Healthwatch Kingston Pulse Check report: Chronic fatigue syndrome (ME) and fibromyalgia services

Survey - September 2022 to February 2023

Community focus group - 7 March 2023

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healthwatch
Kingston upon Thames

Contents

1. Introduction

In April 2021, Healthwatch Kingston launched its ‘Pulse Check’ community engagement programme to work more closely with people living with long-term conditions in Kingston and mlisten to their views and experiences of health and social care services.

Healthwatch Kingston was approached by the Richmond and Kingston ME Group, to help raise awareness of the issues faced by people living with myalgic encephalomyelitis (ME), also called chronic fatigue syndrome (CFS) and fibromyalgia, also called fibromyalgia syndrome (FMS).

Myalgic encephalomyelitis, *‘ME is a long-term complex, multi-system, chronic medical condition that has considerable personal, social, and economic consequences and a significant impact on a person's quality of life, including their psychological, emotional and social wellbeing. The most common symptom is an overwhelming extreme tiredness that can affect people of all ages (including children), genders and backgrounds, being more common in women than men.’*
(NICE ME/CFS guidelines, 2021).

Fibromyalgia, is also a long-term condition that can cause widespread pain.

(See Appendix B for an NHS overview of ME/CFS, on page 24, and Appendix C for an NHS overview of fibromyalgia, on page 28).

In conversations with members of the Richmond and Kingston ME Group, Healthwatch Kingston heard, *‘the voices of people living with ME/CFS and fibromyalgia were not being heard, and that their conditions were largely misunderstood’*. Survey respondents with ME/CFS shared that they also had symptoms of fibromyalgia and were being treated for both.

As long-term conditions are a focus in the Kingston Health and Care Plan 2022-24, and also a priority for Healthwatch Kingston (see pages 8 and 39 in our Annual Report 2022-23), we agreed to support this community engagement to find out more about the experiences of people living with ME/CFS and fibromyalgia in Kingston and what they thought about local health and social care services. This report adds ME/CFS and fibromyalgia services to Healthwatch Kingston’s other Pulse Check reports on diabetes, neurodiversity and MS (multiple sclerosis) services.

“We know that people with ME/CFS have had difficulty in getting their illness acknowledged, and the guideline provides guidance for suspecting and diagnosing the condition, recognising that

there is no specific test for it. The guideline emphasises the importance of a personalised management plan for areas such as energy management - including the importance of rest and staying within the individual's energy limits - the treatment of specific symptoms, and guidance on managing flares and exacerbations."

Peter Barry, Consultant Clinical Advisor for NICE and chair of the guideline committee, NICE ME/CFS guidelines outlining steps for better diagnosis and management published in October 2021.

2. Recommendations

Healthwatch Kingston Pulse Check report:
Chronic Fatigue Syndrome (ME) and Fibromyalgia services and support
Recommendations for service improvements

Recommendations for GPs (and other health and social care professionals):

1. Healthwatch Kingston recommends that GPs (and other health and social care professionals) ensure their patients are informed about the time it may take to confirm an ME/CFS or fibromyalgia diagnosis and the diagnosis process. GPs also need to explain the types of symptoms patients may experience, the treatment available (emphasising the need for continuity of care), and length of time it can take for referrals to specialist services after diagnosis.
2. Healthwatch Kingston recommends that patients diagnosed with ME/CFS or fibromyalgia, are referred to ME/CFS or fibromyalgia specialists and/or other appropriate services, so that plans can be developed for long term follow-up care (as recommended in the National Institute for Health and Care Excellence (NICE) ME/CFS guidelines, published on 29 October 2021).
3. Healthwatch Kingston recommends GPs and other health professionals offer/refer patients to mental health services and support as soon as an ME/CFS or fibromyalgia diagnosis has been made, to minimise delays in access to NHS mental health support.

Recommendations for South West London Integrated Care Board:

4. Healthwatch Kingston recommends that South West London Integrated Care Board work with secondary care providers to ensure patients with multiple and complex health conditions have access to nutritional advice for support with dietary needs.

Recommendations for South West London Integrated Care System (ICS):

5. Healthwatch Kingston recommends accessible information about community based ME/CFS and fibromyalgia services and support is provided via Connected Kingston, through Healthwatch Kingston's 'Find services' online directory and also other relevant ICS member communication channels.
6. Healthwatch Kingston recommends south west London health and social care providers consider travel support for people with ME/CFS and fibromyalgia if they are required to travel long distances to access specialist health and care services, as this can be difficult when you are living with pain and/or fatigue. This is particularly important when people need to travel to non-local services such as the CFS Service at Sutton Hospital.
7. Healthwatch Kingston recommends south west London health and social care services provide ME/CFS and fibromyalgia awareness training to their staff and volunteers, with reference to the new NICE ME/CFS guidelines (published in October 2021).
8. Healthwatch Kingston recommends south west London health and social care services develop joined up care pathways and carer support, similar to those in place to support people with Long Covid (Post Covid Syndrome).

