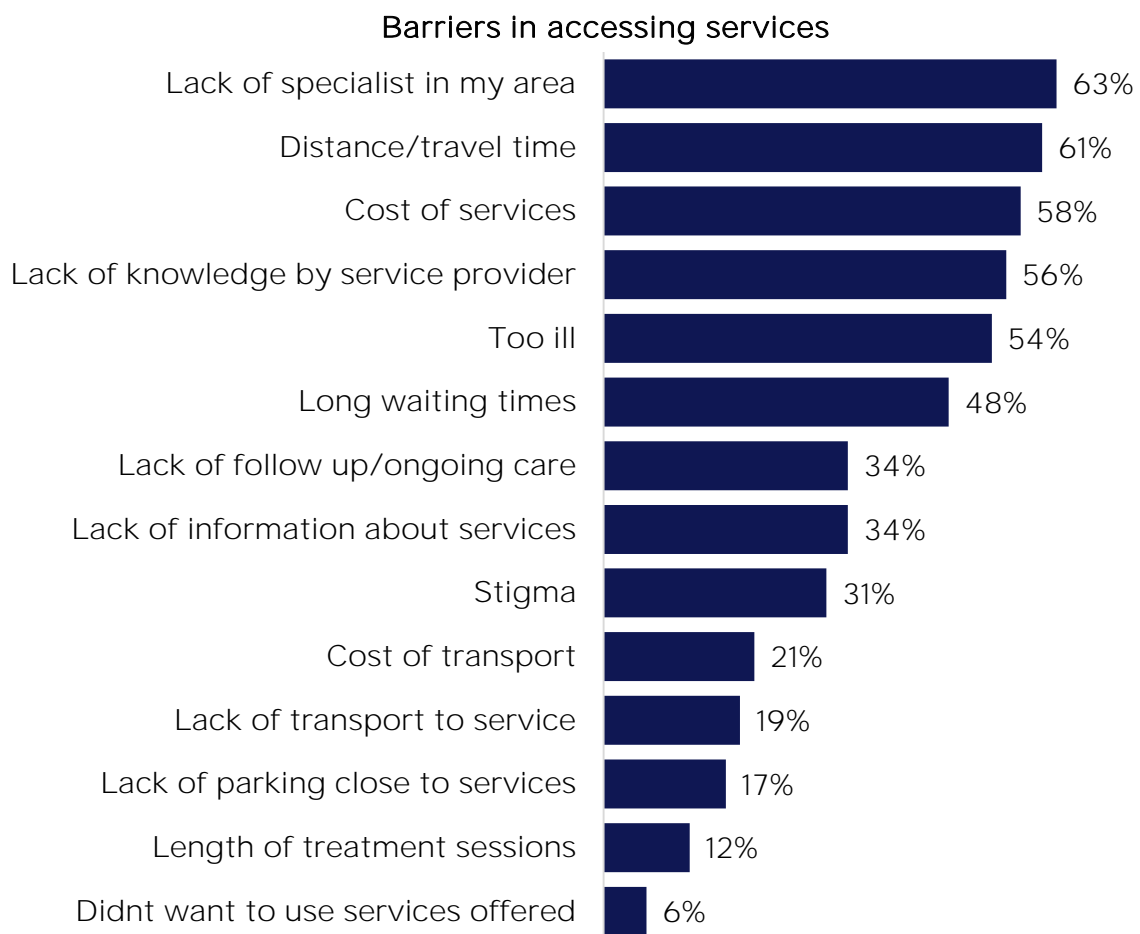
Barriers to accessing services

Q66 What barriers have you experienced in accessing services (GP/specialist clinic/consultant) for ME/CFS? (n=516)

Analysis notes:	Groupings from 'other specify' cannot be directly compared with options provided in the survey as respondents may have been more likely to consider the 'other' options if they were listed as a pre-defined answer code.

The primary things stopping people from accessing services revolve around the lack of availability of appropriate services in an accessible location, cost, lack of knowledge of the condition and being too unwell.

Figure 23 – Barriers to accessing services

Barriers in accessing services

Barrier	Percentage
Lack of specialist in my area	63%
Distance/travel time	61%
Cost of services	58%
Lack of knowledge by service provider	56%
Too ill	54%
Long waiting times	48%
Lack of follow up/ongoing care	34%
Lack of information about services	34%
Stigma	31%
Cost of transport	21%
Lack of transport to service	19%
Lack of parking close to services	17%
Length of treatment sessions	12%
Didnt want to use services offered	6%

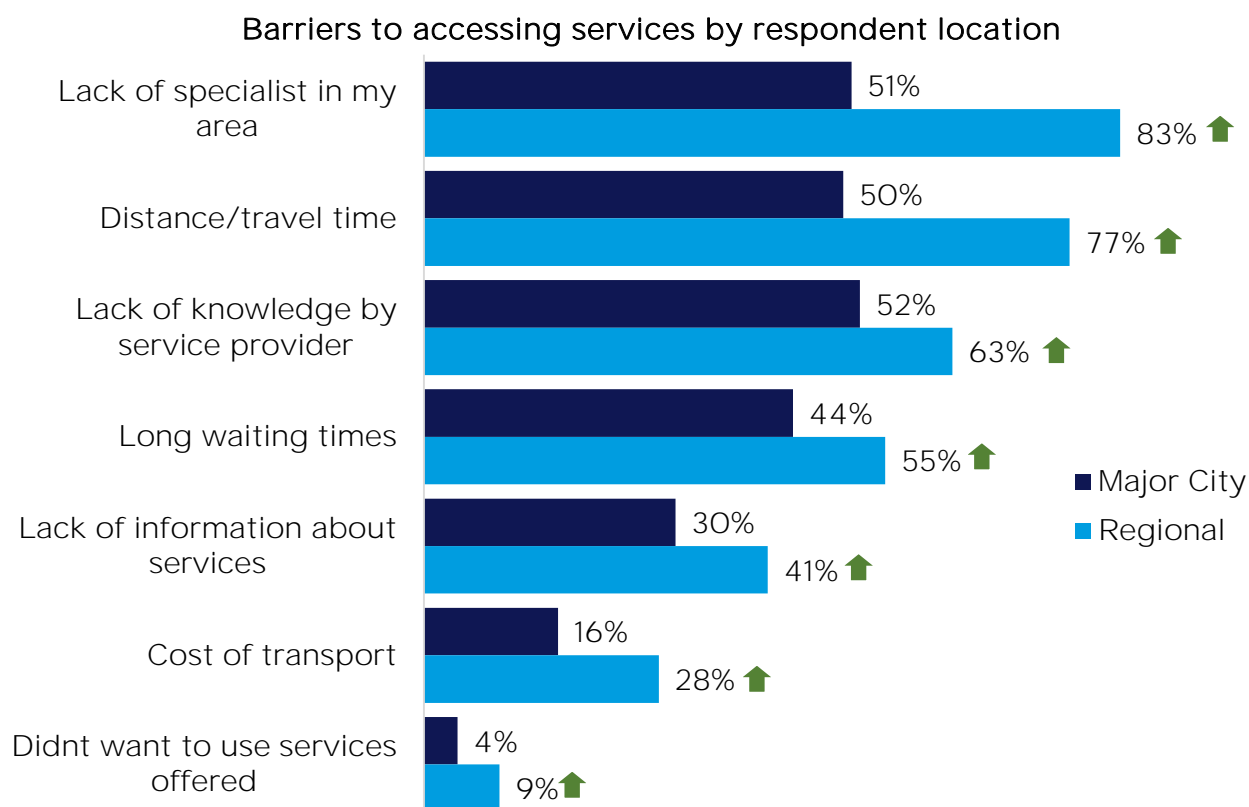A wide variety of additional suggestions were put forth in the provided text box. These have been grouped for the purpose of analysis, but it should be borne in mind that the likely popularity of these options based on number of mentions alone cannot be directly compared to the popularity of the options in the chart above, as respondents may have been more likely to select these if they were included in the question list.

Figure 24 – Additional barriers to accessing services

Theme	mentions
Poor treatment options	11
Lack of services	10
Attitude of practitioner	10
Diagnosed as psychological condition	6
Symptom / disease related	5
Cost of medication / treatment	4
Poor diagnosis	2
Unaware of services	2

Understandably, a range of barriers are more common amongst regionally located respondents.

Figure 25 – Barriers to accessing services by respondent location

Barriers to accessing services by respondent location

Barrier	Major City	Regional
Lack of specialist in my area	51%	83%
Distance/travel time	50%	77%
Lack of knowledge by service provider	52%	63%
Long waiting times	44%	55%
Lack of information about services	30%	41%
Cost of transport	16%	28%
Didnt want to use services offered	4%	9%

Whilst barriers to accessing services were identified across the spectrum, it is of note that those with severe or very severe symptoms more often experienced a range of barriers that impacted their access to health services.

Figure 26 – Barriers to accessing services by symptom severity

Barriers to accessing services by symptom severity
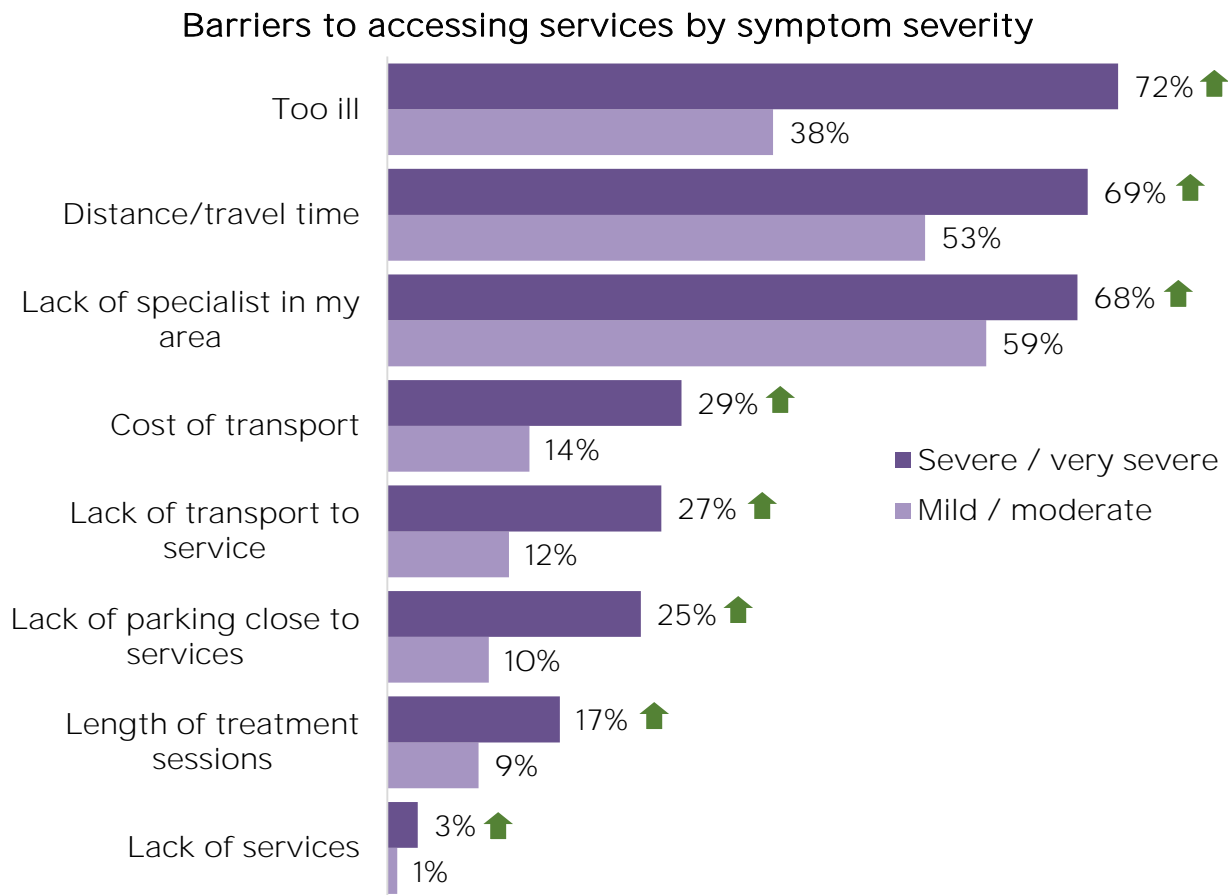
Younger people more commonly cite the barriers as being too ill (60% 15-29, compared to 38% 60+), distance/travel time (67% 15-29, compared to 41% 60+), cost (67% 15-29, compared to 34% 60+), and/or wait times (63% 15-29, compared to 32% 60+).
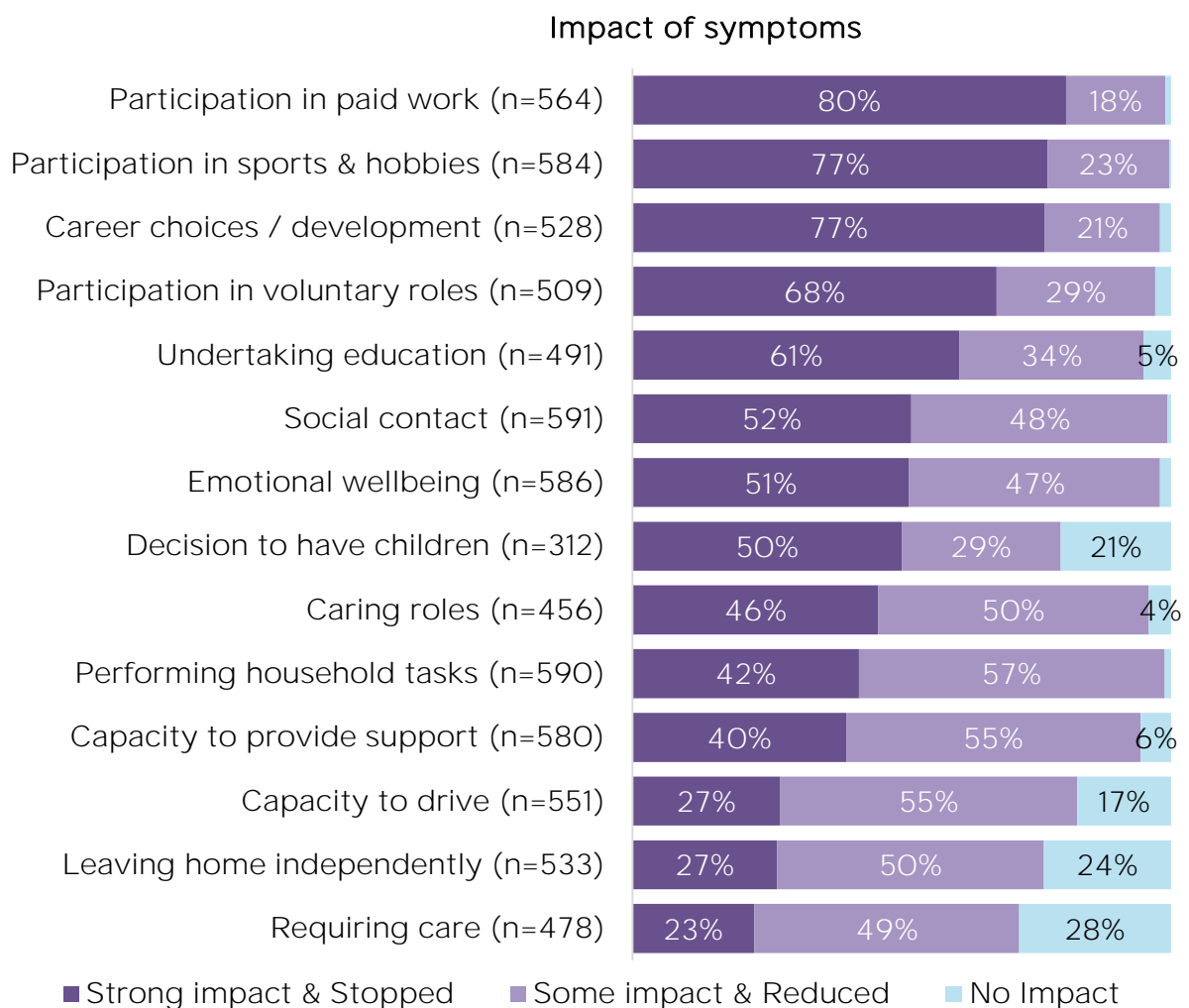
Impact on life

