Understanding Fibromyalgia

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Introduction

In spring 2026 we undertook a piece of work to better understand the experiences of people living with Fibromyalgia, with a particular focus on access to health, wellbeing and community services.

42 people responded to our poll, with **90%** of people **living with Fibromyalgia**. Most people were from the Horsham, Worthing, Crawley, and Chichester areas of West Sussex.

Key findings

- 77% of respondents had received a Fibromyalgia diagnosis.
- The time taken for a diagnosis of Fibromyalgia was overwhelmingly long: 56% had waited up to 5 years, and 38% had waited 5–10 years.
- A large number of people told us that they found the diagnosis process difficult and felt they needed more support, understanding and clearer information from healthcare professionals.
- People told us that they viewed some services positively, in particular - GP support, pain management, MSK and physiotherapy. Whilst mental health support was highlighted as an area of dissatisfaction.

The main improvements people told us they would like to see were:

- Better understanding and knowledge of Fibromyalgia among healthcare professionals.
- More time for healthcare professionals to explain the condition clearly to patients.
- Easier access to reliable information and ongoing support.
- Practical help from social prescribers, support groups, and occasional check-ins with primary care.
- Better support with benefits, housing, and social care applications.
- Clearer self-care guidance strategies such as hydrotherapy, meditation, acceptance therapy, and pain management.

Poll findings

Although our poll was a small statistical sample, it has helped to identify key themes, challenges, barriers and patterns relating to living with Fibromyalgia.

Overall, respondents described a need for consistent, informed, and compassionate support, with better signposting and appropriate joined-up care to help people live well with Fibromyalgia and to improve their quality of life.

I wish somebody would just take the time to explain this condition.

I wish there were more help and not just handed leaflets about fibromyalgia and off you go!!

To see someone professional who understands fibromyalgia and can help us to understand it. My physio was always blaming everything on fibromyalgia but now realises not everything is down to fibromyalgia, which is a start.

Addressing ignorance among the medical profession and having dedicated support service. My GP is under such pressure; they don't treat my condition unless something new changes.

The doctors at the hospital are still arguing over what exactly the problem is. It is unhelpful having some say it's one thing, some who say it's the other and some who say it's something completely different. There is no consistency of care at the hospitals. I constantly see locums who've had 10 minutes to read decades of investigations.

They each want to start again and treat me as a new patient. To the point, I don't want to have anything to do with them.

To be listened to and investigated sooner.

Being eligible for benefits.

Being eligible for PIP, as the current forms are set up for physical disabilities and no understanding of variable conditions.

Crawley council to allow people under the age of 55 to be eligible for a bungalow.

Fast track access to social services care application.

Self-care support strategies explained.

Understanding more as to how self-care could support.

To have a routine, with sunlight, would change my life. But I'm genuinely struggling. I am attending evening meditation classes to remain grounded, present in the moment and acceptance.

Access to Hydrotherapy.

I really think social prescribing would be beneficial.

I have heard about acceptance therapy which is important for those facing a chronic illness and the grief that surrounds the loss of your previous way of being.

Access to manual lymphatic drainage massage.

Other suggestions shared.

A more pragmatic approach to diagnosis and support -self-care, management and medical -as all three need to be working together as one area is not more important than another.

A reference point from the GP rather than keep being referred to physiotherapist, which doesn't help in the long term.

Better GP knowledge.

I don't really understand nerve pain - my pain is joint and skin, as if I've been burned so clothes are painful. Information, signposting, a map as to where to look, for 'help' to improve my life would be useful.

Maybe have groups for support.

Responders shared what support or resources would most improve their quality of life and general wellbeing.

Knowing more about this condition and how it will affect my health and future life.

My mental health would have been better if doctors take their time to explain to patients clearly. For years I blamed myself and said is all in my head.

Actual practical help from someone. I have no support system, no one around me. If I can't leave the house to get groceries, I don't eat. I don't know how to navigate getting help for that.

An occasional check-in to see how I'm doing, how my health is doing would be nice - focused on the fibromyalgia. But locally consultants give you the diagnosis pat you on the head and then you never hear from them. Or they send you on a course to help your mental health and cope with long-term illness and that's the last of you hear for a decade.

I am aware of what is out there. My GP was very good, and it was them that referred me to the Pain Clinic and services already mentioned. I would always ask for help if required.

Summary and next steps

This small statistical sample followed up on community engagement activities we carried out we heard from a number of people who had experienced challenges and a lack of support after a fibromyalgia diagnosis.

The insight we gathered indicates consistent themes, challenges and barriers relating to the impact of living with Fibromyalgia.

The Poll findings would suggest there is benefit in circulating this poll summary report once published, to our contact listing as well as primary care, musculoskeletal (MSK)services, pain management, mental health service, social prescribing, and community support teams.

Other themes and recommendations

- Professional awareness and training.
- Consider if a short briefing or learning session on Fibromyalgia could better support understanding amongst healthcare professionals.
- Improve information and signposting.
- Collate links to clear, accessible information on Fibromyalgia, diagnosis, self-care, support services, benefits advice, and local community resources.
- Mental health support concerns.
- Share feedback about dissatisfaction with mental health support and explore contact information and what additional support might look like.
- Map existing local support.
- Identify what support is already available locally, including peer support groups, hydrotherapy, pain management programmes, and practical help.
- Feed findings into service improvement conversations.
- Use the poll responses and quotes to inform discussions with commissioners, providers, and voluntary and community sector partners.

Thank you

We would like to thank all who took the time to complete the poll. Also, **Fibro Friends and Families Crawley** who supported the development of the poll.

Respondents' characteristics

Female (31)
Male (7)
Prefer not to answer (1)

Disabled (27)
Carer (9)
Long-term condition (36)

Christian (15)
No religion (18)
Prefer not to say (3)
Other (4)

Working full time (3)
Working part-time (9)
Seeking work full time (1)
Student(1)
Unemployed (7)
Retired (17)
Volunteer (2)

White British (37)
Black other (1)
Prefer not to say (2)

Talk to us

If you have questions about the content of this report, please either call 0300 012 0122 or email cheryl.berry@healthwatchwestsussex.co.uk

How this insight will be used?

We will share this report with the local NHS, Local Government, and other providers to help them understand where things are working well and services are adapting to meet peoples' needs, and to help them identify any gaps.

We see this as a continuation of discussions taking place and will continue to use this fresh insight and the solutions presented to challenge for a better future

Healthwatch is your health and social care champion.

For help, advice, and information or to share your experience

We also help people find the information they need about health, care and community and voluntary health and care support services in West Sussex.

Here to help you on the next step of your health and social care journey

You can review how we performed and how we report on what we have done by visiting our website **www.healthwatchwestsussex.co.uk**

Healthwatch West Sussex works with **Help & Care** to provide its statutory activities.

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