Recommendations for Kingston Council:

9. Healthwatch Kingston recommends Kingston Council ensures that social care assessments of people living with ME/CFS and fibromyalgia consider the new NICE ME/CFS guidelines (published in October 2021 and be particularly mindful of the intermittent nature of these particular conditions.
10. Healthwatch Kingston recommends that Kingston Council assesses applications for 'Blue Badges' and other requests for access to services from Kingston Council, such as carer support / benefits / housing support / 'Living Well at Home' occupational therapy etc., with particular consideration to the intermittent nature of ME/CFS and fibromyalgia.
11. Healthwatch Kingston recommends that south west London Integrated Care Service leads commission Voluntary, Community and Social Enterprise (VCSE) organisations and groups to provide peer support while people are waiting for a ME/CFS and fibromyalgia diagnosis but also for after diagnosis.

3. Research methodology

Healthwatch Kingston and the ‘Richmond and Kingston ME Group’ co-designed a service user survey to collect feedback from people living ME/CFS and fibromyalgia.

The survey was made available to the public via our website and social media channels. This Pulse Check community engagement aimed to gather people's opinions about what it was like to live with ME/CFS and fibromyalgia, and invited people to share their experiences of accessing NHS and social care services, what the service quality was like, and any aftercare if this was provided.

In total, 39 community engagement participants informed this Healthwatch Kingston Pulse Check report. We received 29 online survey responses. Two of these respondents requested additional telephone interviews, as they wanted to share extra information about their experiences. They explained the reason for this was due to the symptoms of their condition and they struggled with long periods looking at a computer screen. We spoke to a further ten people at a series of Kingston community engagement events and this feedback has been included within this report.

In order to check we had listened, reflected a true representation of the key issues and themes, and that it resonated with members of the ‘Richmond and Kingston ME Group’, Healthwatch Kingston hosted an online feedback session. This provided an opportunity for people who had engaged the research, to review our findings and to co-produce draft recommendations for the report.

A local clinical professional agreed to review our draft report to check that the medical information and the current ME/CFS and fibromyalgia service provision was accurately described.

4. Limitations

The ME Association estimates between 0.2-0.4% of the UK population live with ME/CFS (that is 2-4 in every 1000 people) and according to Fibromyalgia Action UK, around 2.9-4.7% of the UK population live with fibromyalgia.

The 2021 census records published in the Population Report for Kingston upon Thames, states there are currently 168,063 people living in Kingston. Using the statistics outlined above, there could be up to 672 affected by ME/CFS, and 3361 people affected by Fibromyalgia in Kingston. Healthwatch Kingston acknowledges this report is informed by a comparatively small number of people compared to the numbers potentially affected in Kingston, but we were grateful to all 39 participants (29 survey and ten community events) who shared informative experiences and rich insights to inform our work.

Both ME/CFS and fibromyalgia are known to make everyday tasks, like reading, difficult. This was echoed by several of the 29 survey participants who reported they had struggled to complete the survey online. Healthwatch Kingson did invite participants to contact us by telephone should they require support to complete the survey or if wanted to share additional experiences verbally - Only two people requested this to share extra information with us.

Healthwatch Kingston also offered to join a local community group to discuss their ME/CFS and fibromyalgia support needs, but this was not possible at the time it was arranged as the people we had agreed to meet were not feeling able to participate due to fatigue and brain fog. It was also felt that discussions in public would be triggered and cause their conditions to flare-up (a sudden worsening of the symptoms of a condition).

5. Local service offer

Specialist services and support for Kingston residents living with ME/CFS and fibromyalgia are delivered through three providers.

Kingston Hospital has the following departments:

- Kingston Hospital Pain Clinic - It has a multidisciplinary team comprising of consultant anaesthetists, clinical psychologists, physiotherapists, a pain specialist nurse, and an acupuncturist.
- Rheumatology / Immunology / Physiotherapy.

Epsom and St Helier University Hospitals’ ME/CFS Department

Currently, the nearest ME/CFS department is at Malvern Centre on the old Sutton Hospital site (Cotswold Road, Sutton SM2 5NF, which is now part of the Epsom and St Helier University Hospitals NHS Trust). The department has a multidisciplinary team consisting of the clinical lead, clinical nurse specialists, clinical psychologists, an occupational therapist, and a physiotherapist. The Malvern Centre is in the London borough of Sutton. The distance between central Kingston to the Malvern Centre by car is about 9.3 miles. Using public transport, patients must take at least two buses (£1.75) or two trains (£8.60) for an average of 1 hour 20 minutes each way just to get to the Malvern Centre. Healthwatch Kingston learned that this is a challenging journey for many living with ME/CFS and fibromyalgia.

Richmond and Kingston ME group

The main goal of this community self-help support group is to help anybody who has been impacted by ME/CFS by offering them support and information. They hold eight meetings each month comprising, one in person meeting, three chatting online meetings and four activity-based online meetings via zoom. Activities include silent reading, crafting, and practising mindfulness. They are also supporting anyone with Long Covid, Fibromyalgia and Lyme Disease.

Healthwatch Kingston notes that whilst there is a support group locally for people living in Kingston with ME/CFS that additionally offers help to people with Fibromyalgia, there is no specific peer support for anyone with Fibromyalgia as such, leaving them without a full cover of their condition.