Level of impact on everyday activities

Q32 What impact have your symptoms had on your life? (n=312-588)

Analysis notes:	Not all respondents provided an answer to all variables in this question. It is not possible to know whether those who didn't respond skipped providing an answer because there was no impact, or whether it was because it was not applicable (or that they didn't have the time to complete the question). Therefore, there is a risk that incidences of stating an impact may be inflated. Frequencies are calculated based on the number of respondents who provided an answer for each activity.

The key areas of life where ME/CFS is having a significant impact on everyday activities relate to work, participation in sport and hobbies, and career choices/development.

Figure 27 – Changes to everyday activities

Impact of symptoms

Activity	Strong impact & Stopped	Some impact & Reduced	No Impact
Participation in paid work (n=564)	80%	18%	
Participation in sports & hobbies (n=584)	77%	23%	
Career choices / development (n=528)	77%	21%	
Participation in voluntary roles (n=509)	68%	29%	
Undertaking education (n=491)	61%	34%	5%
Social contact (n=591)	52%	48%	
Emotional wellbeing (n=586)	51%	47%	
Decision to have children (n=312)	50%	29%	21%
Caring roles (n=456)	46%	50%	4%
Performing household tasks (n=590)	42%	57%	
Capacity to provide support (n=580)	40%	55%	6%
Capacity to drive (n=551)	27%	55%	17%
Leaving home independently (n=533)	27%	50%	24%
Requiring care (n=478)	23%	49%	28%

■ Strong impact & Stopped   ■ Some impact & Reduced   ■ No Impact

When calculating the incidence of stating *strong impact & stopped* as a percentage of the entire sample (n=610, to provide a measure across all sufferers, rather than just those who answered the question), overall proportions are a little lower, but the top 4 remain the same:
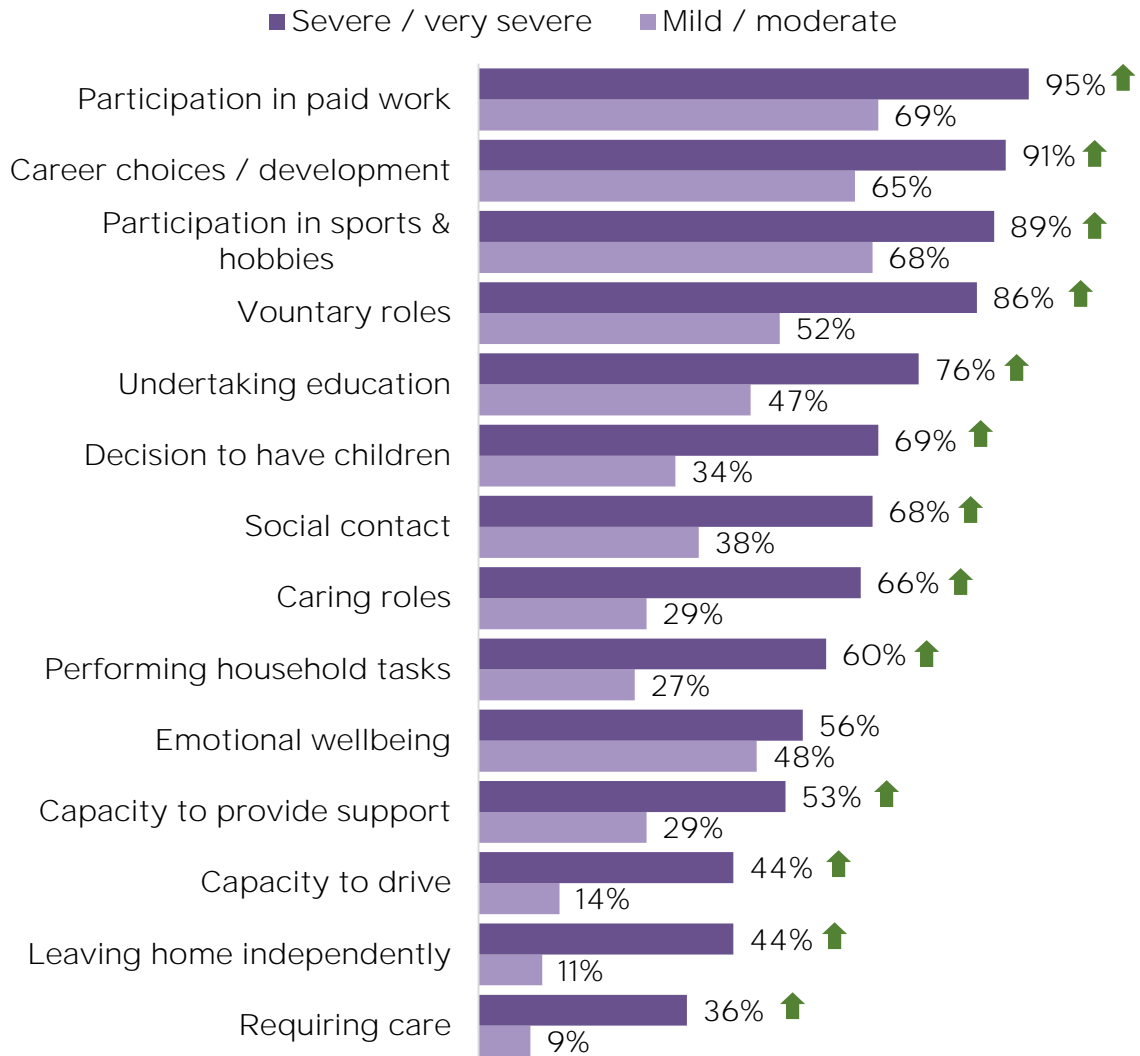
- Participation in paid work (74%);
- Participation in sports and hobbies (74%);
- Career choices / Development (66%); and
- Participation in voluntary roles (56%).

Furthermore, when calculated as a percentage of all respondents (including those who said 'not applicable'), 26% indicated ME/CFS had a strong impact on (or stopped) their decision to have children. A range of notable variations occurred when analysing the data by demographics and symptom related information:

- More than eight in ten (86%) males who answered the question indicated that ME/CFS had a strong impact or stopped their participation in paid work (compared to 75% of females), and 60% say that it has had a strong impact on their emotional wellbeing (compared to 49% of females).
- Over 80% of 30-49 year olds report that ME/CFS has had a strong influence or stopped them from participating in sport (compared to 64% 60+ year olds).
- ME/CFS hits hardest in terms of career decisions and choices from age 30 through to 59 (72%+).
- Almost half (44%) of 30-39 year olds indicate that ME/CFS has had a strong impact or stopped them from having children (compared to 26% or less amongst those in older age groups). 40% of those who don't have children indicate the ME/CFS has had a strong influence on this decision.
- As would be expected, those with severe / very severe symptoms more commonly rate these aspects as strong impact / stopped.

Figure 28 – Strong impact by severity of symptoms

Strong Impact & Stopped by severity of symptoms

■ Severe / very severe   ■ Mild / moderate

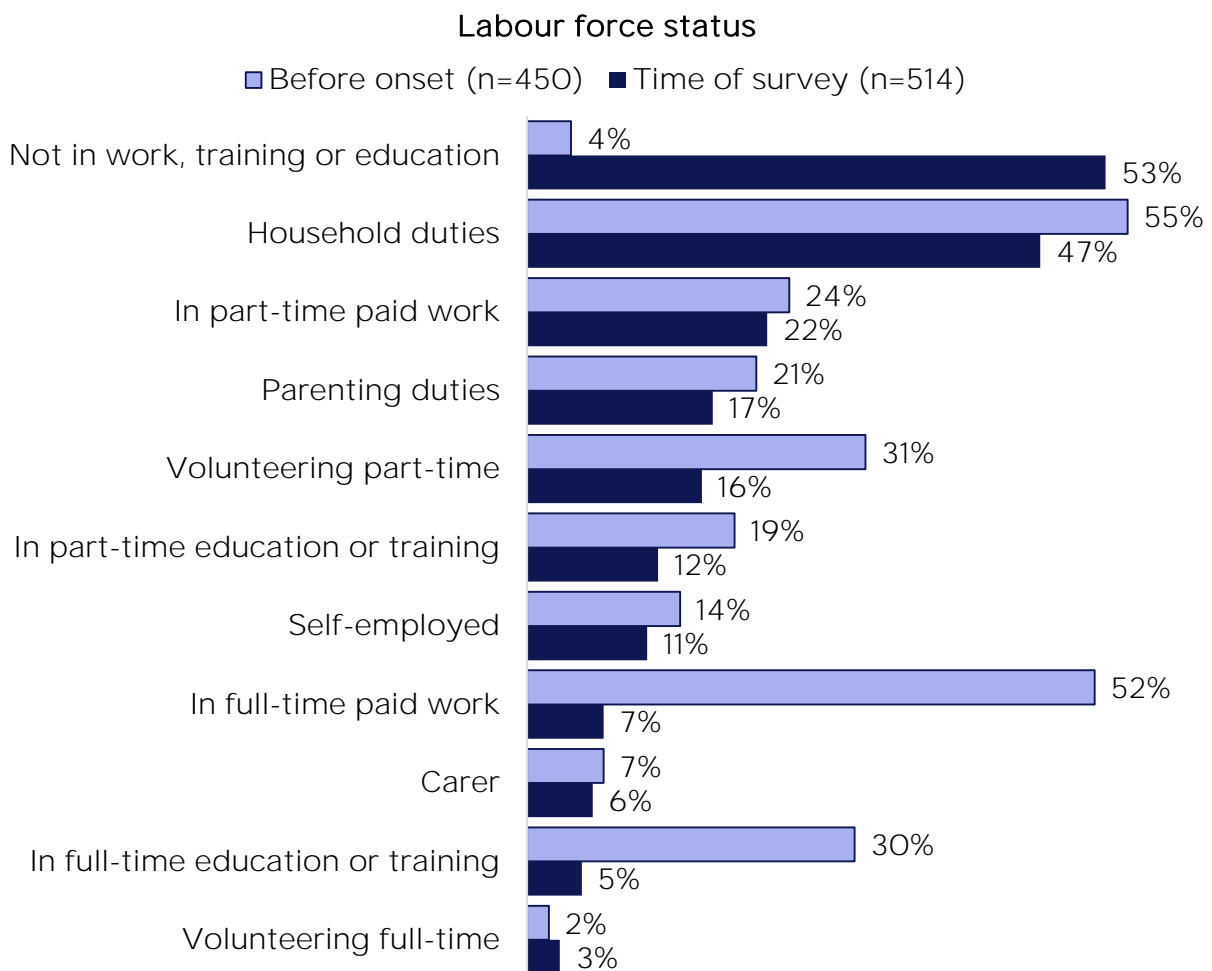| Category	Severe / very severe	Mild / moderate
Participation in paid work	95% ⬆	69%
Career choices / development	91% ⬆	65%
Participation in sports & hobbies	89% ⬆	68%
Vountary roles	86% ⬆	52%
Undertaking education	76% ⬆	47%
Decision to have children	69% ⬆	34%
Social contact	68% ⬆	38%
Caring roles	66% ⬆	29%
Performing household tasks	60% ⬆	27%
Emotional wellbeing	56%	48%
Capacity to provide support	53% ⬆	29%
Capacity to drive	44% ⬆	14%
Leaving home independently	44% ⬆	11%
Requiring care	36% ⬆	9%

