



# #SpeakUp project report

Helping improve health and social care provision for people with ME/CFS and fibromyalgia

**Sheffield ME & Fibromyalgia Group**



Sheffield  
ME & Fibromyalgia  
Group

**and**

**Healthwatch Sheffield**

**healthwatch**  
Sheffield

**July - September 2022**

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## What is #SpeakUp

#SpeakUp is Healthwatch Sheffield's small grant scheme, which provides funding to local not-for-profit, third sector, voluntary and community groups to run projects enabling local people to share their experiences of health and care services in Sheffield.

## Sheffield ME and Fibromyalgia Group

We are a registered charity (number 1095416) supporting anyone in South Yorkshire and North Derbyshire living with ME/CFS, fibromyalgia and/or long covid. We provide welfare benefits and social care advocacy, social and wellbeing activities, peer support via online and in-person groups, online talks by clinicians, researchers and other experts, befriending and information sharing via e-news and a quarterly magazine. We are also committed to raising awareness of the conditions and promoting positive changes to local service provision for people living with these illnesses.

## Healthwatch Sheffield

Healthwatch Sheffield is part of the national Healthwatch network, which helps adults, children and young people influence and improve how NHS and Social Care services are designed and run. They are completely independent and not part of the NHS or Sheffield City Council. Their mission is to understand people's experiences, and help influence decision-makers in the city with people's views.



Helping improve health and social care provision for people with ME/CFS and fibromyalgia

### ME/CFS & Fibromyalgia

Prevalent debilitating long term conditions, but largely unknown or misunderstood

## 1 Identifying barriers to appropriate support

### What we did

Online + paper survey (112 responses)  
Online + in-person focus groups and testimonies

# SUMMARY OF FINDINGS

## A strenuous battle, from diagnosis to support:



**Most valuable sources of support:** friends, family, local charities/organisations



**Most accessed support:** GPs - but generally not as valuable

"I have been ill with ME for over 30 years and received little if no support from health care services"

"Feel like I had to fight to get a diagnosis then told to go away and deal with it."

Lack of trust and sense of resignation

## Accessibility of healthcare services impinged by:

### Communication

(cognitive function, verbal, memory)



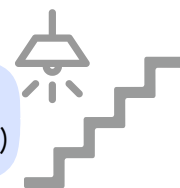
### Inaccessible process

for booking appointments



### Healthcare venue

(physical + sensory barriers)



### Transport

(cost & exhaustion)



**Fear of being disbelieved**



## Quality of healthcare received affected by:

### Lack of knowledge

from healthcare professionals about the conditions and how to support patients

### Lack of understanding and trust

from healthcare professionals, leading to symptoms not being investigated and patients feeling let down

**2021 NICE guideline on ME/CFS** largely not implemented

## Awareness & provision of social care services:

Lack of awareness from the patient community

"Such services are so difficult to access that I haven't had the energy to begin the process."

"Not for me..."

Inaccessible application process

"not disabled enough"

Inappropriate (or lack of) care workers





Helping improve health and social care provision for people with ME/CFS and fibromyalgia

Based on participants' suggestions, our own analysis of the findings, and discussions with decision makers.

## 2 Recommendations for health and social care professionals

See end of report for full details of the recommendations

### Accessibility of healthcare services:

#### Flexible appointments systems

- Booking: providing a time slot for the call back
- Online booking
- Increase telephone/video appointment offer
- SMS reminders
- Longer appointments
- Ability to bring a support person along
- Post-appointment summary of consultation
- Annual check-in/check-up appointments systematically scheduled
- Healthcare professional suggesting date for next appointment



#### Accessible venues

- Stair-free consulting and waiting rooms, close to the entrance/exit
- Stair-free place to sit/rest on arrival
- Resting places between rooms if far apart
- Dimmed lights in venues
- More parking spaces
- Home visits for a wider range of services



### Quality of healthcare:

#### Improving experience of getting a diagnosis

- ME/CFS service to simplify referral process
- Training for GPs on diagnostic criteria (NICE)

#### Improving experience of support

- Training for healthcare professionals on:
  - the conditions & specificities of symptoms
  - 2021 NICE guideline for ME/CFS
  - Wider support available for patients
- Providing tools to communicate with patients
- Continuity of care: 1 doctor per patient
- Patient's records to mention specific needs
- "Practice champions" labels for practices
- The ICB to use the NICE guidelines for the development of a South Yorkshire protocol for the management of the conditions
- Short document for GPs explaining the conditions and a NICE guideline summary



### Social care services:

#### Raising awareness

- Healthcare professionals to signpost patients to social care & advocacy services
- Training for social care staff on the conditions
- Updating the info for social care services to include these conditions



#### Improving experience of support

- Agency for patients over assessment process through better communication
- Simpler and more transparent appeal process & support
- Central point of information for direct payments and problems re carers/PAs
- Sheffield City Council to provide financial health checks



# Introduction

## Aims of the project

This project aims at raising the voices of people living with ME/CFS and fibromyalgia, and initiating positive changes to health and social care delivery for this community. Accessing health care professionals who have a real understanding of these conditions and its impact is not available to many. The other significant issue often raised by the community is access to good quality and reliable social care locally.

These barriers to accessing care, on top of directly affecting people's health due to not receiving the right care, can cause mental distress, anxiety and further marginalisation. Particularly among people with ME/CFS and fibromyalgia, this additional stress can cause serious exacerbation of symptoms.

In October 2021 a new NICE guideline for ME/CFS was published, which overturned some previous recommendations that were ineffective or harmful to patients. The implementation of this new NICE guideline by health professionals is a concern for many of our members living with the condition. One of the recommendations of the new guideline is to implement an annual review for patients, which is something that people don't feel comfortable talking about directly with their GP as a result of many years of being unheard and misunderstood.