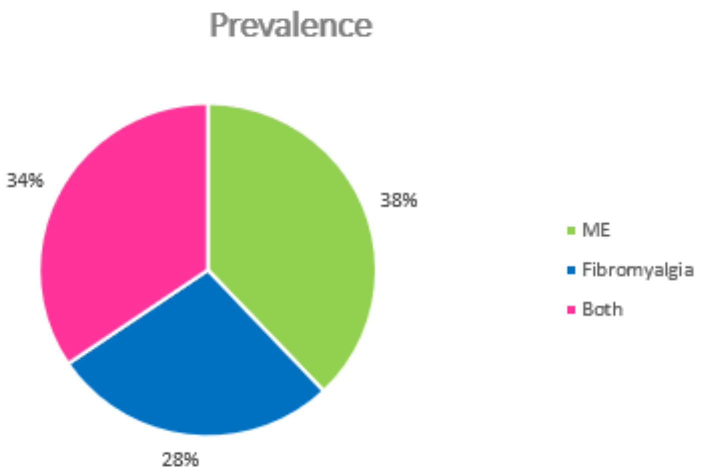
Healthwatch Kingston also heard from local residents and service users that they frequently have to travel long distances to access specialist health and care services, and this can be difficult when you are living with pain and/or fatigue.

To find out more about support available for people living with ME/CFS and/or fibromyalgia in the Royal Borough of Kingston upon Thames, and support for professionals go to the Healthwatch Kingston All About: ME/CFS and fibromyalgia services.

6. What we have learned

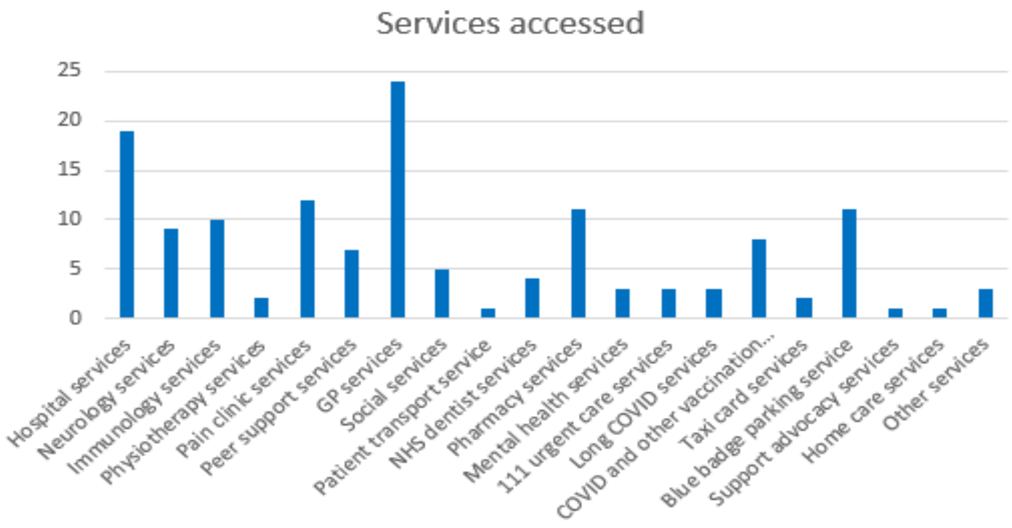
Survey respondents

29 people responded to our Pulse Check online survey. 38% of them shared they were diagnosed with ME/CFS and 28% with fibromyalgia. 34% of respondents noted they were living with both conditions. Most of our respondents were from Kingston (26 people) while three were from Sutton. Two surveys were answered by family carers. Two respondents were happy to be interviewed over the phone.



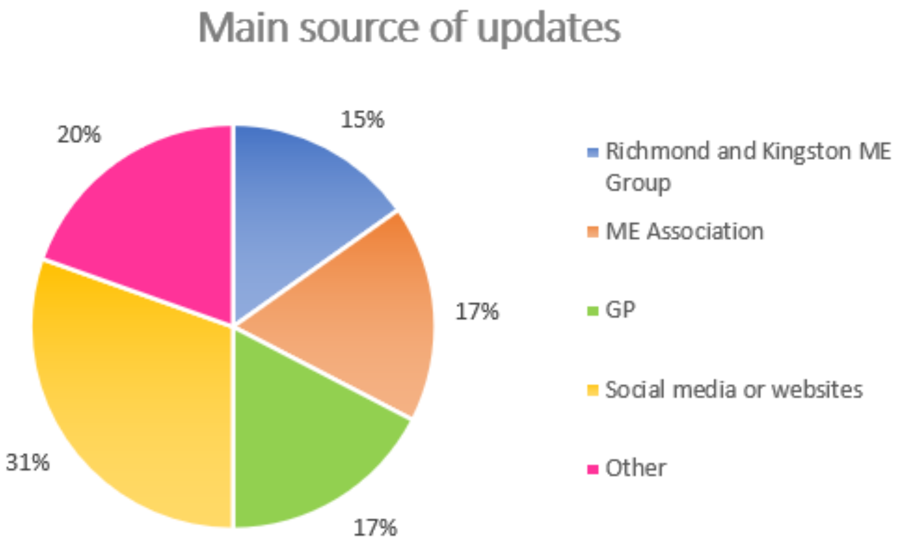
Services

The main services accessed by respondents to the survey were GP and hospital services and the pain clinic. Other services that featured highly were neurology, immunology, Covid/other vaccinations, Blue Badges and peer support, and pharmacy services. A few people reported accessing physiotherapy, social services, patient transport, NHS dentist, mental health services, 111, taxi card services and advocacy support.