Participation in the workforce

Q37 In relation to the following statements, please select all those that apply to you at the stated time periods (before onset and at time of survey) (n=528)

Analysis notes:	The question does not allow for assigning attribution of a change in circumstances directly to ME/CFS. Findings are presented as indicative, however further detail regarding the causes of change in circumstances would be required to confidently attribute the change to ME/CFS.
	Question allows for multiple choices to be selected.

Findings show a significant shift away from full time work or study after onset of symptoms.

Figure 29 – Labour force status before and after onset of ME/CFS

Labour force status

☐ Before onset (n=450)   ■ Time of survey (n=514)

Category	Before onset	Time of survey
Not in work, training or education	4%	53%
Household duties	55%	47%
In part-time paid work	24%	22%
Parenting duties	21%	17%
Volunteering part-time	31%	16%
In part-time education or training	19%	12%
Self-employed	14%	11%
In full-time paid work	52%	7%
Carer	7%	6%
In full-time education or training	30%	5%
Volunteering full-time	2%	3%

Three in five (60%) of those who were in part-time and 57% of those who were in full time work before onset indicated that they were not in work, training or education at the time of the survey. It is not possible to determine from the findings whether this was due to ME/CFS or other causes.

When assessing the timeframe in which duties shifted, it is clear that for those in full time work or study a significant shift towards not being in work/training or working/studying part time occurs within a year of onset of symptoms.

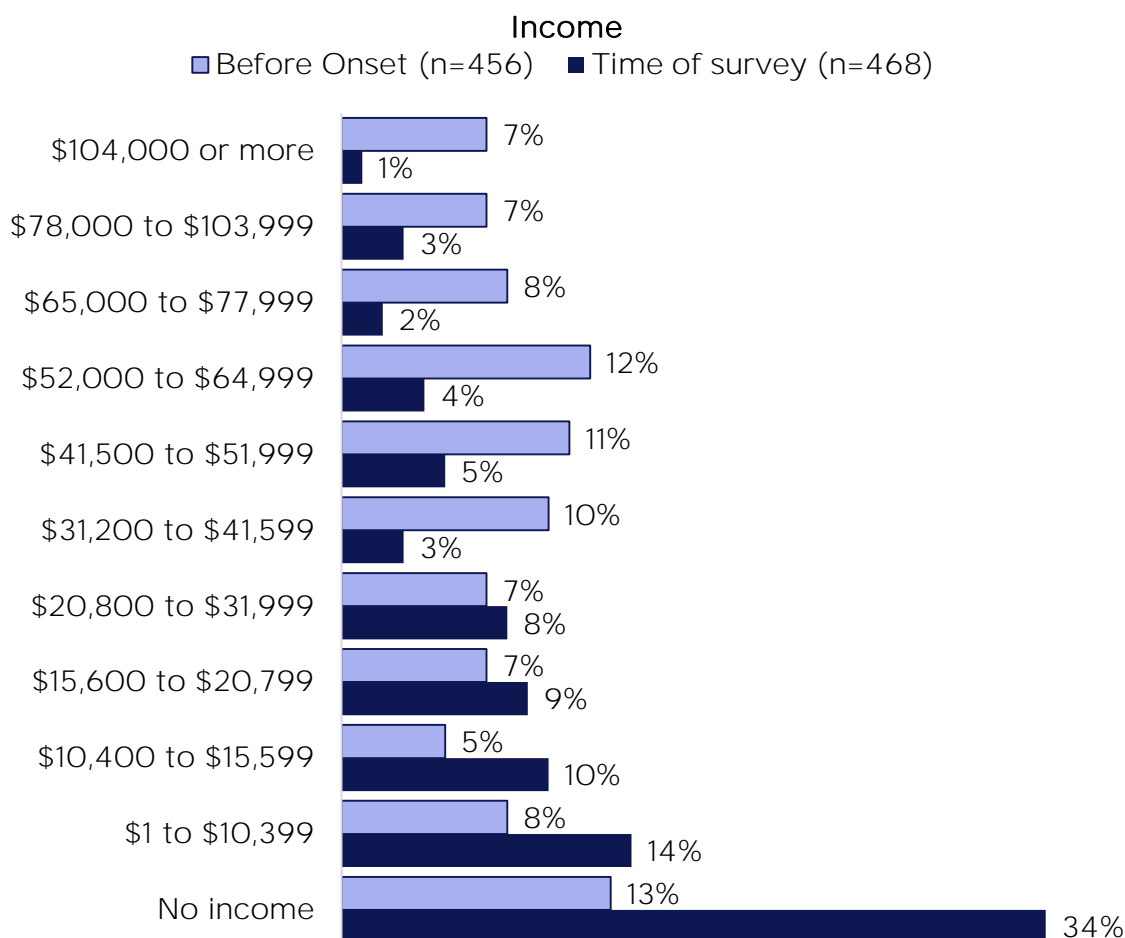Males went from 71% in full time work prior to onset, to just 9% at the time of survey.

Income

Q38 What was your estimated annual income level from employment at the following times? (n=482)

Analysis notes:	The question does not allow for assigning attribution of a change in circumstances directly to ME/CFS. Findings are presented as indicative, however further detail regarding the causes of change in circumstances would be required to confidently attribute change to ME/CFS.

Consistent with the previously reported shift away from full time work, many reported a lower income bracket at the time of survey than prior to onset. At the time of the survey 34% of respondents indicated that they had no income, which compares to an Australian average of 9% of 15+ year olds with no income.

Figure 30 – Income before and after onset of ME/CFS

Income

□ Before Onset (n=456) ■ Time of survey (n=468)

Income	Before Onset	Time of survey
$104,000 or more	7%	1%
$78,000 to $103,999	7%	3%
$65,000 to $77,999	8%	2%
$52,000 to $64,999	12%	4%
$41,500 to $51,999	11%	5%
$31,200 to $41,599	10%	3%
$20,800 to $31,999	7%	8%
$15,600 to $20,799	7%	9%
$10,400 to $15,599	5%	10%
$1 to $10,399	8%	14%
No income	13%	34%

When taking the mid-point for each category (with $104,000 set as $104,000 and No income set as $0) the mean income changes from $41,448 prior to onset to $17,572 at time of survey.

Those who self-report severe symptoms show higher instances of no income at time of interview (41%, compared to 28% of those with mild or moderate severity).

Employer awareness

Q39 If currently employed, does your employer know you have ME/CFS? (n=111 applicable responses)

Analysis notes:	Finding calculated as a percentage of those who answered the question, said in the previous question they were currently employed, and **selected an option other than 'not applicable'.**

Almost three quarters (65%) of those for whom this question was applicable indicated that their employer was aware that they have ME/CFS; nearly all of whom (97%) told the employer themselves.

Those who were diagnosed through means other than a GP or ME/CFS specialist show a higher incidence of not telling their employer (53%, compared to 20% of those diagnosed through an ME/CFS specialist); further research would be required to explore why this is the case and whether it is a finding worth addressing. PVFS / Fibromyalgia sufferers also show a high incidence of not telling their employer (56%, compared to 27% ME/CFS sufferers).
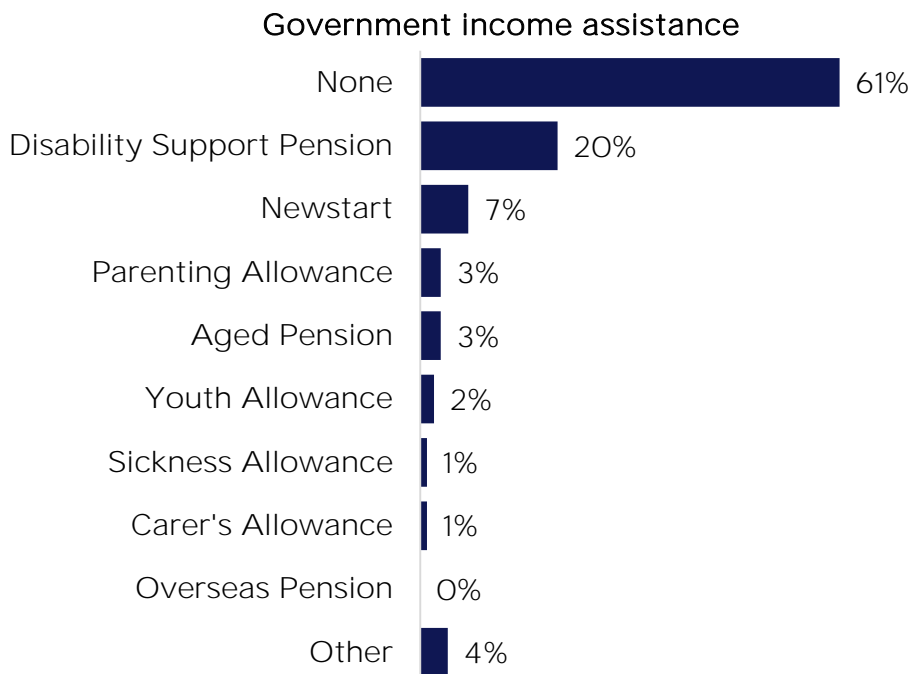
Government assistance

Q43 Do you receive government income assistance? (n=473)

Analysis notes:	Multiple responses were allowed for this question. It is not possible to determine whether those who didn't answer this question skipped it because they are not receiving government support, or for other reasons. Due to this, it is possible that the percentages reported for receiving income assistance are higher than would have been the case had this question been mandatory.

Two in five (39%) of those who answered this question indicated that they receive some form of government income assistance, the most common being a disability pension. When calculated as a percentage of the entire sample (including those who didn't provide an answer), 30% indicated that they receive government income assistance.

Figure 31 – Government income assistance

Government income assistance

Category	Percentage
None	61%
Disability Support Pension	20%
Newstart	7%
Parenting Allowance	3%
Aged Pension	3%
Youth Allowance	2%
Sickness Allowance	1%
Carer's Allowance	1%
Overseas Pension	0%
Other	4%

Those who specified their current income as $10,400 to $15,599 showed the highest incidence of receiving government income assistance (62%), with 41% of those on this income level at the time of interview on a Disability Support Pension.

Only 45% of those who reported having no income and 37% of those earning between $1 and $10,399 said that they were receiving government income assistance.

A higher proportion of those living in regional parts of the country indicated they receive assistance (45%, compared to 36% of those living in major cities). Furthermore, a higher proportion of those with severe symptoms receive government income assistance (48%, compared to 33% of those with mild/moderate symptoms). Almost a third (31%) of those with severe symptoms indicated they were on a Disability Support Pension.

Treatments

Impact of increased activity

**Q34 How does increasing your level of exercise/activity make you feel?** (n=586)

Q35 If you feel worse after increasing your activity levels, how long is it before you feel worse? (n=521)

Q36 If you feel worse after increasing your activity levels, how long does it generally take you to recover to your previous level? (n=521)

It is clear from the findings that increasing exercise and/or activity makes most people feel worse. A total of 89% reported feeling worse, with 54% reporting they feel worse straight away and 35% reporting that they initially feel better, but then feel worse later. Very few indicate that this increased exercise approach helps them feel better (5%).