Objectives of this project:

- To gather the community's view on barriers to accessing health and social care support
- To hear from the community about the state of implementation of the 2021 NICE guidelines among their healthcare support services (a year after being released)
- To improve the confidence of the community in citing the NICE guidelines to their GP

## More about ME/CFS and fibromyalgia

These conditions are largely unknown or misunderstood by care professionals and the wider society. One participant reported: *"there is substantial ignorance within society, at large, about living with chronic illnesses and it would be good to address this so that people living with ME/Fibromyalgia/Long COVID are not only validated but also supported generally within society and specifically within the Health Care System"*.

However, ME/CFS (myalgic encephalomyelitis/chronic fatigue syndrome) and fibromyalgia are not rare diseases. It is estimated that in Sheffield, over 1,100 people live with ME/CFS (0.2-0.4% of the population<sup>1</sup>) and over 27,800 live with fibromyalgia (around 1 in 20<sup>2</sup>). Additionally, hundreds of thousands of people in the UK are living with long term symptoms of COVID-19, of whom 43% meet the criteria for ME/CFS<sup>3</sup>.

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<sup>1</sup> <https://meassociation.org.uk/medical-matters/items/prevalence-population-estimates-mecfs/>

<sup>2</sup> <https://www.nhs.uk/conditions/fibromyalgia/>

<sup>3</sup> <https://meassociation.org.uk/2022/08/research-me-cfs-is-common-in-long-covid/>

Core symptoms of ME/CFS:

**Post-exertional malaise (exacerbation of symptoms)**

**Sleep disturbance**      **'Brain fog' (cognitive dysfunction)**

**Debilitating fatigue**    + many secondary symptoms (POTS, chemical sensitivities)

Core symptoms of fibromyalgia:

**Widespread pain**      **Headaches**      **'Brain fog'**

**Profound fatigue**      **Unrefreshing sleep**      **IBS**

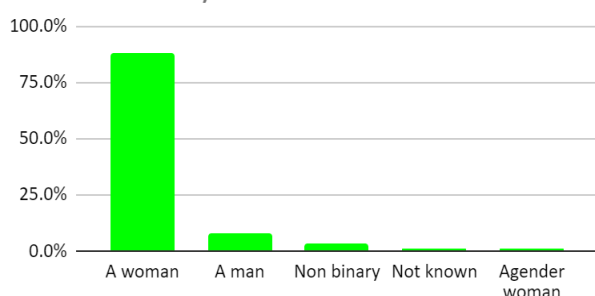
## What we did

We ran a **survey** from 3rd August to 15th September 2022 that was shared both online and in paper copies posted to our charity's members and distributed into accessible venues around Sheffield such as NHS buildings, libraries and community centres. The survey gathered **112 responses** (94 online and 18 paper responses) from individuals who have been diagnosed with ME/CFS and/or fibromyalgia.

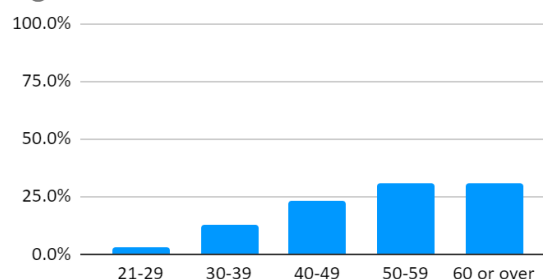
Most people who shared their feedback lived in Sheffield (and were registered with at least 31 different GP practices across the city). Most people who didn't live in Sheffield occasionally had to access Sheffield-based health or support services.

## Demographics of the survey participants

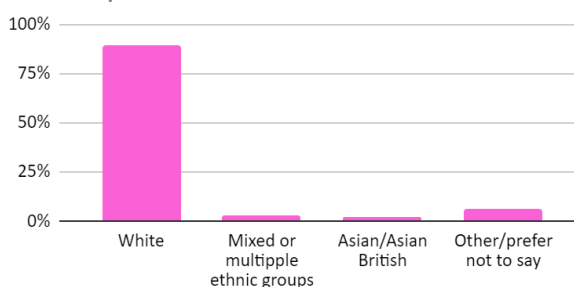
Gender identity



Age



Ethnicity



We organised **focus groups**, 6 online and 6 in person in accessible venues across Sheffield. These engaged **38 participants** who were able to dive deeper into their experiences. The themes of the focus groups were:

- Overcoming barriers
- Accessing social care support
- NICE guideline on ME/CFS
- But how do YOU feel? (e.g. when seeing GP)
- Your support circles
- Expression through the arts

We also gathered in-depth experiences from 4 people via interviews and longer testimonies.

The findings presented in this report combine information gathered via the survey, focus groups, interviews and testimonies.

# Findings

## A strenuous battle, from diagnosis to support

### Getting a diagnosis

The majority of people we spoke with during this project and more widely within our support group's activities reported that getting a diagnosis of ME/CFS, or of fibromyalgia, took several years of intense research and persistence. For most, limited help was available from their GP following the diagnosis, and accessing support was a further battle.