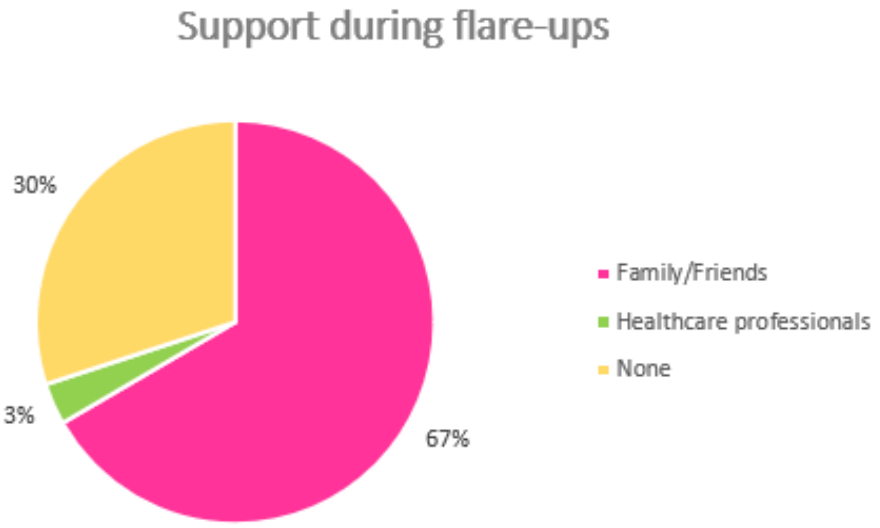
Information sources

People sought updates about their conditions across a range of outlets wherever it was available, which illustrates the need for information, resources and facilities for people living with ME/CFS and fibromyalgia, even though we heard that there was little available for people at the time of our survey. Most people surveyed (31%) relied on information posted on social media or websites which people mentioned was not always accurate or reliable.



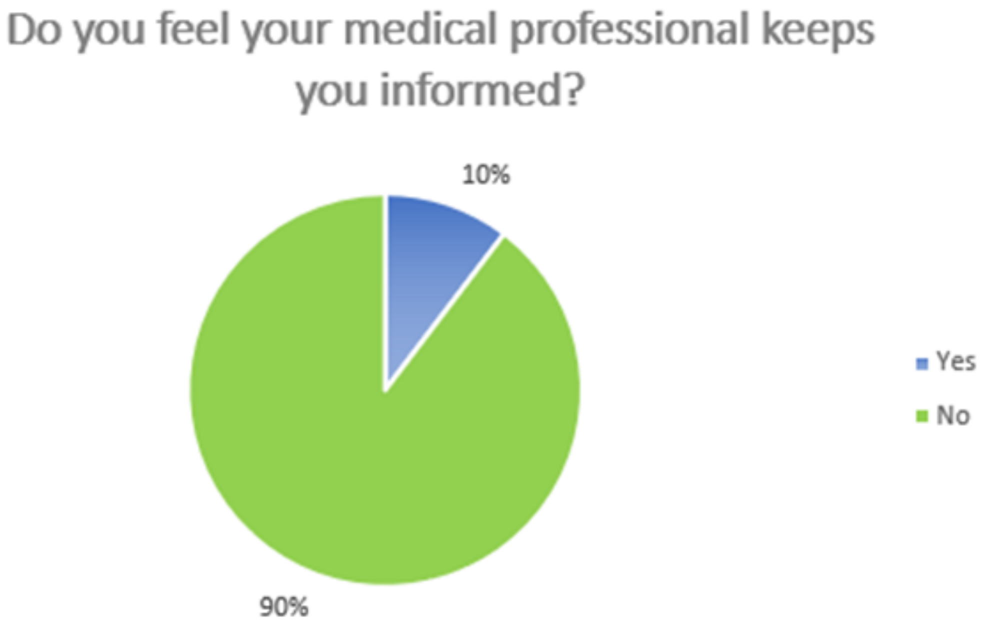
Support during condition ‘flare-ups’

Participants were asked about their source of support when experiencing flare-ups (a sudden worsening of the symptoms of a condition). 67% of the online survey respondents depend on their family and friends for support during flare-ups.



Information from medical professionals

Respondents were asked whether they felt that their medical professionals kept them well informed about their medical condition. Worryingly, 90% of respondents felt that their medical professionals were not providing them with adequate updates on ME/CFS and/or Fibromyalgia.



Symptoms

People have described the symptoms of ME/CFS and fibromyalgia as a ‘heavy burden’:

“I feel drained the whole time, particularly in the morning.”

A disabling condition:

“The amount of energy I have had over the years has tended to be so low, so that minor ailments can be debilitating.”