Figure 32 – Impact of increased exercise / activity

How increasing exercise/activity makes you feel

Better, 5%
About the same, 5%
Worse, 54%
Better at first, then worse, 35%
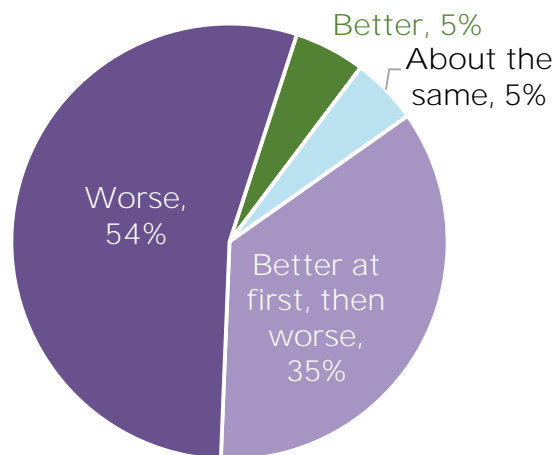
Those who reported their symptoms as severe/ very severe showed a higher incidence of indicating that increasing exercise makes them feel worse.

Figure 33 – Impact of increased exercise / activity by severity of symptoms

Impact of increasing exercise by severity of symptoms

Severe / very severe (n=266): 3% | 26% | 68%
Mild / moderate (n=313): 8% | 6% | 43% | 42%

■ Better   ■ About the same   ■ Better at first, then worse   ■ Worse
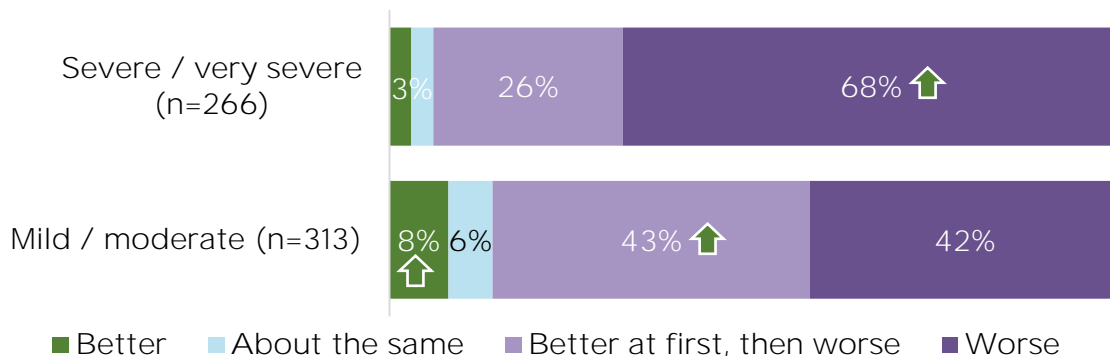
Of those who feel worse from increased exercise / activity, just over a quarter (28%) will do so immediately, whilst for a third (35%) it takes hours to feel worse, and for four in ten (37%) feeling worse will occur 1-2 days later.

Most of those who report that increased exercise/activity makes them feel worse indicate that it takes days to recover (69%), while for others it takes weeks (27%). Only 4% report that they recover in a matter of hours.

A range of notable variations occurred when analysing the data by demographics and symptom related information:

- 40-49 year olds and 50-59 year olds show a higher incidence of reporting that increased exercise makes them feel worse (62% and 59% respectively), compared to 40% 30-39 year olds.
- Males show a higher incidence of reporting that increased activity makes them feel better (12%, compared to 4% females), whilst a significantly higher proportion of females stated that it makes them feel worse (57%, compared to 41% males).

Treatment effectiveness

Q72 For each of the treatment approaches listed below that you have tried, please indicate: (n=610)
- whether it was helpful or not,
- who suggested it, and
- whether you have used it in the last 12 months.

Analysis notes:	Given that there was an instruction in the survey script to leave the cells blank if they had not used a specialist, the findings for this question have been calculated from a base of all respondents, not just those who answered the question. Given it is not possible to identify who skipped this question due to lack of time **versus those who didn't** visit specialists, it is possible that these figures are under-reported.

Most had tried a range of treatments, primarily revolving around rest, supplements, diet and pain medication.

Figure 34 – Treatments tried by more than a quarter of respondents

Incidence of trying a treatment

Treatment	Ever used	Used in 12 months prior to interview
Rest, including bed rest	70%	64%
Vitamin/mineral supplements	68%	59%
Dietary changes	64%	56%
Medication to ease pain	61%	51%
Pacing	57%	52%
Medication to aid sleep	57%	47%
Meditation/Mindfulness	48%	41%
Medication to help mood	43%	28%
Graded Exercise Therapy	37%	24%
Antibiotics	34%	24%
Massage	33%	27%
Naturopath	29%	17%
Acupuncture	28%	16%
Herbal medicine	28%	19%
Cognitive Behaviour Therapy	28%	16%
Other medication	27%	21%

The responses indicate that a wide range of treatments had been tried by participants with varying success rates.

The treatments most commonly rated as very helpful were rest, pacing, and medication for sleep. Rest and pacing were both self-prescribed.


Figure 35 – Most effective treatments

	Very helpful	Recently used	Primary referrer
Rest, including bed rest	60%	64%	56%
Pacing	58%	52%	28%
Medication to aid sleep	40%	47%	46%
Massage	37%	27%	53%
Meditation/Mindfulness	37%	41%	41%
Medication to help mood	36%	28%	55%
Dietary changes	36%	56%	30%

■ Specialist ☐ GP ☐ Self
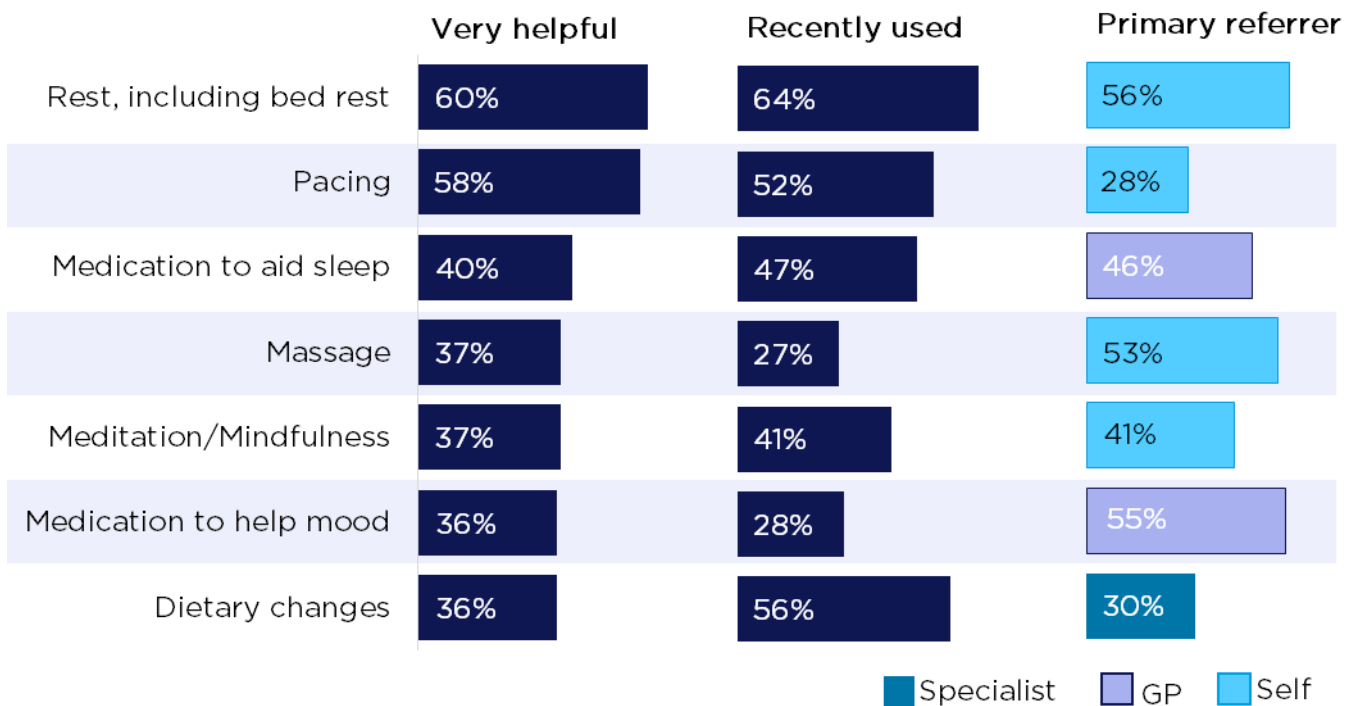
GPs and specialists seldom recommend the top two most effective treatments; rest (17% recommended by GP and 17% by specialist) and/or pacing (9% recommended by GP and 27% by specialist).

The two poorest performing treatments in terms of respondents stating they made things worse; graded exercise therapy (GET, 47% said it made things worse) and graded activity therapy (GAT, 38% said it made things worse) are both most commonly recommended by specialists (39% of referrals for these treatments were from specialists).

Figure 36 – Least effective treatments
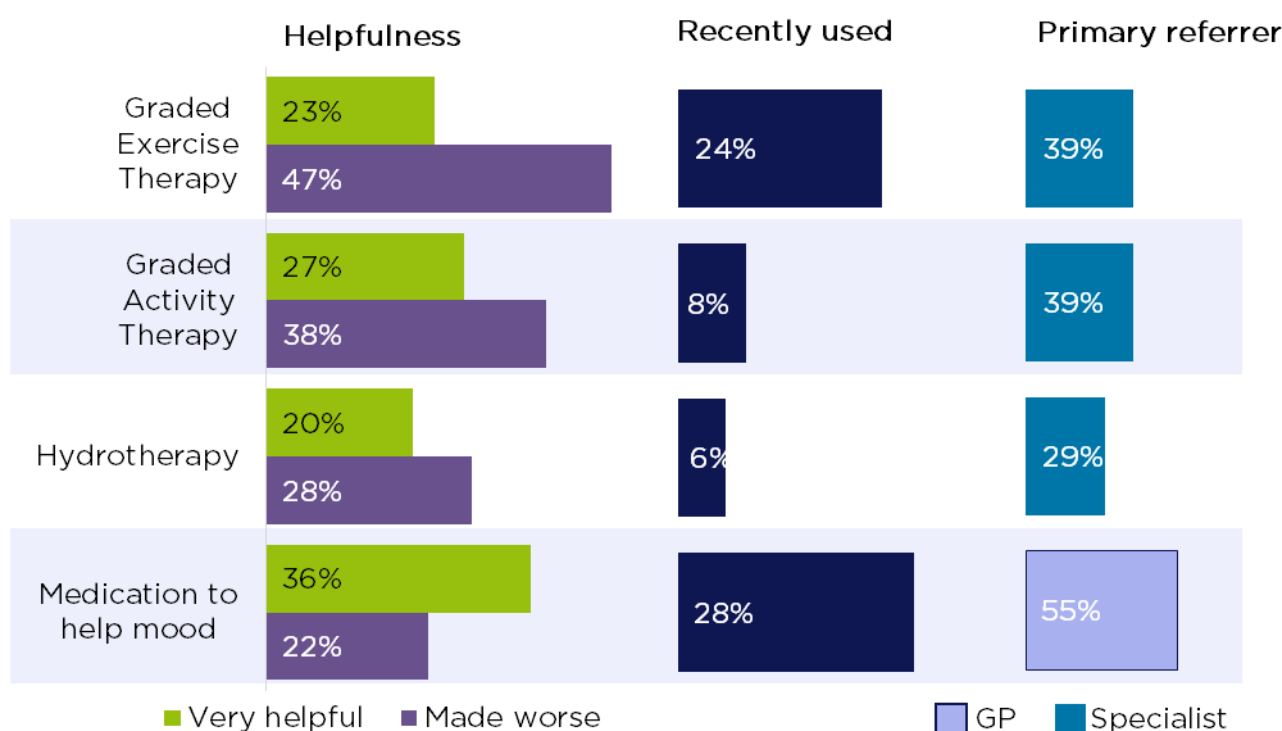
When analysing findings by severity of symptoms, those who self-reported their symptoms as mild/moderate showed higher instances of rating a number of treatments as **very helpful**:

- Medication to help mood (32%, compared to 25% of those with severe/very severe symptoms).
- Pacing (64%, compared to 52% of those with severe/very severe symptoms).
- Dietary changes (42%, compared to 30% of those with severe/very severe symptoms).
- Vitamin/mineral supplements (32%, compared to 21% of those with severe/very severe symptoms). 32% of those with severe/very severe symptoms reported no change (21% mild/moderate).
- Naturopath (34%, compared to 15% of those with severe/very severe symptoms).
- Graded exercise therapy (32%, compared to 16% of those with severe/very severe symptoms).
- Graded activity therapy (50%, compared to 18% of those with severe/very severe symptoms).