*"Feel like I had to fight to get a diagnosis then told to go away and deal with it."*

One participant explained:

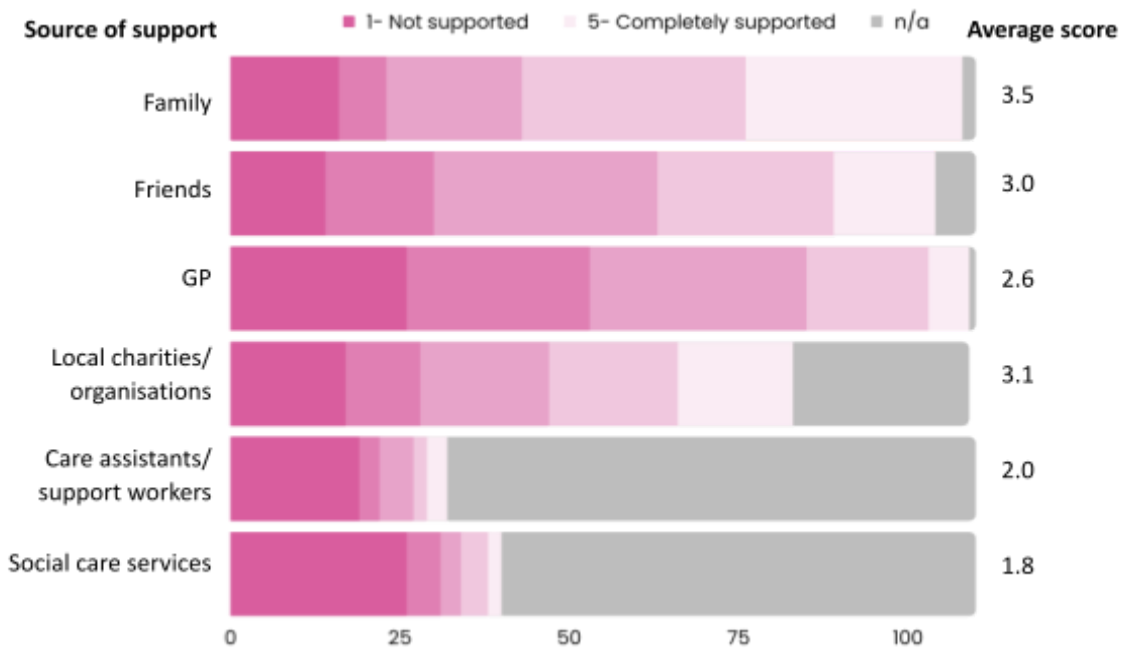
*"My ME 'journey' began many years ago, when I was diagnosed with a fatigue condition in 1990 but I suspect that I had the illness many years previous to that when it was termed 'yuppie flu'. It was not until 2002 that I was referred to the Infectious Diseases Clinic at the Hallamshire Hospital and was under the care of Prof Green until his retirement from clinic in 2016 and was consequently discharged. Since that time it has been pretty much a self help regime. I have tried many different alternative therapies with mixed results and also completed a six week course of Counselling/CBT."*

### Sources of support

Within the survey, we wanted to explore where people go for support, which sources of support are the most helpful, and how GPs and social care services rank.



**How supported do you feel by each of the options provided? (number of responses)**



For most people, family, friends and local charities/other organisations were seen as the biggest sources of support, however not for all. All the statutory sources of support had lower average scores.

*“Chronic long term illnesses can be incredibly difficult to manage. Family members can range from supportive to bullying. Friends can assume that as you look fine (when they see you) you are able to keep up with them, physically.”*

*“Workplaces can be unsympathetic and unsupportive. It’s always a judgement call as to who you tell about your conditions, knowing you may be disbelieved. It means that we are wary in all our interactions, including medical appointments. This fear is a tremendous barrier.”*

Some have supportive relationships but the lack of statutory support is putting strain on the people having to care for them instead:

*“Totally unsupported except for partner who is on knees with trying to do a lot of things”*

Care workers and social care services were the least commonly accessed source of support. Among the 70 “not applicable” responses, about half were people not aware of the services and half people who hadn’t accessed the services. The low ratings (1 or 2) corresponded mainly to people who weren’t aware of the services or who hadn’t accessed them, or people who hadn’t successfully implemented their award due to shortage or lack of knowledge of care workers about their condition. The social care topic is expanded in the section on [Awareness & provision of social care services](#).

*“I’m very mostly housebound with m.e. [...], live on my own, and have been like this for the last 14 years. [...] i am not able to afford all my care and house maintenance needs and ive now begun antidepressants. accessing help is very difficult as i struggle to read and use the phone, and i couldn’t physically get to an appointment by myself.”*



It should be noted that GP practices were the most commonly accessed source of support. Even above family and friends, this is the place most people went to in order to ask for help – so it is important for people to feel confident, heard, and receive the support they need here. This is currently not often the case.

*“[After being diagnosed with fibromyalgia] I was given a leaflet about the pressure points and that was that. I had no advice, my doctor said there was nothing they could do to help me.”*

Participants reported having to balance when to see a doctor and do an energy calculation to see if the stress and energy used to book and attend the appointment is worth putting into. People also said they *“worry I’m wasting their time”*. During an appointment, people mentioned having to *“manage anger and frustration”* when not being heard or understood.

**3 words to describe how you feel when seeing your GP...**  
(the size of the word represents prevalence)



**Art workshop - “How do you feel...”**



## After seeing your GP



### Lack of trust in services

This is one of the most prominent issues to come out of this study. Due to their previous experiences, or the experiences they've seen others go through, many people simply do not trust that health and social care services will try to, or be able to, support them effectively. Sometimes this is due to the attitudes and knowledge of professionals they've seen, and sometimes it's due to the lack of appropriate services for their needs:

*"When you mention fibromyalgia to doctors that look comes over their faces, so I don't go to the doctors unless I am forced to"*

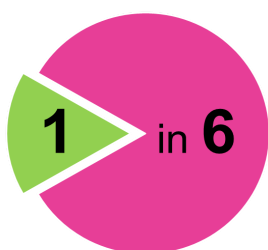
Many people's experiences span decades, and they have seen little change over the years:

*"I have been ill with ME for over 30 years and received little if no support from health care services"*

All of this has left people with a sense of resignation, and people are often not engaged with services any longer as they don't believe they are willing or able to help.