“I’m now a wheelchair user.”

Just over half (55%) of the respondents contracted Covid 19 during the pandemic. 3 of them ended up developing Long Covid. Many respondents reported that Covid aggravated their ME/CFS and fibromyalgia symptoms:

I feel like I have been worse since I caught Covid.’’

[Covid] increased my pain, tiredness and brain fog/confusion.”

And to some extent triggered flare-ups:

My symptoms lasted for about 5-months and caused a fibro flare-up.”

Multimorbidity

The majority of our Pulse Check survey respondents shared they live with multimorbidity. NICE defines the term "multimorbidity" as the co-existence of two or more chronic health conditions (a chronic condition - also known as chronic disease or chronic illness - is a health condition or disease that is persistent or otherwise long-lasting in its effects or a disease that comes with time). From our survey, the most common chronic conditions among respondents were asthma and chronic obstructive pulmonary disease (COPD).

About 26% of survey respondents said they had either asthma or COPD which made these the two most common chronic conditions among survey respondents. Other present long-term conditions included, Long Covid, functional neurologic disorder (FND), hypermobile Ehler Danlos Syndrome, osteoarthritis, chronic pain, rheumatoid arthritis, migraine, Hughes Syndrome, Polycystic ovary syndrome (PCOS) and allergic reactions. Two respondents also suffered from heart failure and were due to have surgery.

Impact on mental health

Respondents were asked if ME/CFS and fibromyalgia had affected their mental health. Nearly half (48%) of people reported that ME/CFS and fibromyalgia had severely affected their mental health. 43% felt that ME/CFS and fibromyalgia had slightly affected their mental health.

Almost all (96%) of respondents experienced mental fatigue which caused difficulties with concentration and loss of interest. Examples of how respondents described this included:

I have a lack of ability to concentrate.”

Isolation, loss of interests, inability to plan.”

Respondents shared they had difficulties adjusting to living with chronic conditions:

It’s hard not to live life as once did.”

At first learning to adapt to the pain and fatigue was really difficult. The guilt you feel for your kids at not being about to be like other parents. Also, people aren't really interested in how you feel when you have a long-term condition, you just become an inconvenience or people think you’re negative, so you learn to lie and tell people you're OK when really, you’re not. Its lonely and isolating.”

Anxiety and depression are two of the most common complications of ME/CFS and fibromyalgia. Almost two thirds (59%) of the respondents were suffering from anxiety while just over half (52%) had depression:

I developed anxiety and depression since getting ill.”

Makes you feel depressed and worried about how to look after yourself in the future, as things get slowly worse.”

If I'm fatigued, I become more depressed and anxious, it is one of the symptoms. It indicates my body doesn't have the energy to cope with stress. Also, high stress uses up lots of energy. Of course it's also depressing having the condition and not being able to do what I used to do.”

It is also depressing having the condition and not being able to do what I used to do.”

Diagnosis delay and associated uncertainty

A ME/CFS and/or fibromyalgia diagnosis is usually made after about 3 months because the GP or specialist has to closely monitor the symptoms and rule out any other underlying conditions.

Diagnosis delay was a common theme. While almost a quarter (24%) of the respondents were diagnosed within one year, the majority said they had to wait for at 2 to 5 years to get their diagnosis. 28% reported a ME/CFS and/or fibromyalgia diagnosis after 5 years. One Pulse Check survey respondent said:

Doctors thought I was getting old. I had to see 5 consultants over several years before my diagnosis.”

14 out of the 29 survey respondents shared who diagnosed them. Half were diagnosed by their GPs, a third were diagnosed by specialists such as immunologists and rheumatologists, and one person said they had self-diagnosed.

Due to the length of time and uncertainty of getting diagnosed by an NHS GP, some respondents told us that they had resorted to seeking diagnoses from private specialists. One said:

I was diagnosed privately by an endocrinologist.”

We also learned from some that even though their GPs were committed to running tests, after they had been diagnosed, there was no follow-up service and support:

My GP took it seriously, and eliminated other conditions by extensive testing, but once I got the diagnosis, I was on my own with it.”

Gaps in care pathways

Some respondents told us there was limited collaboration between their GPs and clinical care specialists and that they had not only faced long waits for assessment, but then also for access to care from specialists. 41% of Pulse Check survey respondents reported having to wait for over 3-months before getting the specialist advice and care they needed. A couple of people shared:

“I had one appointment with the ME/CFS clinic, I was referred by my GP. This was only over the phone, and they were able to give me a diagnosis but no other support. I have been told I will get a face-to-face appointment with them, but the waiting list is huge, and I cannot get an appointment until the latter half of 2023.”

“My physiotherapy didn’t work, so, 6-months ago they [GP] referred me to a rheumatologist and I am still waiting.”

Unhelpful treatment

Some of the respondents highlighted that they face difficulties finding painkillers or antidepressants that work for them:

“I have been on medication since my diagnosis. Nothing seems to work anymore.”

“I just live with it and take a lot of paracetamol. I can't take ibuprofen because I took it too much when younger and gave myself an ulcer. I was on amitriptyline for a few years, but I came off it because I don't want to have unnatural sleep and I need to get up early for work.”