Those who self-reported their symptoms as severe/very severe showed higher instances of rating a range of therapies as making their condition **much worse**:

- Exercise on Prescription (53% compared to 15% of those with mild/moderate symptoms).
- Cognitive Behavioural Therapy (13%, compared to 3% of those with mild/moderate symptoms).
- Acupuncture (13%, compared to 2% of those with mild/moderate symptoms).
- Graded Activity Therapy (33%, compared to 9% of those with mild/moderate symptoms).

- Graded Exercise Therapy (42%, compared to 20% of those with mild/moderate symptoms).

The following figure shows findings in terms of the common treatments suggested by each type of provider, as well as the treatment types where that provider tends to be the primary referrer of the treatment.

<p style="text-align:center">Figure 37 – Common treatments by referrer</p>

GPs	
Number of people who indicated a GP as a person who suggested a treatment:	N=387
Top 5 suggested treatments by GPs: *% of all mentions of GPs as the source of a suggested treatment*	Medication to ease pain (40%) Medication to aid sleep (40%) Medication to help mood (35%) Antibiotics (35%) Vitamin/mineral supplements (24%)

Self	
Number of people who indicated self as a person who suggested a treatment:	N=380
Top 5 suggested treatments by self: *% of all mentions of self as the source of a suggested treatment*	Rest, including bed rest (59%) Meditation / mindfulness (30%) Massage (28%) Pacing (24%) Dietary changes (24%)

Specialist	
Number of people who indicated a specialist as a person who suggested a treatment:	N=312
Top 5 suggested treatments by specialist: *% of all mentions of specialist as the source of a suggested treatment*	Medication to aid sleep (38%) Dietary changes (36%) Medication to ease pain (34%) Vitamin/mineral supplements (30%) Pacing (29%)

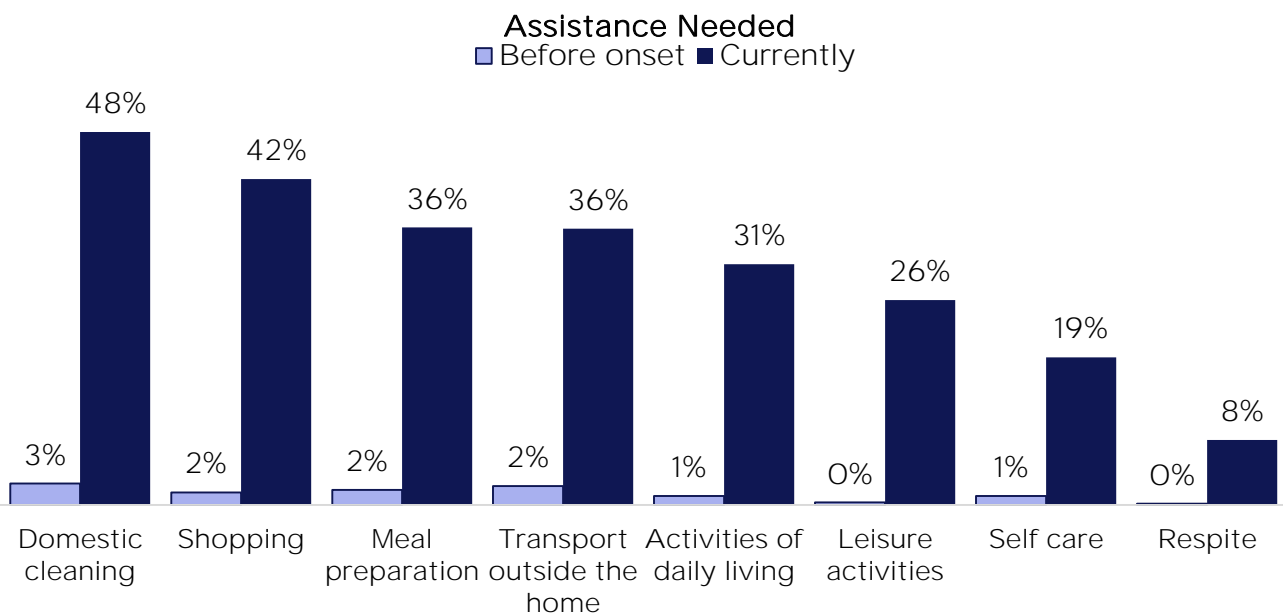| Alternative therapist	
Number of people who indicated an alternative therapist as a person who suggested a treatment:	N=236
Top 5 suggested treatments by alternative therapist: *% of all mentions of alternative therapist as the source of a suggested treatment*	Herbal medicine (40%) Vitamin/mineral supplements (38%) Naturopath (32%) Dietary changes (295) Acupuncture (25%)

Support

Need for assistance

Q83 Have you needed help for the following? (n=610)

Analysis notes:	As this question was not mandatory and didn't capture 'none', the assumption has been made that those who didn't answer don't need support. This is not explicitly stated and therefore cannot be considered to be correct; however to analyse this data on just those who answered the question runs the risk of significantly overstating needs.

Very few people indicated that they needed assistance before onset of symptoms. However, at the time of survey many indicated they require assistance with common household duties.

Figure 38 – Assistance needed

Assistance Needed
□ Before onset ■ Currently

Category	Before onset	Currently
Domestic cleaning	3%	48%
Shopping	2%	42%
Meal preparation	2%	36%
Transport outside the home	2%	36%
Activities of daily living	1%	31%
Leisure activities	0%	26%
Self care	1%	19%
Respite	0%	8%

Mirroring the impact of onset of symptoms on employment, the need for assistance arises within the first year after onset of symptoms.

As would be expected, higher proportions of those with severe symptoms specified a current need for assistance with a range of activities.

Those with severe or very severe symptoms show a higher incidence of needing assistance with all listed activities, with the top five in order of priority being domestic cleaning, shopping, transport, meal preparation and activities of daily living.

Figure 39 – Assistance needed by severity of symptoms

Current assistance needed by severity of symptoms

■ Mild / moderate   ■ Severe / very severe

	Severe / very severe	Mild / moderate
Domestic cleaning	66%	36%
Shopping	62%	28%
Transport outside the home	58%	19%
Meal preparation	56%	21%
Activities of daily living	48%	19%
Leisure activities	39%	17%
Self care	31%	11%
Respite	14%	4%
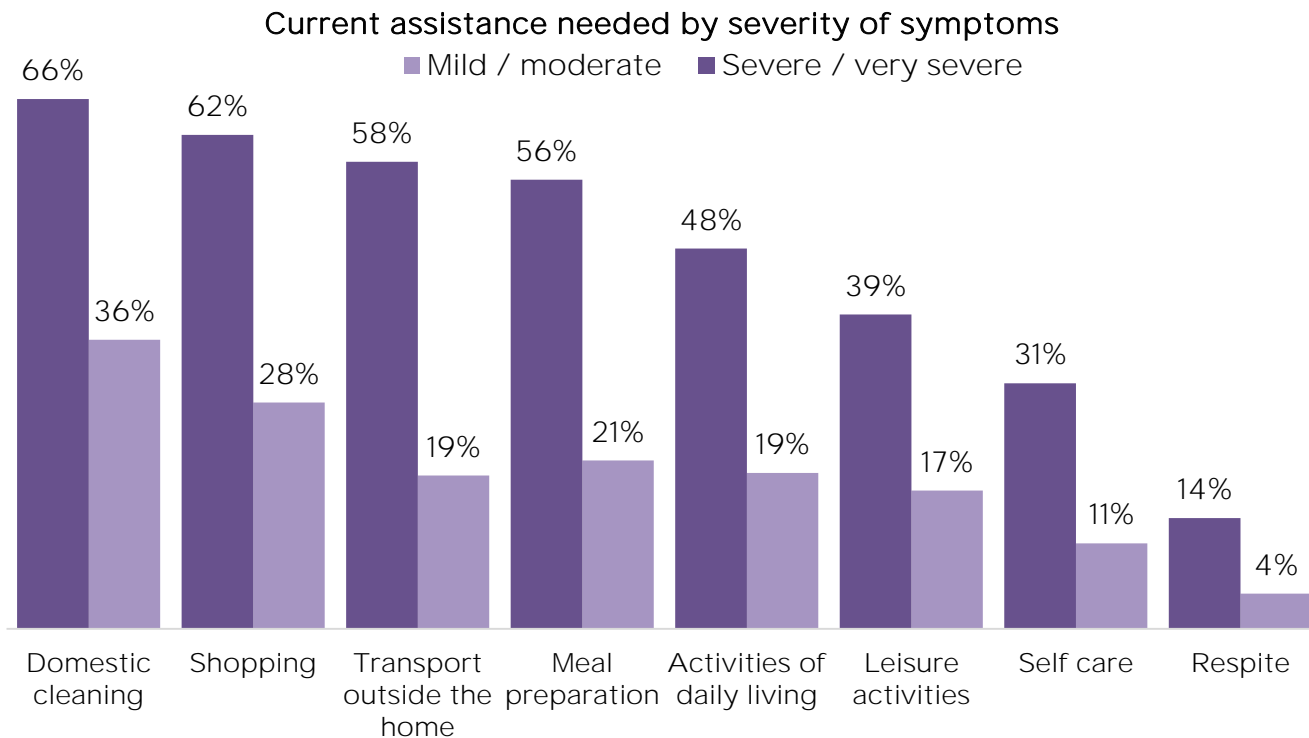
Carers

Q85 If you receive care from someone to help you with any of the above, what is their relationship to you? (n=413)

Q86 If your main carer is a family member, what is their relationship to you? (n=315)

Q87 If your main carer is a friend or family member, do they receive a carer's allowance? (n=320)

Analysis notes:	Q85 Includes multiple responses. To assess the proportion of the entire sample who has a carer, percentages for Q85 are calculated using the full sample (n=610) as a base. This is assuming those who didn't provide an answer don't have a carer, however the survey was not structured to capture that answer, therefore the findings may not be accurate.

Family members are the most common caregivers for those with ME/CFS, with 88% of those who indicated that they have received care in the past, or at the time of interview, citing family as the provider of that care. Just over six in ten (68%) of the entire sample have received care from someone for their ME/CFS.

Figure 40 – Carer relationship
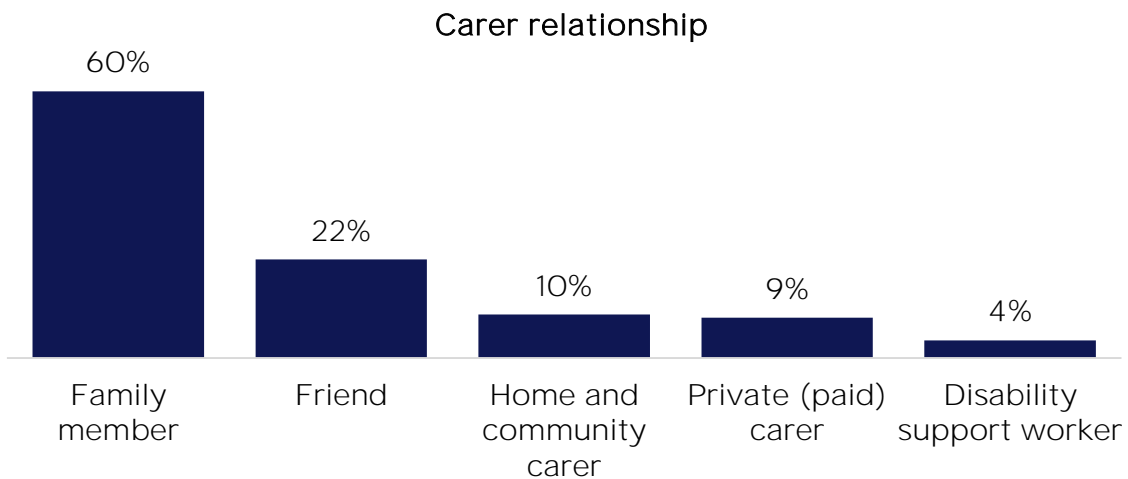
Family carers are most commonly partners (61%) or parents (35%). Only 13% of family carers receive a carers allowance.

Those who self-reported their symptoms as severe or very severe show a higher instance of having received care from a home and community carer (16%) than those with mild/moderate symptoms (5%).

Disability support services

Q88 What government funded disability support services have you accessed, if any? (n=148, calculated percentages using whole sample, n=610)

Q90 Have you ever applied for a Disability Support Pension or Sickness Allowance? (n=495, calculated percentages using whole sample, n=610)

Q91 Were you successful in obtaining Disability Support Pension or Sickness Allowance? (n=293)

Analysis notes:	As this question was non-compulsory we have expanded the base for analysis out to the full sample to ensure an accurate representation of the proportion of respondents who have accessed services. This is making an assumption that those who did not complete the question (300 people) skipped it because they don't access these services. Calculating the figure in this way may have resulted in understated figures.