The following sections expand on three themes from the study: accessibility of healthcare services, quality of healthcare received (including the implementation of the 2021 NICE guideline on ME/CFS) and the awareness and provision of social care services.

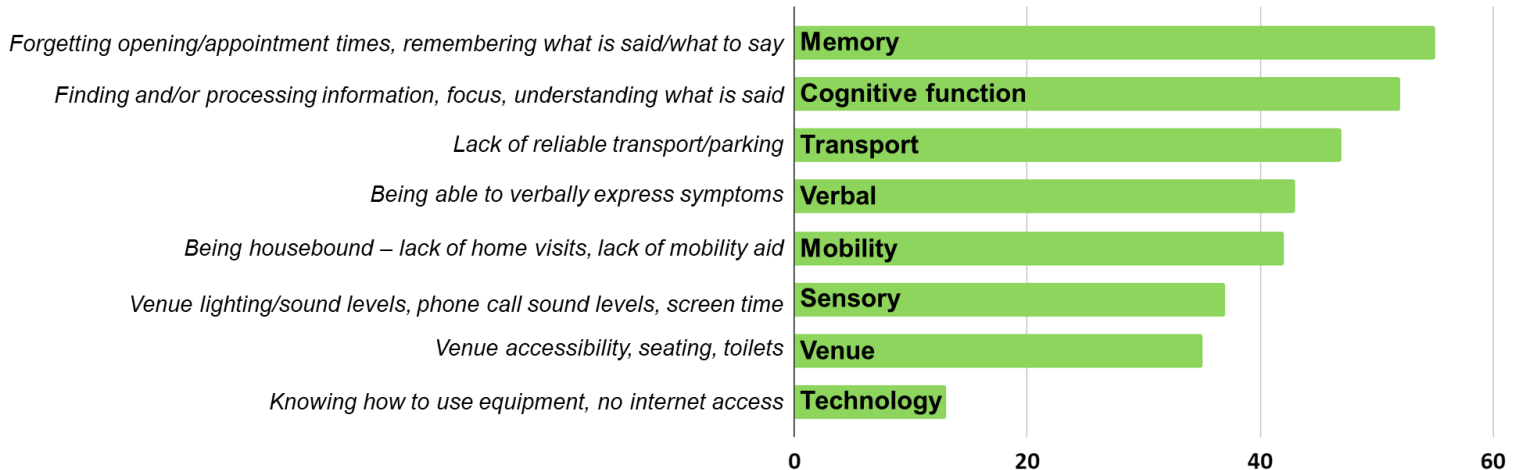
## Theme 1: Accessibility of healthcare services



We investigated the barriers that people face when accessing healthcare services. Notably, just 1 in 6 people said they don't usually experience any difficulty in accessing healthcare or support.

Of those who felt they did experience difficulties, these were sometimes extensive – people selected an average of 3.4 barriers which made accessing healthcare harder for them.

**What usually makes it difficult for you to access healthcare services? (number of responses)**



Memory and cognitive functions are the main barriers, due to the specificities of these health conditions. These make it difficult to prepare for an appointment, but also during and after the consultation, to get the message across to the GP and to process and remember the information received.

Transport and venue accessibility are mostly an issue because of the fatigue caused by the conditions. The length of the journey and the fact that the healthcare venue didn't have a place to rest on arrival was a significant barrier.

*“Worrying about where to park and if there will be space takes a lot of energy before the appointment has even begun”*

*“I’ve also missed a few routine scans at northern general hospital because didn’t have the energy to face the parking”*

People also reported that the costs of transport, especially taxis, was an issue, and that public transport was difficult to navigate with their health condition.

*“[I] feel unsteady and too nervous to use public transport alone”*

For some people, travel isn't possible at all, and home visits are necessary:

*“[I’d like] home visits with the same standard of care as would be available if I could go out”*

Where the healthcare service is in charge of booking transport for patients, this doesn't always work well as people reported hospitals refusing to book, or wheelchair accessible taxis being unavailable.

People spoke at length about improving physical accessibility in healthcare settings. This includes disabled parking and wheelchair access. In particular, venues with stairs and with a long way to travel once you're inside were issues – this was raised for both GP practices and hospital appointments.

Participants also spoke about sensory sensitivities which make healthcare settings such as GP surgeries inaccessible for them. This included bright lighting, loud waiting areas, strong

perfume/smells, and the hold music on the phone. For people with ME/CFS and fibromyalgia, these factors can cause a flare-up of symptoms and make brain fog more severe. This is then likely to impinge even more on patients' ability to communicate.

Far fewer people selected technology as a barrier, however we are aware that most people completed the survey online and therefore this issue might be more widespread than our sample suggests.

## Additional barriers raised

### Getting an appointment

The process of booking an appointment is in itself strenuous: calling within a small morning window, then waiting all day for a call back. It has been deemed as unsuitable by people living with the conditions and suffering from extreme fatigue.

*"The whole endeavour [of making an appointment] can take half an hour and is tiring. Sometimes I have to stop and try again the next morning."*

*"I'm no good mornings can't hang sentence together, waiting for the surgery to answer exhausts me for the rest of the day & I may not even get an appointment"*

Not being able to book appointments in advance was also raised as a barrier, as sometimes the issue is not as urgent but is still significantly affecting people's quality of life.