Two respondents who had fibromyalgia were referred to physiotherapists for pain management, but said this was not so effective for them:

“The physio tried to help me, but they admitted fibro is not well understood.”

They [the physiotherapist] didn't know what might help me.’’

Lack of understanding

The majority of respondents highlighted that health professionals they had come into contact with had a limited understanding of ME/CFS and/or fibromyalgia:

The GPs were sympathetic, but knew little about the condition.”

It all seems to be a big mystery to the people that are meant to help me.”

Most things were fine, but there wasn't a great deal of understanding about ME/CFS.”

There was a very poor understanding of ME within the practice.”

Others had come to terms with the fact that there is no current cure:

There is nothing anyone can do.”

Aftercare

Respondents noted that there are very few aftercare services available to them. Out of the 12 respondents that answered our survey question about aftercare services, eight reported that they were not offered any aftercare and only two were receiving follow-ups from their GPs. A couple of responses explained in more detail:

None, once I'm discharged from a service there aren't follow ups, apart from the Sutton Hospital Chronic Fatigue Service, where the follow up is up to a year and then discharged.”

No follow up or further advice from the immunologist, no follow up from the GP other than to say let us know when you need a new prescription for pain *relief (that I can't take). I've been unwell for over 14 years now and have had to learn to manage my own conditions. When I flare-up, I have to change my diet, up my vitamins, rest when needed and slow down."*

One respondent succinctly summed up:

Aftercare? What is that?"

7. Conclusion

The findings from this Healthwatch Kingston Pulse Check community engagement work have illustrated the need to not only raise awareness and understanding about ME/CFS and fibromyalgia with NHS and social care professionals, but also the importance of ensuring people waiting for an ME/CFS and/or fibromyalgia diagnosis are informed about the time it may take and that expectations are managed. Clarity for patients and professionals about ME/CFS and fibromyalgia care pathways between local GPs and specialist services would help provide the reassurance required through joined up care for people living with intermittent symptoms from these long-term conditions.

Healthwatch Kingston notes that fibromyalgia is more prevalent in women than men, diagnosed often in middle age, but it can also affect children. It will be important therefore to involve providers of services for children and young people to ensure care is available for all ages. Consideration should also be made to how fibromyalgia can occur simultaneously with other life experiences, such as the menopause, and therefore, recognition of different multiple service needs is important to support health and wellbeing of local populations experiencing ME/CFS and fibromyalgia.

Our recommendations for service improvements are on page 5 and 6 of this report.

8. Thank you and next steps!

Healthwatch Kingston would like to thank everyone that has shared their experiences to support our work. Your information will be used and stored for the purpose of this project, and in accordance with the Healthwatch Kingston upon Thames' Privacy Statement which can also be provided in paper form on request by email: info@healthwatchkingston.org.uk

Everything we say and do is informed by what local people tell us. We will publish this Pulse Check report on our website and share with Healthwatch England, the Care Quality Commission, the Royal Borough of Kingston upon Thames, South West London Integrated Care Board, the Voluntary Community and Social Enterprise sector and other south west London Integrated Care Service stakeholders.

Our particular thanks to members of the Richmond and Kingston ME Group for their guidance and involvement in this community engagement.

Appendix A: Pulse Check ME/CFS/Fibro survey questions

1. **Do you live in Kingston upon Thames?**
2. **Do you have ME/CFS, Fibromyalgia or both?**
3. **Do you have another long-term condition, if so, what?**
4. **Do you care for someone who has ME/CFS or Fibromyalgia?**
5. **Can you tell us about your experience of caring for someone living with ME/CFS or Fibromyalgia?**
6. **Approximately how long did it take for you to be diagnosed with the ME/CFS or Fibromyalgia?**
7. **Can you tell us about your experience getting your diagnosis?**
8. **In the last two years have you made a request to your GP to be referred to more specialist care and advice?**
9. **How long did you have to wait before receiving the care and advice you needed?**
10. **Do you have any of the following symptoms?**

Physical fatigue / Mental fatigue / Post-Exertion Malaise (collection of bad symptoms after a small physical, mental, or emotional effort)restless leg syndrome / sleeping (and other sleeping issues) / Brain Fog (problems with concentration) / Pain / Extreme sensitivity to pain / Headaches/Migraines / Muscle sting (twitching, burning, aching, stabbing pains) / Muscle fatigue / Memory loss / Dizziness / Fast or irregular heartbeat / Stiffness / Irritable bowel syndrome / Restless leg syndrome / Pins and needles / Anxiety / Depression.

11. **Have you used any of the following services?**

Hospital services / Neurologist / Immunologists / Pain Clinic / Voluntary and community organisations (e.g. Richmond and Kingston ME group) / Social Services / Patient transport services / Taxi card services / Blue badge parking / GP services / NHS dentist / Pharmacy services / Home Care / Care Home / Mental health services / 111 – urgent care / Long Covid Services / Covid and other vaccination services / Support and Advocacy / Other services.