Just over one in ten of the sample indicated that they have accessed the Disability Support Pension.

Figure 41 – Government funded disability support services

Govt funded disability support services
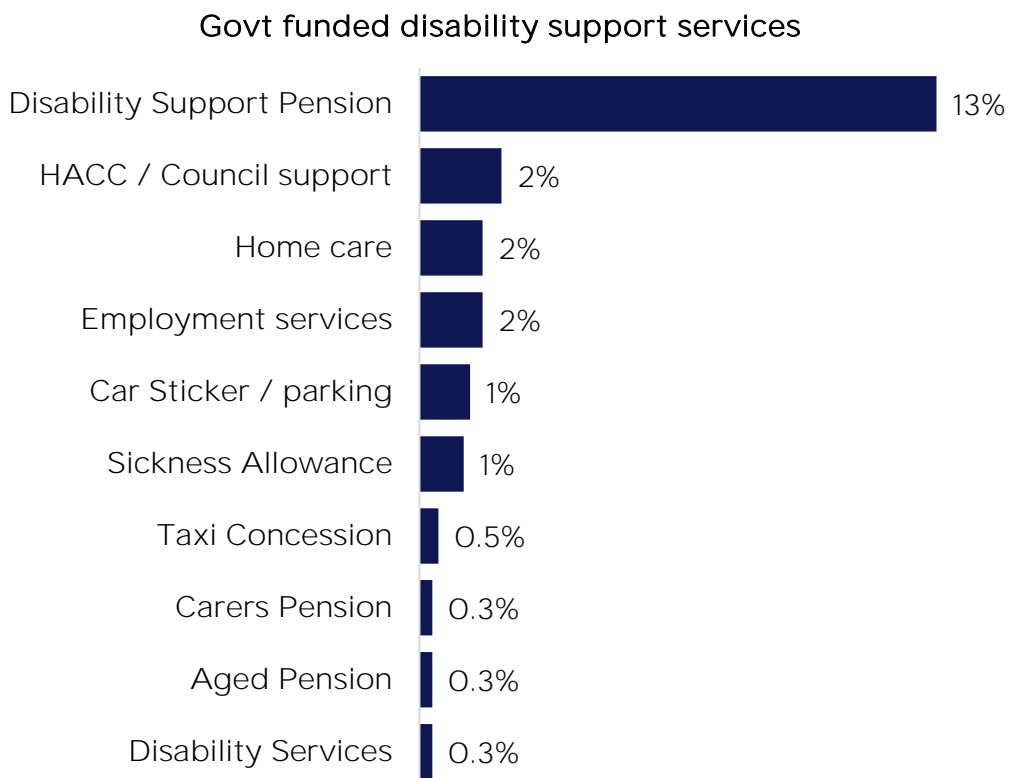
A higher proportion of those who reported severe/very severe symptoms indicated they were receiving government funded disability support services (31%, compared to 20% of those with mild/moderate symptoms). HACC/council services were more commonly accessed by those with severe/very severe symptoms (4%, compared to 1% of those with mild/moderate symptoms).

Almost half (49%) indicated they had ever applied for Disability Support Pension or sickness allowance, increasing to 63% of those with severe/very severe symptoms.

When asked how many times they had tried applying, only 160 respondents answered this question, of whom 38% had applied more than once. Four in five (85%) of the 293 people who specified an outcome for their DSP sickness allowance application indicated that their application had been successful.

At the time of undertaking the survey, the National Disability Insurance Scheme (NDIS) had not been introduced. Future surveys should include data on NDIS applications.

Benefit application advice

Q92 Were you able to find useful advice about applying for this benefit/s? If so, where? (n=322)

Q93 Was your GP helpful when it came to providing supporting evidence for your application/appeal? (n=296)

Analysis notes: Results include multiple responses.

Many prepared their application without any support. Those who received support mostly did so through healthcare professionals and/or GPs. Just over one in ten (13%) of those who answered this question said that they had received support in some way from Emerge Australia.

Figure 42 – Benefit application advice

Sources of benefit application advice

Source	Percentage
No support/advice available	46%
Healthcare practitioners	26%
GP	15%
Centrelink	12%
Other organisation	11%
Online support groups	10%
Emerge factsheets	9%
Specialist	7%
Emerge info line	6%
Other advice agency	4%
Misc internet	1%
Emerge (general)	1%
Support group	1%

Four out of five (84%) of those for whom the question was applicable indicated that their GP was helpful with their application.

Less than one in ten (7%) of the sample indicated they had faced difficulties with accessing superannuation.

Sources of information on ME/CFS

Q99 What are your major sources of information and support for ME/CFS?
(n=499)

Online groups are a key resource for people finding information about ME/CFS. The Emerge Journal was also mentioned by almost a quarter of those who answered this question, and 27% selected one or more Emerge related options. It should be borne in mind that given this survey was promoted through the Emerge Journal, this would almost certainly skew responses regarding this resource.

Figure 43 – Sources of information about ME/CFS

Major sources of info on ME/CFS

Source	Percentage
Online groups	35%
Emerge Journal	23%
Health professionals	23%
Internet	18%
Books	11%
Friends / family	5%
Emerge (general & internet)	4%
Friends	4%
Support group	3%
Medical Journals	2%
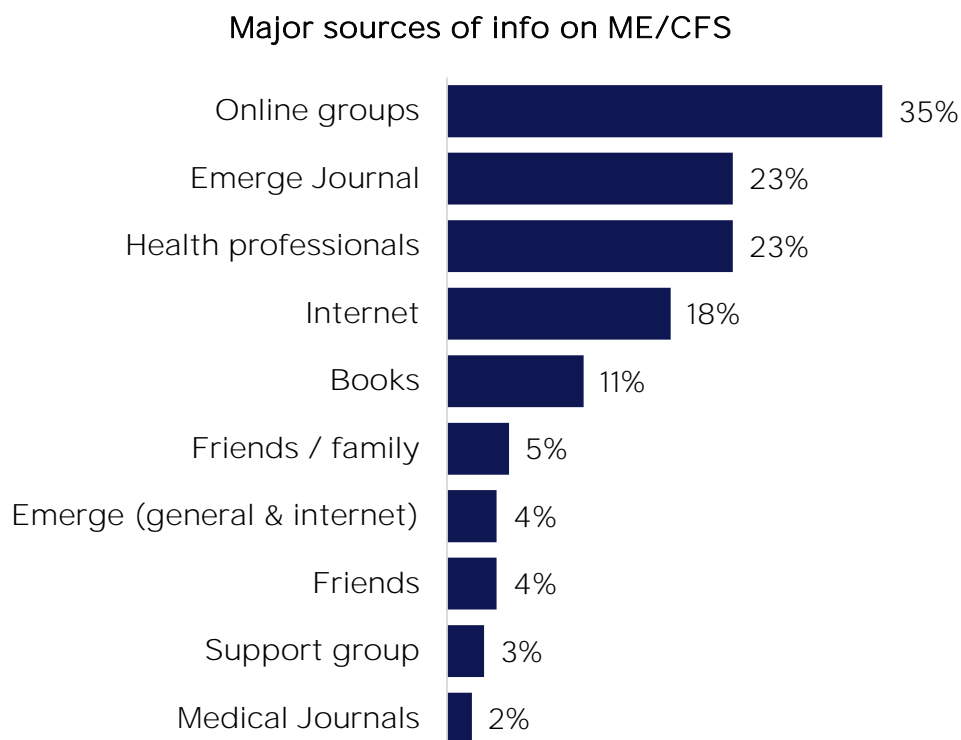
APPENDICES

The following is the full survey with text as written in the online form. A subset of these questions were analysed for this report. The following questions have been presented as written in the online survey. A range of suggestions to improve wording and structure have been made in the next section (Appendix 3). Programming instructions to signify the question type and other structural features have been included in [ALLCAPS].

Demographics

Q1. **Which state do you live in?** [SINGLE RESPONSE]
Victoria
Tasmania
Northern Territory
New South Wales
Queensland
South Australia
Australian Capital Territory
Western Australia
NA - Living overseas (please specify country) [TEXT BOX]

Q2. **What is your postcode?** [TEXT BOX]

Q3. **How would you describe your locality?** [SINGLE RESPONSE]
Major city (inner)
Major city (outer)
Regional area
Rural area
Remote area

Q4. **What is your date of birth?** [DAY / MONTH / YEAR]

Q5. **Do you identify as:** [SINGLE RESPONSE]
Male
Female
Other

Q6. **Were you born in Australia?** [SINGLE RESPONSE]
Yes
No
[OTHER BOX] If not, please tell us your country of birth and year of arrival in Australia

Q7. **Is English the primary language spoken in your household?** [SINGLE RESPONSE]
Yes
No
[OTHER BOX] If not, please tell us the primary language

Q8. **Do you identify as Aboriginal and/or Torres Strait Islander?** [SINGLE RESPONSE]
Yes, Aboriginal
Yes, Torres Strait Islander
Yes, Aboriginal and Torres Strait Islander
No

Q9. **What is your current relationship status?** [SINGLE RESPONSE]
Married
Partnered (living together in an opposite-sex or same-sex relationship, including de facto)
Committed relationship not living together
Separated (previously lived with an opposite-sex or same-sex partner, including in a marriage, registered or de facto relationship)
Divorced
Widowed
Never married or lived with a partner
Other
[OTHER BOX] Has your ME/CFS had an effect on this status?

Q10. **Do you have any children?** [SINGLE RESPONSE]
Yes
No (skip to next section)
[OTHER BOX] If yes, how many?

Q11. **Of those, how many are under the age of 18?** [TEXT BOX]

Q12. **How many are currently living with you?** [TEXT BOX]

Q13. **Does your ME/CFS have an impact on this?** [TEXT BOX]

Diagnosis
Q14. **Have you been diagnosed?** [SINGLE RESPONSE]
Yes
No

Q15. **What is your diagnosis?**
Please note this question is only about ME/CFS, not any additional illnesses you may have. [MULTIPLE RESPONSE]
ME (myalgic encephalomyelitis)
CFS (chronic fatigue syndrome)
ME/CFS
PVFS (post-viral fatigue syndrome)
Other (please specify) [TEXT BOX]

Q16. **Who were you diagnosed by?** [SINGLE RESPONSE]
GP
ME/CFS clinic or specialist
I diagnosed myself
No formal diagnosis
Allied Health Professional (please specify)
Other (please specify)
[OTHER BOX] Please specify here for the options Allied Health Professional or Other

Q17. **When did you obtain your diagnosis?**
Month (MM) [TEXT BOX]
Year (YYYY) [TEXT BOX]

Q18. **When did you first notice the symptoms of ME/CFS?**
Month (MM) [TEXT BOX]
Year (YYYY) [TEXT BOX]

Q19. **Did you have a gradual or sudden onset?** [SINGLE RESPONSE]
Gradual
Sudden

Q20. **What is your understanding of why your symptoms started? Were there any triggers?** [TEXT BOX]

Q21. **How many and what kind of health professionals did you see between noticing symptoms and obtaining an ME/CFS diagnosis?** [TEXT BOX]

Q22. **What diagnostic tests did you undergo to obtain your ME/CFS diagnosis?** [TEXT BOX]

Q23. **Could you please describe your experience of obtaining a diagnosis?** [TEXT BOX]

Q24. **Were you diagnosed with other conditions between noticing symptoms and obtaining an ME/CFS diagnosis? If so, which conditions?** [TEXT BOX]

Q25. **Do you currently have any other conditions as well as your ME/CFS? If so, which conditions (eg Fibromyalgia, Multiple Chemical Sensitivities, Irritable Bowel syndrome, Sjogren's syndrome, Interstitial cystitis, etc.)?** [TEXT BOX]

Q26. **Is there anyone else in your family currently or previously with ME/CFS? If so, who?** [TEXT BOX]

Q27. **Do/did any of your family members suffer from another chronic illness other than ME/CFS?**
Please state their relationship and illness. [TEXT BOX]

Physical symptoms and impacts

Q28. **Please tell us what level your symptoms have been at for the past three months.** [SINGLE RESPONSE]
Mild: you have a significant reduction in activity levels compared to pre-illness
Moderate: you have an approximately 50% reduction in activity levels compared to pre-illness
Severe: you are mostly housebound
Very severe: you are mostly bedbound and require assistance with daily functions
[OTHER BOX] How long have your symptoms been at this level?