*"Cannot get to see a doctor if you phone for a telephone appointment before 08.00. If you phone at 08.02 all phone appointments have gone. You cannot make appointments in advance. I sometimes watch a programme on channel 5 to see what a GP looks like."*

### Fear of being disbelieved

Several participants reported that the anxiety of whether or not they're going to be believed by their GP often stops them from accessing support in the first place, and can also exacerbate symptoms. This point is developed further in the next section.

*"I tend to put off making [appointments] or lack confidence to express myself verbally and fully for fear of being dismissed."*

*"I could write a book on it having spent most of my life in waiting rooms. I do everything to avoid going now as I never know what I am going to face - a good or bad experience and the stress of going makes my condition worse."*

### Positive findings:

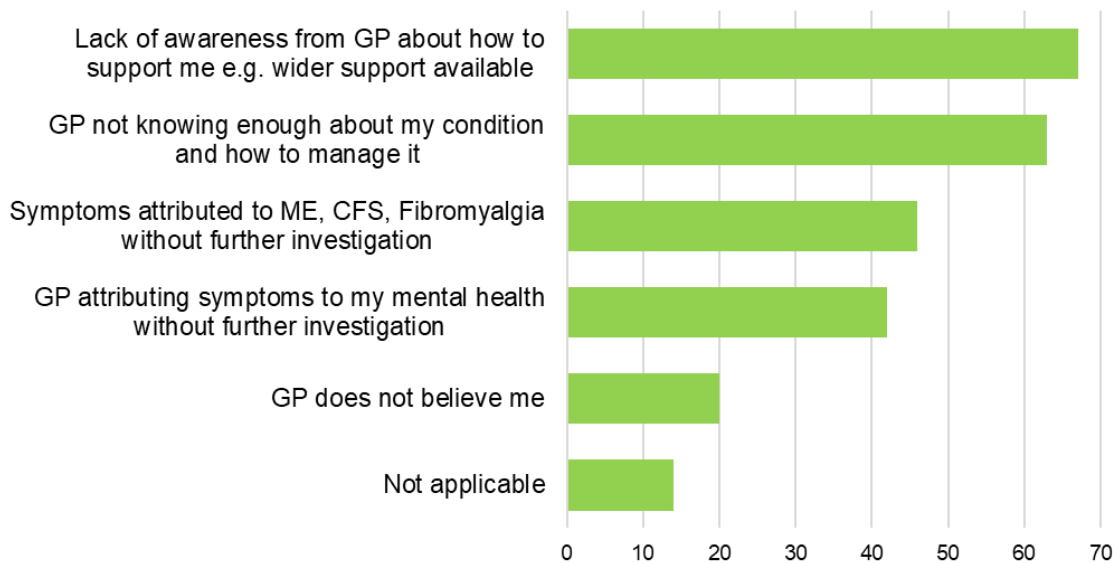
- GP offering double appointments or scheduling regular appointments
- Text reminders from some GP surgeries, reducing cognitive load
- Telephone appointments as a result of the pandemic were a positive change, as long as the call is scheduled and done from a visible phone number. Some people do prefer face to face appointments as they struggle on the phone.
- Dimmed lights in the ME Service waiting room: reduces symptoms exacerbation

## Theme 2: Quality of healthcare received

We explored further the experiences of patients with their health professionals, especially within their GP practice. Results show that the quality of healthcare received by patients is greatly affected by:

- The **lack of knowledge** from healthcare professionals about the conditions and how to support patients
- The **lack of understanding and trust** from healthcare professionals, leading to symptoms not being investigated and patients feeling let down

**Are any of the following barriers to getting your health needs met by your GP?** (number of responses)



All the options scored highly; most people felt they were experiencing several barriers at once. The lack of knowledge, dismissive attitude and disbelief from healthcare professionals is particularly distressing for patients.

### Misunderstanding and disbelief

People mentioned that their GPs were “*dismissive*” or “*don’t understand*”, and people felt their “*symptoms weren’t taken seriously*”, or even that they experienced “*hostile questioning*”. The stigma around people living with ME/CFS is acknowledged in the new NICE guideline for the diagnosis and management of this condition:

**1.1.2 Recognise that people with ME/CFS may have experienced prejudice and disbelief and could feel stigmatised by people (including family, friends, health and social care professionals, and teachers) who do not understand their illness.**

**Take into account:**

- **the impact this may have on a child, young person or adult with ME/CFS**
- **that people with ME/CFS may have lost trust in health and social care services and be hesitant about involving them.**

[www.nice.org.uk/guidance/ng206/chapter/Recommendations](http://www.nice.org.uk/guidance/ng206/chapter/Recommendations)

Many respondents would like to see “*more understanding from health practitioners*”, for “*GPs to listen to me*” and simply to be “*believed about symptoms*”.

*“Attitudes. I’ve sometimes been questioned about why I use a wheelchair.”*

As one of our participants noted, “*It is vitally important therefore for Health Professionals to get better training – to appreciate and understand that Fibromyalgia/ME/Long COVID sufferers are not just a set of symptoms - complex as they are - but human beings trying to make sense of a painful and challenging existence.*”

Patients report feeling like they constantly have to fight, and this takes up so much of their limited energy. This sometimes leads to people deciding not to even try to access healthcare support, which can be detrimental to their health but also to their access to financial support such as benefits. Indeed, during an assessment there would be no proof that they have recently been to the GP, meaning no proof that they are so unwell.

It has been reported by many people that their GP does not understand their complex needs, and this is sometimes due to not being allowed to discuss more than one issue at a time during a consultation, which is difficult with a multi-symptom condition. Patients have to decide which issue is most urgent for any given appointment. This is why continuity of care is of the utmost importance for this patient group - for their GP to be able to see the complexity and range of symptoms, and for patients to minimise their energy.