12. **If you were able to access the above services, please let us know which hospital / where you were able to do so?**
13. **Can you tell us more about your experience of gaining access to services?**

14. **Can you tell us more about your experience of the quality of services received?**
15. **Can you tell us your experience of any after care services you may have received?**
16. **Where do you get information about your condition?**
17. **Do you feel your medical professional keeps you informed about your condition?**
18. **Has ME/Fibro affected your mental health?**
19. **Has ME/Fibro affected your physical health?**
20. **Has ME/Fibro affected your work/family life?**
21. **Has ME/Fibro affected your ability to carry out everyday tasks?**
22. **Did you have Covid?**
23. **If yes, did this result in Long Covid? Please tell us more.**
24. **If you had Covid/Long Covid, how did this affect your ME/Fibro?**
25. **Where do you receive support for your condition?**

Family/Friends / Church / Community / Healthcare professional / None

26. **If you care for someone with ME/CFS or Fibromyalgia, do receive any addition support? If so, where from?**
27. **Are you registered as disabled?**
28. **Have you had a care needs assessment from Kingston Council?**
29. **Have you accessed any of the following services?**

Universal Credit/Tax Credit (UC)/(TC) / Employment and Support Allowance (ESA) / Personal Independence Payment (PIP) / Attendance Allowance (AA) / Housing Benefit (HB) / Other benefits, let us know.

30. **If you applied for benefits, did you receive help with your application?**
31. **As a result of your ME/CFS or Fibromyalgia do you have a Blue Badge?**

Appendix B: NHS Overview of myalgic encephalomyelitis or chronic fatigue syndrome (ME/CFS)

Myalgic encephalomyelitis, also called chronic fatigue syndrome or ME/CFS, is a long-term condition with a wide range of symptoms. The most common symptom is extreme tiredness.

ME/CFS can affect anyone, including children. It's more common in women, and tends to develop between your mid-20s and mid-40s.

[Healthwatch Kingston notes the views of the Richmond and Kingston ME Group on this NHS overview: *'ME/CFS can affect anyone, including children. It's more common in women affecting them 2.4 times more than men, according to the most recent data from the UK Biobank on page 84 of NICE ME/CFS guidelines, 2021. (There is no evidence that suggests the illness develops between mid-20s and mid-40s as it can affect children from a very early age. In our support group most members are in their 40s and 60s. This is the range where we have seen more people with the condition, but it doesn't necessarily mean that people developed it in that period of age).'*]

Symptoms of ME/CFS

Common symptoms of ME/CFS include:

- Feeling extremely tired all the time – finding it very hard to do daily activities
- Still feeling tired after resting or sleeping
- Taking a long time to recover after a physical, mental, social or emotional activity or exertion (Healthwatch Kingston notes that NICE Guidelines mention that post-exertional malaise - also known as post-exertion symptoms exacerbation - is the worsening of symptoms after an activity or exertion that is often delayed in onset by hours or days, is disproportionate to the activity or exertion and has a prolonged recovery time that may last hours, days, weeks or longer)
- Problems sleeping, such as waking up often during the night
- Problems with thinking, memory, and concentration.

Some people with ME/CFS may also have other symptoms, including:

- Muscle or joint pain
- Headaches
- Sore throat

- Flu-like symptoms
- Feeling dizzy or sick
- Fast or irregular heartbeats (heart palpitations)
- The severity of symptoms can vary from day to day, or even within a day.

People with ME/CFS told Healthwatch Kingston about additional symptoms:

- Irritable bowel syndrome (IBS), a digestive condition that causes stomach pain and bloating
- Postural orthostatic tachycardia syndrome (POTS), a condition that causes heart rate to increase very quickly after getting up from sitting or lying down.

NHS information notes: The symptoms of ME/CFS are similar to the symptoms of some other illnesses, so it's important to see a GP to get a correct diagnosis.

Find out more about the symptoms of ME/CFS.

Diagnosing ME/CFS

There is not a specific test for ME/CFS, so it's diagnosed based on your symptoms and by ruling out other conditions that could be causing your symptoms.

The GP will ask about your symptoms and medical history. You may also have blood and urine tests.

As the symptoms of ME/CFS are similar to those of many common illnesses that usually get better on their own, a diagnosis of ME/CFS may be considered if you do not get better as quickly as expected.

Find out more about diagnosing ME/CFS.

Treating ME/CFS

Treatment for ME/CFS aims to relieve the symptoms. Your treatment will depend on how the condition is affecting you.

While there is currently no cure for ME/CFS, there are treatments that may help you manage the condition.

Treatments include:

- Cognitive behavioural therapy (CBT)
- Energy management (known as pacing) – where you're given advice about how to make best use of the energy you have without making your symptoms worse.
- Medicine to control symptoms such as pain and sleeping problems.

[Healthwatch Kingston notes the views of the Richmond and Kingston ME Group on this NHS website treatments list and felt the following was more appropriate based on their experience:
'Treatments include:

- *Multidisciplinary care based on the person's needs and following the recommendations of the NICE ME/CFS guidelines, from October 2021.*
- *Cognitive behavioural therapy (CBT), but only for patients with mild or moderate ME/CFS.*
- *Energy management (known as pacing) – where you're given advice about how to make best use of the energy you have without making your symptoms worse.*
- *Medication to control symptoms such as pain and sleeping problems.*
- *Lifestyle changes.'*]

[Healthwatch Kingston also notes the statement about use CBT from the Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management NICE guideline, Published on 29 October 2021:
'The committee wanted to highlight that cognitive behavioural therapy (CBT) has sometimes been assumed to be a cure for ME/CFS. However, it should only be offered to support people who live with ME/CFS to manage their symptoms, improve their functioning and reduce the distress associated with having a chronic illness.']