Q29. **Which of your symptoms are the worst?** [TEXT BOX]

Q30. **Which of your symptoms is the most frequent?** [TEXT BOX]

Q31. **Which ONE of your symptoms impacts most strongly on your life?** [TEXT BOX]

Q32. **What impact have your symptoms had on your life?** [GRID – SINGLE RESPONSE PER ROW]

[COLUMNS]
Strong impact/Stopped
Some impact/Reduced
No impact
N/A

[ROWS]
Participation in paid work
Undertaking education
Caring roles
Performing household tasks
Social contact
Participation in sports and hobbies
Voluntary roles
Decision to have children
Career choices/development
Emotional wellbeing
Capacity to provide emotional/practical support to others
Requiring full/part time care
Leaving your home independently
Capacity to drive

[OTHER BOX] Please tell us a bit more about any of the above:

Q33. **Have there been any other impacts not covered above?** [TEXT BOX]

Q34. **How does increasing your level of exercise/activity make you feel?** [SINGLE RESPONSE]
Better
Better at first,
About the same
Worse

Q35. **If you feel worse after increasing your activity levels, how long is it before you feel worse?** [SINGLE RESPONSE]
Immediately
Hours later
1-2 days later

Q36. **If you feel worse after increasing your activity levels, how long does is it generally take you to recover to your previous level?** [SINGLE RESPONSE]
Hours
Days
Weeks

Employment and education

Q37. **In relation to the following statements, please select all those that apply to you at the stated time periods** [GRID – MULTIPLE RESPONSE PER COLUMN]
[COLUMNS]
Currently
Before onset
1 year after onset
2-5 years after onset
6-9 years after onset
10+ years after onset
[ROWS]
Not in work, training or education
In part-time paid work
In full-time paid work
Volunteering part-time
Volunteering full-time
In part-time education or training
In full-time education or training
Self-employed
Household duties
Parenting duties
Carer
NA
Other
[OTHER BOX] Other (please specify)

Q38. **What was your estimated annual income level from employment at the following times?** [GRID – MULTIPLE RESPONSE PER COLUMN]
[COLUMNS]
Currently
Before onset
1 year after onset
2-5 years after onset
6-9 years after onset
10+ years after onset
[ROWS]
No income
$1 to $10,399
$10,400 to $15,599
$15,600 to $20,799
$20,800 to $31 999
$31 200 to $41 599
$41,500 to $51,999
$52 000 to $64 999
$65,000 to $77,999
$78,000 to $103,999
$104,000 or more
NA

Q39. If currently employed, does your employer know you have ME/CFS? [SINGLE RESPONSE]
Yes, because I told them
Yes, because I asked somebody to tell them
Yes, because they found out
No
Not sure
Not applicable

Q40. What specialist support have you received at your current work/education facility, if any?
Please also describe the attitude of your employer/educator towards providing support [TEXT BOX]

Q41. What difficulties have you encountered in your workplace/education facility in relation to your ME/CFS? [TEXT BOX]

Q42. What has helped you to have a positive experience in your workplace/education facility? [TEXT BOX]

Q43. Do you receive government income assistance? Select all that apply (Disability pension and sickness allowance will be covered later) [MULTIPLE RESPONSE]
None
Youth Allowance
Newstart Allowance
Austudy
Parenting Payment
Other (please specify) [TEXT BOX]

Social impacts

Q44. Please tell us a little about the effect you having M.E./CFS has had on those close to you, eg. family, friends, colleagues and employer. [TEXT BOX]

Q45. Evaluate the following statements. [GRID – SINGLE RESPONSE PER ROW]
[COLUMNS]
None
One
Two
Three or four
Five to eight
Nine or more
[ROWS]
FAMILY: Considering the people to whom you are related by birth, marriage, adoption, etc... How many relatives do you see or hear from at least once a month?
How many relatives do you feel at ease with that you can talk about private matters?
How many relatives do you feel close to such that you could call on them for help?
FRIENDSHIPS: Considering all of your friends including those who live in your neighbourhood How many of your friends do you see or hear from at least once a month?
How many friends do you feel at ease with that you can talk about private matters?

How many friends do you feel close to such that you could call on them for help?

Q46. **Mood, worries and stress.**
Please read each statement and choose a number 0, 1, 2 or 3 which indicates how much the statement applied to you over the past week. There are no right or wrong answers. Do not spend too much time on any statement.
The rating scale is as follows:
0 Did not apply to me at all - NEVER
1 Applied to me to some degree, or some of the time - SOMETIMES
2 Applied to me to a considerable degree, or a good part of time - OFTEN
3 Applied to me very much, or most of the time - ALMOST ALWAYS
[GRID – SINGLE RESPONSE PER ROW]
[COLUMNS]
0
1
2
3
[ROWS]
I found it hard to wind down
I was aware of dryness of my mouth
I couldn't seem to experience any positive feeling at all
I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)
I found it difficult to work up the initiative to do things
I tended to over-react to situations
I experienced trembling (eg, in the hands)
I felt that I was using a lot of nervous energy
I was worried about situations in which I might panic and make a fool of myself
I felt that I had nothing to look forward to
I found myself getting agitated
I found it difficult to relax
I felt down-hearted and blue
I was intolerant of anything that kept me from getting on with what I was doing
I felt I was close to panic
I was unable to become enthusiastic about anything
I felt I wasn't worth much as a person
I felt that I was rather touchy
I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)
I felt scared without any good reason
I felt that life was meaningless

Experience with healthcare professionals
GP

Q47. **How many times in the past 12 months have you seen your GP about your ME/CFS? If you have not seen a GP in the last 12 months, when was the last time you were seen by a GP?** [TEXT BOX]

Q48. On a scale of 1 to 5, where 1 is very poor and 5 is very well, how well-informed do you feel your GP is about ME/CFS? [TEXT BOX]

Q49. On a scale of 1 to 5, where 1 is very poor and 5 is very well, how sympathetic is do you feel your GP is to ME/CFS? [TEXT BOX]

Q50. On a scale of 1 to 5, where 1 is very poor and 5 is very good, how do you rate the service your GP provides to you regarding your ME/CFS? [TEXT BOX]

Hospital

Q51. How many times in the past 12 months have you been to hospital because of your ME/CFS? [TEXT BOX]

Q52. How many times in the past 12 months have you been to hospital not as a result of your ME/CFS? [TEXT BOX]

Q53. On a scale of 1 to 5, where 1 is very poor and 5 is very well, how well-informed do you feel hospital staff were about ME/CFS? [TEXT BOX]

Q54. On a scale of 1 to 5, where 1 is very poor and 5 is very well, how respectful do you feel hospital staff were about ME/CFS? [TEXT BOX]

Emergency

Q55. How many times in the past 12 months have you been to the emergency department because of your ME/CFS? [TEXT BOX]

Q56. How many times in the past 12 months have you been to the emergency department for a reason other than your ME/CFS? [TEXT BOX]

Q57. On a scale of 1 to 5, where 1 is very poor and 5 is very well, how well-informed do you feel emergency department staff were about ME/CFS? [TEXT BOX]

Q58. On a scale of 1 to 5, where 1 is very poor and 5 is very well, how respectful do you feel emergency department staff were about ME/CFS? [TEXT BOX]

ME/CFS Clinic

Q59. Have you ever been to an ME/CFS clinic to see a specialist? [SINGLE RESPONSE]
Yes
No

Q60. Was the clinic in your local area? [SINGLE RESPONSE]
Yes
No

Q61. In months, how long was the waiting period for an initial appointment? [TEXT BOX]

Q62. How many times in the past 12 months have you been to an ME/CFS clinic to see a specialist? [TEXT BOX]

Q63. On a scale of 1 to 5, where 1 is very poor and 5 is very good, how do you rate the service your ME/CFS clinic provided to you? [TEXT BOX]

Q64. **The table below offers a list of specialists you may have seen about your ME/CFS.** Please tell us:

a. how many times in the past 12 months you have seen them

b. how well-informed you feel they were about ME/CFS (1 = very poor, 5 = very good)

c. how you rate the service they provided regarding ME/CFS (1 = very poor, 5 = very good)

Note: If you have not used that type of specialist, please leave responses blank

[GRID – DROP-DOWN LISTS]

[COLUMN 1 – Times seen in past 12 months]	[COLUMN 2 – How well informed]	[COLUMN 3 – Service provided]
Once	Very poor	Very poor
Twice	Poor	Poor
3 to 5 times	Neither	Neither
6 to 9 times	Well	Good
10 plus times	Very well	Very good
None		

[ROWS]
Cardiologist
Clinical psychologist
Dietitian
Endocrinologist
Gastroenterologist
Immunologist
Neurologist
Occupational therapist
Osteopath
Paediatrician
Physiotherapist
Psychiatrist
Other
[OTHER BOX] Please specify (other)

Q65. **What would make a real difference to your healthcare?** (Select all that apply)

[MULTPLE RESPONSE]
Telephone/internet health services
Medicare rebate for telephone/internet health professional consultations
Home visits by healthcare professionals
Better informed GP
More effective medication
Having more of a say in your treatment
Other (please specify) [TEXT BOX]

Q66. What barriers have you experienced in accessing services (GP/specialist clinic/consultant) for ME/CFS?
(Select all that apply) [MULTPLE RESPONSE]
Too ill
Lack of specialist in my area
Distance/travel time
Lack of follow up/ongoing care
Lack of transport to service
Cost of transport
Lack of parking close to services
Cost of services
Long waiting times for treatment/symptom management or referral
Length of treatment session(s)
Didn't want to use any of the services on offer
Lack of information about services
Lack of knowledge about ME/CFS by service provider
Stigma
Other (please specify) [TEXT BOX]

Q67. What has helped you overcome these barriers? [TEXT BOX]

Q68. What could help you overcome these barriers? [TEXT BOX]

Q69. Have you ever let anyone know about good treatment you have received?
[SINGLE RESPONSE]
No
Yes
[OTHER BOX] Who?

Q70. Have you ever made a formal complaint about treatment you have received for your ME/CFS? [MULTPLE RESPONSE]
No
Yes, about my GP
Yes, about the specialist ME/CFS clinic I attended
Yes, about the consultant I saw
Yes, about an allied health professional (please specify below)
Yes, about an alternative health provider (please specify below)
Yes, other (please specify below)
[OTHER BOX] Specify here

Q71. If the answer was yes, how satisfied were you with the response you got?
[SINGLE RESPONSE]
Very satisfied
Satisfied
Neither satisfied nor dissatisfied
Unsatisfied
Very unsatisfied

Managing your symptoms

Q72. **For each of the treatment approaches listed below that you have tried, please indicate:**
- whether it was helpful or not,
- who suggested it, and
- whether you have used it in the last 12 months.

If you have not tried the approach, please leave the responses blank.

[GRID – DROP-DOWN LISTS]

[COLUMN 1 – Was it helpful?]	[COLUMN 2 – Who suggested it?]	[COLUMN 3 – Used in past 12 months?]
Very helpful	GP	Regularly
Helped a little	Specialist	Occasionally
Made a little worse	Alternative therapist	Rarely
Made much worse	Counsellor	Once
No change	Internet	No
	Self	
	Other person	

[ROWS]
Medication to ease pain
Medication to aid sleep
Medication to help mood
Other medication, eg. for nausea
Pacing
Graded Exercise Therapy (GET)
Graded Activity Therapy (GAT)
Exercise on Prescription (EOP)
Rest, including bed rest
Dietary changes
Vitamin/mineral supplements
Cognitive Behaviour Therapy (CBT)
Emotional Freedom Technique
Gupta programme
Lightning process
Relaxation training
Meditation/Mindfulness
Mickel therapy
Neurological Linguistic Programming (NLP)
Massage, inc. lymphatic drainage
Perrin technique
Acupuncture
Aromatherapy
Herbal medicine
Homeopathy
Hydrotherapy
Kinesiology
Naturopath
Oxygen therapy
Other (please specify)

[OTHER BOX] Other (please specify)

Q73. **Please tell us a bit more about how these approaches affected you.** [TEXT BOX]

Q74. **Please describe your relationship with the healthcare professional you have seen most frequently for the treatments indicated above.** [TEXT BOX]

Healthcare costs

Q75. **How much would you spend in an average month on traditional medical appointments (GP/specialist etc) to manage your symptoms?** [TEXT BOX]

Q76. **How much would you spend in an average month on medication to manage your symptoms?** [TEXT BOX]

Q77. **How much would you spend in an average month on alternative therapy to manage your symptoms?** [TEXT BOX]

Q78. **What percentage of your average monthly medical costs are covered by:**
Medicare? [TEXT BOX]
Private health insurance? [TEXT BOX]
Self (or family/friends/carer)? [TEXT BOX]

Q79. **Do you have private health insurance?** [SINGLE RESPONSE]
No (skip to next page)
Yes

Q80. **If yes, was this obtained before or after your diagnosis with ME/CFS?** [SINGLE RESPONSE]
Before
After

Q81. **If obtained after diagnosis, did you encounter any difficulties in obtaining an insurance policy due to your ME/CFS diagnosis?** [SINGLE RESPONSE]
No
Yes
[OTHER BOX] Please specify

Q82. **Have you encountered any difficulties in claiming expenses from your health insurance?** [SINGLE RESPONSE]
No
Yes

[OTHER BOX] Please specify

Support services

Q83. **Have you needed help for the following?** (Please select all that apply for the time periods provided) [GRID – MULTIPLE OPTIONS PER COLUMN]
[COLUMNS]
Currently
Before onset
1 year after onset
2-5 years after onset
6-9 years after onset
10+ years after onset

[ROWS]
Self care
Meal preparation
Transport outside the home
Domestic cleaning
Shopping
Activities of daily living
Respite
Leisure activities
[OTHER BOX] Other (please specify)

Q84. **What are the average monthly costs of this care?** [TEXT BOX]

Q85. **If you receive care from someone to help you with any of the above, what is their relationship to you?** (Select all that apply) [GRID - MULTIPLE RESPONSE PER COLUMN]
[COLUMNS]
Currently
Ever
[ROWS]
Family member
Friend
Home and community carer
Private (paid) carer
Disability support worker
[OTHER BOX] Other (please specify)

Q86. **If your main carer is a family member, what is their relationship to you?** [TEXT BOX]

Q87. **If your main carer is a friend or family member, do they receive a carer's allowance?** [SINGLE RESPONSE]
Yes
No
Not sure

Q88. **What government funded disability support services have you accessed, if any?** [TEXT BOX]

Q89. **What non-government or community based disability support services have you accessed, if any?** [TEXT BOX]

Q90. **Have you ever applied for a Disability Support Pension or Sickness Allowance?** [SINGLE RESPONSE]
Yes
No
Not sure
[OTHER BOX] If yes, how many times?