*“Having to see someone different every time and start from scratch is too hard”*

It was pointed out that it was not acknowledged that some standard procedures or rehabilitation exercises (e.g. after surgery) were much more painful for patients with fibromyalgia.

## **Investigation of symptoms**

Many people said that symptoms they presented to their GP were not explored in their own right – with 46 people saying symptoms were attributed to ME/CFS/Fibromyalgia without further investigation, and 41 people saying symptoms were attributed to their mental health without further investigation. 30 people selected both of these barriers, suggesting that they have a particularly difficult time getting new symptoms investigated thoroughly. Several people also mentioned that their GP attributed their symptoms to their weight without further investigation.

A participant shared: “*As I have noted previously, due to being labelled as an ME patient, members of the medical profession appear reluctant to find out if these new symptoms are due to ME/fibromyalgia or another condition. It is a fight to move forward because in my experience it is always a matter of more of the same, so to speak.*”

Another participant shared two experiences when her “*fibromyalgia diagnosis got in the way of a proper investigation*”:

Spasms in the neck:

*“Very early on during lockdown I started to get very worrying spasms in my neck and phoned the GP and eventually got through to receive a phone call back from a doctor who had never seen me, and who decided that my ‘pain in the neck’, despite it being a new*

*and intense pain for me, could only really be Fibromyalgia! But just in case it wasn't I was sent for an Xray which confirmed that I had osteoarthritis in the neck. I realise I was very lucky to get an Xray - but there was no follow up or visit to the GP to discuss the implications of this discovery. I was left to 'manage the pain' – although it wasn't Fibromyalgia as had first been suggested – and I continued in considerable discomfort.*

*When I visited the dentist, some months later, she examined my mouth and took an Xray. She discovered that I had an abscess on the root of my wisdom tooth in the lower jaw, which needed an operation. She felt sure that a large part of the pain I was experiencing was due to the abscess and nothing to do with Fibromyalgia. She did stress, however, that because of my condition the pain might be more extreme and intense."*

Acute chest pain:

*"Just recently I experienced acute chest pains – these were new to me – and I ended up in A & E twice. I was checked over and tested to ensure that I wasn't having a heart attack – fortunately I wasn't – but as soon as I mentioned that I had fibromyalgia – all investigations into the chest pain and the rather high blood pressure stopped.*

*I was sent home after the first time with no explanation for the pain from either the hospital or a follow up from the GP. The second time it was suggested that it was simply a flare up of my fibromyalgia.*

*I had been thoroughly frightened by the whole experience and didn't know what was causing the pain – or who I could turn to for support. In desperation I paid for a consultation with a private doctor – who not only listened to what I had to say but was able to offer explanations for the pain and strategies and medication to deal with it. The doctor was not satisfied with the blanket assertion that any pain I had had to be fibromyalgia – so was prepared to investigate further – and I felt a lot better for him doing so."*

Patients with ME/CFS and fibromyalgia often have to do their own research to find out what could help. They reported *"walking on eggshells"* when talking to their GP, torn between the need to get themselves heard and the fear of looking *"upsetting or neurotic"* because of their frustration.

### **Ineffective treatment**

Some people described being offered various medications over the years, which haven't helped:

*"I have tried lots of different drugs with little effect"*

Several participants mentioned having been diagnosed with mental health issues and prescribed antidepressants for their symptoms.

*"I have had ME and fibromyalgia for over 20 years but the only treatment offered has been repeat prescriptions or anti-depressants"*

*"Sadly I always seem to be diagnosed with an anxiety/depression label and offered drugs such as anti-depressants/SSRI's which I have always found to be sensitive to even when*

*prescribed a low dosage, I have largely self regulated myself on these drugs due to lack of monitoring and review from the GP.”*

## 2021 NICE guideline for ME/CFS - has anything changed?

Further input about the new NICE guideline (released in October 2021) was gathered from people who stated they had a diagnosis of ME/CFS. We linked [this summary](#) of the new NICE guideline to help people understand what might have changed, and wanted to explore if anything had changed for those who had seen their doctor since October.

84% of participants were aware of this new guideline before taking part in the survey.

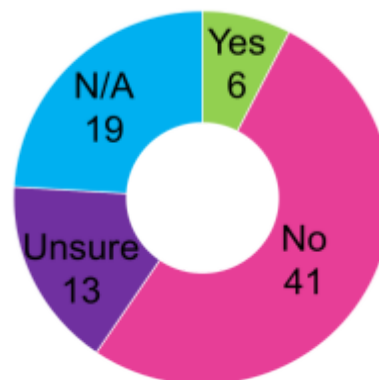
Only 6 out of 79 respondents noticed a positive change in their GP led care since the new guidance was released.

Only **3** out of 68 participants, having visited their GP since October 2021, mentioned having been offered a management plan to be reviewed annually as the NICE guideline advises. People noted that no annual review has ever been put in place for them in their GP practice, whereas it is for people living with other long term conditions.

6 people mentioned having been offered at least one of the following cures, contraindicated according to the new NICE guideline since October 2021: physical activity, talking therapy, lightning process.

Additional feedback included that doctors often don't know what to offer now that GET (graded exercise therapy) is not advised by NICE.