Some people with ME/CFS will improve over time, especially with treatment.

Many people with ME/CFS will need to adapt their daily routine and pattern of activities on a long-term basis. There may be periods when your symptoms get better or worse.

Find out more about treatments for ME/CFS.

Causes of ME/CFS

It's not known what causes ME/CFS, but there are a number of theories – for example, it may be triggered by an infection, or certain factors could make you more likely to develop the illness.

Suggested causes or triggers for ME/CFS include:

- Viral infections, such as glandular fever
- Bacterial infections, such as pneumonia
- Problems with the immune system
- Hormone imbalance
- Your genes – ME/CFS seems to be more common in some families.

Living with ME/CFS

Living with ME/CFS can be difficult. Extreme tiredness and other physical symptoms can make it hard to carry out everyday activities. You may have to make some major lifestyle changes.

ME/CFS can also affect your mental and emotional health, and have a negative effect on your self-esteem.

As well as asking your family and friends for support, you may find it useful to talk to other people with ME/CFS.

ME Association is a charity that provides information, support and practical advice for people affected by the condition.

You can find a local support group on the ME Association website.

Appendix C: NHS Overview fibromyalgia

Fibromyalgia, also called fibromyalgia syndrome (FMS), is a long-term condition that causes pain all over the body.

Symptoms of fibromyalgia

As well as widespread pain, other symptoms of fibromyalgia include:

- Increased sensitivity to pain
- Muscle stiffness
- Difficulty getting to sleep or staying asleep, which can make you feel very tired (fatigue)
- Problems with mental processes (known as "fibro-fog"), such as difficulty concentrating or remembering things
- Headaches
- Irritable bowel syndrome (IBS), a digestive condition that causes stomach pain and bloating
- Feelings of frustration, worry or low mood.

The symptoms of fibromyalgia are changeable – for example, they can sometimes suddenly improve or get worse.

See a GP if you think you have fibromyalgia. Treatment can ease some of the symptoms, although they're unlikely to disappear completely.

How fibromyalgia is treated

Although there's currently no cure for fibromyalgia, there are treatments to help relieve some of the symptoms and make the condition easier to live with.

Treatment tends to be a combination of:

- lifestyle changes, such as exercise programmes and relaxation techniques
- multidisciplinary care based on the person needs and following the recommendations of the NICE ME/CFS guidelines, from October 2021
- medicine, such as antidepressants.

In particular, exercise has a number of important benefits for people with fibromyalgia, including helping to reduce pain.

What causes fibromyalgia?

The exact cause of fibromyalgia is unknown, but it's thought to be related to abnormal levels of certain chemicals in the brain and changes in the way the central nervous system (the brain, spinal cord and nerves) processes pain messages carried around the body.

It's also suggested that some people are more likely to develop fibromyalgia because of genes inherited from their parents.

In many cases, the condition appears to be triggered by things that are physical or emotional like an injury, an infection or stress.

Who's affected

Anyone can develop fibromyalgia, but it's more common in women than men. The condition typically develops between the ages of 25 and 55, but people of any age can get it, including children and older people. It's not clear exactly how many people are affected by fibromyalgia, although research has suggested it could be a relatively common condition. Some estimates suggest nearly 1 in 20 people may be affected by fibromyalgia to some degree. One of the main reasons it's not clear how many people are affected is because fibromyalgia can be a difficult condition to diagnose. There's no specific test for the condition, and the symptoms can be similar to a number of other conditions.

Support groups

If you have fibromyalgia, support groups can provide an important network for talking to others living with the condition.

Fibromyalgia Action UK is a charity that offers information and support to people with fibromyalgia.

If you have any questions about fibromyalgia, call the charity's helpline on 0300 999 3333. Fibromyalgia Action UK also has a number of regional co-ordinators who can put you in touch with a support group near you.

Another organisation you may find useful is UK Fibromyalgia.

Healthwatch Kingston was set up by the Health and Social Care Act of 2012 to be the independent champion for local NHS and social care. We seek the views of patients, service users, carers and the public to help services work better for the people who use them. We play an important role bringing communities and services together. Everything we say and do is informed by what local people tell us. As well as encouraging those who run local services to act on what matters to people, we also share local views and experiences with Healthwatch England and the Care Quality Commission who make sure that the government put people at the heart of health and care nationally.

Tell us what you think about the NHS and social care.

Healthwatch Kingston upon Thames
Suite 3, 2nd Floor, Siddeley House
50, Canbury Park Road
Kingston upon Thames
KT2 6LX

www.healthwatchkingston.org.uk
t: 020 3326 1255
e: info@healthwatchkingston.org.uk
X: @HWKingston
Facebook: /HWKingston