Q91. **Were you successful in obtaining Disability Support Pension or Sickness Allowance?** [SINGLE RESPONSE]
Yes
No
Awaiting decision

Q92. **Were you able to find useful advice about applying for this benefit/s? If so, where?** [MULTIPLE RESPONSE]
No support/advice available
Emerge Australia factsheets
Emerge Australia information line
Other organisation (please specify below)
Other advice agency (please specify below)
Healthcare practitioners (please specify below)
Online support groups, including Facebook groups
[OTHER BOX] Please specify here

Q93. **Was your GP helpful when it came to providing supporting evidence for your application/appeal?** [SINGLE RESPONSE]
Yes
No
Not applicable
[OTHER BOX] Comments

Q94. **What has been your experience of dealing with Centrelink during the claim process?** [TEXT BOX]

Q95. **Have you ever accessed government employment services for help to find/secure employment?** [SINGLE RESPONSE]
Yes
No (skip to end)

Q96. **Was this through being on a disability pension or other government payment?** [SINGLE RESPONSE]
Disability pension
Other
[OTHER BOX] Please specify

Q97. **How was this experience for you?** [TEXT BOX]

Q98. **Have you experienced any difficulties in accessing Superannuation?** [SINGLE RESPONSE]
No
Yes
[OTHER BOX] If yes, please describe

Accessing information

Q99. **What are your major sources of information and support for ME/CFS?** [SINGLE RESPONSE]

Friends
Health professionals
Online groups
Books
Emerge journal
Other (please specify) [TEXT BOX]

Q100. **What is your experience with the internet/email?** [SINGLE RESPONSE]

Use it for information/advice/support
Seldom use it because it brings on symptoms
Too sick to use it
Never learnt to use it
Can't afford it

Finally...

Q101. **What was your experience like filling out this survey?** [TEXT BOX]

Q102. **Is there anything you would like to tell us about your condition that has not been covered by this survey?** [TEXT BOX]

Appendix 2: Data cleaning and processing parameters

A total of 774 records were provided. Through the data cleaning process a number of records were removed as per the following specifications:

- Removed those who indicated they live outside of Australia (25 records).
- Removed 139 records where no questions were answered beyond demographics.

Question-specific transformations

Question	Transformation
Q6	If they had written in a Country other than Australia, but hadn't selected an option for Q6, we populated Q6 with the 'outside of Australia' option.
Q16	For Q16 (who were you diagnosed by), those who entered additional information in the other specify box were coded into a number of new answer options.
Q15	Those who entered additional information in the other specify box were coded into a number of new answer options. Data was cleaned so that those with both ME and CFS were only recorded in the ME/CFS code (not the singular ME and CFS codes as well). As a result, those falling within the CFS standalone answer don't have ME as well, and likewise those who fall within the ME standalone answer don't have CFS as well.
Q17-19	Data was recorded as year and month of first symptom and year and month of diagnosis. Given that over 150 respondents provided a year for these questions but not a month, the duration between symptoms and diagnosis was calculated using the year variable only. Time since diagnosis and Time since symptoms was calculated as at the year of survey (2015) based on the year variable. Manual corrections were made to the data file where the respondent entered a year in the month field, switched onset and diagnosis (diagnosis date was before onset), or clearly entered in an error for year (99 instead of 1999, or 1005 instead of 2005).
Q28	To assist with analysis of other findings in the survey, those who said severe or very severe have been grouped together, as have those who said mild or moderate.
Q31	Answers were recorded as free-text and then coded for ease of analysis. Data was manually cleaned to provide a single answer as best as possible. This included reviewing answers to Q29 and Q30 (when 'as previous' was stated), or categorising by the first response provided.
Q32	Degree of impact has been calculated with 'not applicable' removed from the calculation.

Question	Transformation
Q34-36	Responses were removed from Q35 and Q36 if the respondent had specified in Q34 that increased exercise makes them feel better or about the same (Q35 and Q36 were targeted at just those who feel worse).
Q37	A number of people selected both 'in work/education' options as well as the 'not in work, training or education' option in a column. Where this was the case the 'not in work, training or education' entry for that respondent has been removed.
Q38	Question was recorded as a multiple response when it should have been a single response per column. Data was transformed so that there was a single answer per column. Where respondents had provided more than one answer, the response of highest value was accepted.
Q39	Removed data for records where the respondent indicated in Q38 that their 'current' situation was self-employed or not currently employed.
Q43	Where respondents had selected a valid option as well as 'none', the entry for 'none' was removed.
Q48-50	Calculated the proportion of GPs who were rated as uninformed + not sympathetic + poor service rating. For Q49 the answer codes were given more meaningful labels so that the results make sense (very poor sympathetic and very well sympathetic doesn't make sense).
Q64	Given that it is clear from the data that some people only provided an answer for those specialists who were relevant to them, the incidence of specialist visitation has been calculated as proportion of all respondents. Variables have been generated to specify any visitation to a specialist in the 12 months prior to interview.
Q65	Comments entered in the other specify box were thematically grouped into a number of new answer options.
Q66	Comments entered in the other specify box were thematically grouped into a number of new answer options.
Q72	Generated a variable that shows the incidence of respondents selecting an answer for any of the three questions associated with each type of treatment in the list. This enables the generation of a chart to show the incidence of people having tried a treatment.
Q83	Given this question didn't have a 'none' option it has been assumed that those who didn't answer the question skipped it due to lack of relevance.
Q85-87	A net of mentions of 'current' and 'ever' was calculated so that a summary of the incidence of carer types across both timeframes could be generated. For Q87 data was cleaned to ensure that those who had not previously stated that they have a family member as a carer had any answers to this question removed.

Question	Transformation
Q90-91	This question collected answers as free text. These were later coded for ease of analysis. Q91 was cleaned to remove responses from those who had not previously specified that they had made an application (Q90).
Q93	Written other - specify answers were coded into new answer options for analysis. Cleaned to remove responses from those who had not previously specified that they had made an application (Q90).
Q92	A new variable was created to identify when a respondent had selected *any* of the Emerge related options.
Q99	A new variable was created to identify when a respondent had selected *any* of the Emerge related options.

Appendix 3: Considerations for future surveys

Reduce the length of the survey

A number of comments were made in the comment boxes about the survey being too long. Having a long survey means that respondent fatigue sets in and responses to questions near the end of the survey may not be answered as accurately (or at all). This is clearly evident for this survey through the lower number of respondents answering questions later in the survey. Long surveys also reduce the likelihood of the survey being referred to other respondents, and may deter respondents from wanting to participate in future research.

Distribution methodology

The majority of the sample for this survey was in Victoria. Alternative distribution methodologies should be considered to better reach those outside of Victoria.

Question topics

There were a number of findings that suggest that females have a unique set of experiences, particularly with regards to decision-making about having children. Consideration needs to be made about exploring this topic in further detail in future research.

It may be pertinent to explore whether the gender variations in visitation to health professionals was due to differences in referral rates by gender.

It may also be beneficial to explore why those who are diagnosed through means other than GP or ME/CFS specialist have lower instances of telling their employer about their condition, and determine whether this is an issue that needs addressing.

Survey programming

There were a number of data items that needed extensive cleaning, and in a number of cases far from ideal analysis assumptions were being made which could have been easily addressed through survey programming:

- Program skips in the survey to ensure only relevant questions are displayed to respondents. For instance, if they say they didn't apply for a disability pension, hide the questions about the application process.
- Break the more complex questions into simpler forms, or into multiple independent questions. There was feedback in the comment sections that certain questions were too complicated to understand fully.
- Make all questions mandatory, and include "Not applicable", "Don't know" and "I'd prefer not to say" options where required. This helps ensure an accurate representation of the sample when performing analysis of responses. For many questions it has been assumed that those who didn't respond skipped due to lack of relevance to them, but one shouldn't assume respondent behaviour.
- Use data validation on fields where a set type of answer is required - e.g. force fields requiring a date or year to match a valid date format and range.
- Reduce the number of free-text questions, some of these could be replaced with option groups or multiple-response questions (and include an "other specify" option where appropriate). This gives a greater number of relevant responses, will assist in the analysis phase, and also give guidance to the respondent as to how the question

should be answered (thereby reducing the number of answers which were not useful).

- Attach the 'other specify' text box to the relevant answer code within the answer list (instead of it being a stand-alone box at the end of the answer list).

Question-specific feedback

Question	Change
Q6	Set up the other specify box correctly so that if someone types in a country it selects the 'no' option automatically.
Q7	Set up the other specify box correctly so that if someone types in a language it selects the 'no' option automatically.
Q14&16	Reword question to refer to ME/CFS. As it is currently posed ('Have you been diagnosed') it doesn't clearly state with what, therefore could be misinterpreted as meaning diagnosed with anything. Only show Q15-17 for those who say they have been diagnosed.
Q15	Include Fibromyalgia, POTS and Lyme disease so that the incidence of these can be measured.
Q17&18	Date format with validation to ensure consistent entering of data.
Q28	Revise definitions to make them clearer and sequential. Some people may consider 'significant reduction' (definition for mild) to be greater than 50% reduction, whereas the code for moderate specifies a 50% reduction. Split the 'How long have your symptoms been at this level' component into its own question with answer options.
Q31	Present a list of symptoms to select from.
Q32	Review answer codes. For instance 'Requiring care' doesn't seem to fit with the question.
Q35&36	Only show these questions for those who say they feel worse in Q34.
Q37	In future surveys include a follow-up question that asks whether stated changes can be directly attributed to ME/CFS. Consider what you are trying to find out with this question and revise how the question is asked (it collects a lot of information in a very complicated way and could be simplified).
Q38	Flip this question so that the columns are in the rows, and the income options are presented as a drop-down single response option per row. Where changes have been indicated, have a flow-on question as to whether the change was directly related to ME/CFS.
Q39	Program the survey so that only currently employed people see this question.
Q43	Program the question so that the 'none' option is exclusive (that is, if the respondent selects 'none' they can't also select another answer on the list as well). Make the question mandatory so there can be greater confidence that the figures are not being inflated by some people skipping the question due to lack of relevance.
Q49	Update the answer options so they make sense within the context of the question.

Question	Change
Q64	Make this question compulsory rather than asking respondents to leave the cells blank if not relevant, so that we can be sure that those who didn't respond were indeed non-users of these services. Split the question into multiple questions, starting with a compulsory multiple response question asking which specialists they have ever visited, with follow up questions for times seen, well informed and service questions, feeding through just those specialists they initially specified they have ever visited. That way, people only see the specialist rows relevant to them, thereby cutting back the length of the question. This will also allow for more accurate calculation of specialist use. Repeat the column headings every 5 rows.
Q72	Split the question into multiple questions, starting with a compulsory multiple response question asking which treatments they have tried, with follow up questions for helpful, source and usage questions, feeding through just those treatments they initially specified they have ever tried. That way, people only see the treatment rows relevant to them, thereby cutting back the length of the question. This will also allow for more accurate calculation of treatment use. Repeat the column headings every 5 rows.
Q83	Include a 'none' option and make this question mandatory so that we can be sure that calculations are correct.
Q85-87	Include question skips / routing so that those who don't indicate family member carers skip the follow-up questions.
Q88	Include a list of possible answers that people can select from as some may have been missed by not being aware of qualifying services. Also make this question compulsory with a 'none' option to ensure it is collecting holistic information.
Q90	Make this question compulsory so a figure can be reliably calculated based on the whole sample.
Q91	Only show if they specified that they had named an application in Q90.
Q100	Consider making this a multiple response question with an other (specify) option.

Appendix 4: List of figures