Have you noticed a positive change in your GP led care regarding ME/CFS since the guidance was published in October 2021? (number of responses)



### Positive findings:

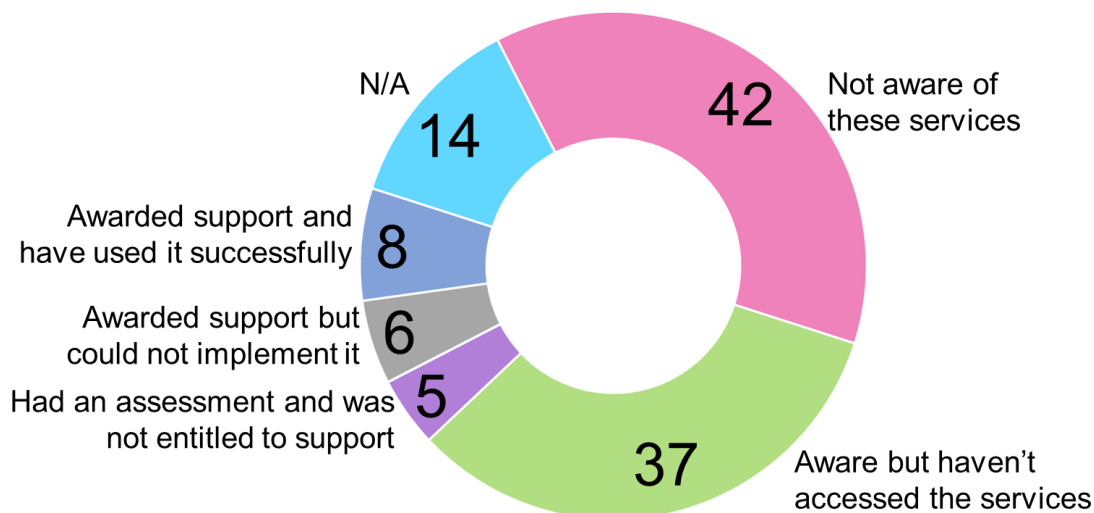
- Healthcare professional knowing about ME and the patient feeling validated
- GP changing attitude after reading the NICE guideline
- Some people reported that their GP was really supportive, others that it depended on the individual GP as they often changed. One person mentioned “I’ve had more issues being believed by NHS specialists than my GP”.



## Theme 3: Awareness & provision of social care services

This section expands on people's experiences of social care services. Two main barriers to accessing these services stand out: the lack of awareness from the patient community, and the thought that these services are not made for them.

**Social care: You may be entitled to further support such as a personal budget or home adaptations. Which of the following options best describes experience with this area of support? (number of responses)**



### A huge lack of awareness from the community

While many people who spoke to us know a great deal about their condition, having had to explain themselves to healthcare staff regularly, over a third of participants didn't know about the sort of support they might be able to access from social care services. Some had resigned themselves to not receiving any support, while for others the process of researching and applying was a barrier:

*"As my symptoms vary, I have assumed that I cannot access these services. No one has told me what is available so I assume there isn't anything for me"*

### Why do people who are aware of social care not access support?

#### A strenuous application process

The process for applying for social care support is thought by many to be unsuitable for people living with the conditions as it is exhausting and time-consuming, which often discourages the person to even try. Participants reported having had a 2-3 hour assessment over the phone during which it was very difficult for them to express their thoughts. Having to

speak to a different person each time adds to the anxiety and energy spent to get through these.

*“My understanding is that such services are so difficult to access that I haven’t had the energy to begin the process.”*

## **Aids and adaptations**

People spoke about getting aids and adaptations to support them. Some people had been assessed and managed to get the adaptations they needed around their homes (shower chairs, hand rails etc). However, adaptations for other people were *“promised, [but] never actually appeared”*; one person has been waiting for their planned aids and adaptations for a year now, while several others resorted to *“paying for [their] own adaptations”* due to the wait, or the uncertainty around whether they would be funded.

*“I know I would have to pay for help so haven’t gone to social services though we are all chronically ill in the family and two of us have ME.”*

## **‘Not disabled enough’ for help**

Several people used this phrase to describe their frustration and their lack of access to support, for example:

*“I’m not disabled enough to get help from the Council like a blue badge, or PIP from the government... just disabled enough that every day is hell”*

During assessment processes, people have been told that having ME/CFS/fibromyalgia meant they *“didn’t qualify”* for financial or practical support, even where people are unable to work or have *“had to change [their] work and cut down on hours”*.

In most of the cases where people described getting adequate support from Adult Social Care, this was because they had an additional condition like autism or having had a stroke.

## **Experiences of care workers**

Some people had employed personal assistants (PAs) to support them, but experiences of this were largely negative due to the lack of understanding of the conditions and their implications (e.g. wearing perfume, coming at variable times). People reported negative attitudes of PAs towards ME/CFS/Fibromyalgia; some people said their PAs were *“very unsupportive with their passive aggression”*, *“dismissive of my need to rest”* and even *“outright questions why I’m having support”*. It was also mentioned that many were unreliable and also didn’t have a driving licence.

The process of recruiting PAs was also mentioned – some people had enquired about the possibility of PAs or carers being provided, but were *“told nothing like this was available”*. When others went through the process of employing PAs themselves this was challenging:

*“Very difficult to recruit PA’s and agencies are awful (inconsistent, unreliable etc)”*

*“I’m not well enough to go through the recruitment, training, supervising, managing involved in directly employing someone myself, and without someone to help with these I’m stuck with no help with anything and deteriorating health”*



## Why can some people not implement the support they were awarded?

The two main reasons people gave for not implementing the support successfully were:

- Support workers being judgemental and dismissive of specific needs (e.g. need to rest and trying to get them involved in tasks)
- Shortage of support workers

*"I have unspent PIP because of a shortage of social care support for years, so I can afford to pay for it myself until this is spent, but there is a massive shortage of care workers and no organisations with availability will take on someone without an official social care package [...]"*

*"I'm not well enough to go through the recruitment, training, supervising, managing involved in directly employing someone myself, and without someone to help with these I'm stuck with no help with anything and deteriorating health. I can't afford to have an agency send some minimum wage untrained and badly managed person around because the stress, noise, and exhaustion of supervising them would make me more unwell than just trying to struggle on my own without."*

### Positive findings

- Accessing aids and adaptations for the home, once directed to the right route. However, most of the time this was due to having a comorbid condition to ME/CFS or fibromyalgia.

# Recommendations

These recommendations for health and social care professionals are based on participants' suggestions, our own analysis of the findings, and discussions with decision makers from the NHS, Sheffield City Council and other local bodies and organisations who also support our client group.

## Accessibility of healthcare services

### **Appointments need to be flexible to accommodate different needs**

ME/CFS and fibromyalgia symptoms such as reduced energy, memory and cognitive issues can all impact on people's experiences of booking and attending appointments. Services could consider the following to improve this:

- Getting a time slot for a call back
- Being able to book appointments online
- Increase telephone/video appointment offer
- SMS reminders of appointments
- Longer appointments
- Post-appointment summary of the consultation
- Being able to have a person supporting the patient during appointments
- Annual check-in/check-up appointment systematically scheduled
- Healthcare professional suggesting a date for the next appointment

### **Healthcare venues should be fully accessible and home visits available for those who need them. This could include:**

- A stair-free place to sit/rest on arrival
- Stair-free consulting and waiting rooms, close to the entrance/exit
- Where rooms are far apart, providing resting places between them e.g. on long corridors between waiting rooms, consulting rooms or bathrooms
- Providing more parking spaces (incl. blue badge parking spaces). This may not be possible for some existing buildings, but could be considered when moving into or designing new buildings
- A range of services that are able to offer home visits, including GPs, nursing, dentistry, ophthalmology and phlebotomy

## Quality of healthcare services

### **Improving the experience of getting a diagnosis from GPs and specialist services**

- ME/CFS Service to improve and simplify the referral process - we understand work is in progress on this, and we recommend that the service seeks patient feedback to understand whether these changes are successful
- Training for GPs on diagnostic criteria as per the NICE guidelines

## Improving the experience of support and treatment

A lack of knowledge among some healthcare professionals (about the health conditions and their symptoms, and about the support that is available for people) has a negative impact on many people's experience and prevents them from accessing the care they need.

Recommendations include:

- Training for GPs and other healthcare professionals on:
  - ME/CFS, fibromyalgia and specificity/variability of symptoms
  - 2021 NICE guideline for ME/CFS
  - Other types of support available (e.g. social care, benefits, alternatives to GET)
- Providing tools for GPs and other healthcare professionals to communicate with their patients (e.g. common language to describe pain, prompts when patient is struggling)
- Identifying the special interest of “practice champions” on the GP practice's website so that patients feel reassured about being able to see professionals with a chronic illness designation.
- Continuity of care: allocating one doctor for a patient to see the width and complexity of symptoms/appointing a care coordinator for continuity of care
- The patients' records should mention specific needs e.g. the optimum or the “no go” appointment times
- The Integrated Care Board to use the new NICE guidelines to support the development of a South Yorkshire protocol for the management of ME/CFS and fibromyalgia
- A document or card for GPs and other primary care professionals explaining the main symptoms of these conditions, and a NICE guideline summary (a copy of the document we co-created with patients during this project can be found [here](#)).

## Awareness and provision of social care services

Many people living with ME/CFS and fibromyalgia do not know about the social care support they may be entitled to. Adding to this, staff in the social care sector are not always aware of the conditions, and there are financial and practical barriers to taking up care. This could be improved by:

- Healthcare professionals signposting to social care services to patients in a timely way. They can also inform people about the advocacy that is available to support people to access care (including Sheffield ME and Fibromyalgia Group)
- Ensuring people have agency over the assessment process by improving communication throughout, and providing people with a written copy of the assessment afterwards
- Making the appeals process simpler and more transparent, and providing support (or signposting to support) for this
- A central point of information and support for direct payments and problems related to employed carers/PAs
- Training for social care staff about ME/CFS and Fibromyalgia
- Updating the information and guidance for social care services to include these health conditions
- Sheffield City Council to provide a financial health check to ensure people are accessing the financial support they are entitled to

# Conclusion and next steps

This study has revealed that people living with ME/CFS and fibromyalgia are facing numerous barriers when accessing health and social care support. For this patient group, inadequate access to support can affect many aspects of life: lowering overall quality of life, symptoms exacerbation, deterioration of mental health, impeding access to financial support.

The barriers to accessing quality care stem from:

- The specificities of symptoms, various and debilitating to the point that an estimated 25% of people with ME/CFS are housebound or bedbound;
- A general lack of awareness and understanding of the conditions among care professionals and the general public;
- A lack of awareness from the patient community about some services (e.g. social care)

Within this project, we have co-created a [leaflet](#) with volunteer participants, to help patients with ME/CFS discuss the new NICE guideline with their GP and receive appropriate support. We have shared this document widely and intend to spread it wider. We are also planning to create a patient leaflet explaining the condition, both for ME/CFS and for fibromyalgia.

We are very excited to be working alongside stakeholders from the NHS, the Council and other key organisations to improve service provision for our community in Sheffield. Our first stakeholder engagement meeting on the 4th October was well attended and extremely positive, with decision makers and people with lived experience engaging and willing to meet again. We are confident that this is the start of meaningful improvement for people living with ME/CFS and fibromyalgia.

Our charity would like to thank Healthwatch Sheffield for providing us with the financial and staffing support to conduct this project. We would also like to thank everyone who participated in this project by filling in the survey, participating in the focus groups, sharing their stories or volunteering to help with interviews and admin work.

*“As a cancer sufferer I have been well treated and would like CFS/fibro to be given similar priority given it is a lifelong condition and sufferers are likely to live with it much longer.”*