

Fibromyalgia Report

Experiences of health and social care services for people with fibromyalgia.

Collected January & February 2017



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1. Thank you

This report is based on the experiences of members of the Fibro Active Support group(s) in Long Eaton and Ilkeston. The group is for people with Fibromyalgia (FM) and Chronic Fatigue Syndrome (CFS) and their carers. It is a positive and inclusive group that focuses on healthy lifestyle, light exercise, support and sharing information as well as educating members about their condition and help them move forward with their acceptance and management of the illness.

They were collected at two engagement sessions between January and February 2017.

Healthwatch Derbyshire would like to thank the Fibro Active Group who supported and cooperated with this engagement activity. We would also like to thank the many participants who gave up their time to talk to us about their experiences.

2. Disclaimer

The comments outlined in this report should be taken in the context that they are not representative of all patients, and their carers who have fibromyalgia, but nevertheless offer a useful insight. They are the genuine thoughts, feelings and issues that patients, and their carers have conveyed to Healthwatch Derbyshire. The data should be used in conjunction with, and to complement, other sources of data that are available.

3. About us

Healthwatch Derbyshire is an independent voice for the people of Derbyshire. We are here to listen to the experiences of Derbyshire residents and give them a stronger say in influencing how local health and social care services are provided.

We listen to what people have to say about their experiences of using health and social care services and feed this information through to those responsible for providing the services. We also ensure services are held to account for how they use this feedback to influence the way services are designed and run.

Healthwatch Derbyshire was set up in April 2013 as a result of the Health and Social Care Act 2012, and is part of a network of local Healthwatch organisations covering every local authority across England. The Healthwatch network is supported in its work by Healthwatch England who build a national picture of the issues that matter most to health and social care users and will ensure that this evidence is used to influence those who plan and run services at a national level.

4. What is fibromyalgia? *(Source NHS Choices)*

Fibromyalgia, also called fibromyalgia syndrome (FMS), is a long-term condition that causes pain all over the body. As well as widespread pain, people with fibromyalgia may also have: increased sensitivity to pain; fatigue (extreme tiredness); muscle stiffness; difficulty sleeping; problems with mental processes (known as "fibro-fog") - such as problems with memory and concentration; headaches; irritable bowel syndrome (IBS) - a digestive condition that causes stomach pain and bloating.

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 (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 a physically or emotionally stressful event.

Anyone can develop fibromyalgia, although it affects around seven times as many women as men. The condition typically develops between the ages of 30 and 50, but can occur in people of any age, including children and the elderly. 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.

5. Why we produced this report

Following the two engagement sessions at the Fibro Active Groups in Erewash, it was agreed that the experiences may have more power if presented together rather than using the usual information sharing protocols that are used by Healthwatch Derbyshire. Also, many areas mentioned by the participants did not relate to specific services and were of a more general nature. It was felt that it would be useful to share the information across the county even though the people who put forward these experiences primarily live in the Erewash area.

Participants at the engagement sessions were not asked specific questions, but instead were invited to talk more generally about their experiences of getting a diagnosis of their condition, support from health professionals, accessing treatment and accessing other forms of support, including support groups.

The engagement sessions consisted of two group discussions with a total of 22 people. In Long Eaton there were 13 people; 11 female and two male and in Ilkeston there were nine people; seven female and two male.

The purpose of this summary paper is to highlight the themes and trends that emerged during the engagement activity and present individuals comments.

6. Key findings

There are several themes that emerged from the engagement, which are as follows:

- Lack of awareness of fibromyalgia among some health professionals
- Dignity and respect is not always given to patients
- Fibromyalgia diagnosis
 - No clear pathway
 - Difficulties in accessing rheumatologists
 - Lack of on-going support from rheumatologists
- Fibromyalgia treatment
 - Lack of consistency and choice across services
 - Difficulties in accessing appropriate medication to meet people's needs

- Mental health is often detrimentally effected by fibromyalgia
- Lack of support for carers
- There is a financial impact on people with fibromyalgia as they may be unable to work full time. Often their partners are also unable to work full time as they are a carer.

7. What people told us

There is a lack of awareness of fibromyalgia among some health professionals

Many participants spoke about lack of understanding and awareness of fibromyalgia. This included health professionals as well as friends, relatives and members of the general public. This caused distress among some participants and felt this exacerbated their condition. However, people also spoke about very supportive GPs and health professionals. People felt awareness and understanding had improved in recent years but there was room for further improvement.

For example:

“My doctor just told me to lose weight. He had no understanding of my condition and would not do me a referral to a specialist.”

“When I was diagnosed my friend said, ‘That’s for people who don’t want to work.’ She is my friend so what do other people think? The doctors and nurses need to be proactive in acknowledging the condition to reduce the stigma of it. People are ignorant of the condition and how it affects people.”

“The GP knows I have this condition but they did not know about the support group. The GPs should know that help is out there as talking to people can be of great benefit.”

“We are often told to just get more exercise. It is far more complicated than that, professionals should have more understanding and empathy. I do exercise and try to move as much as I can when I am well enough.”

“So many people have it, why don’t more doctors and clinicians know what it is? We have to become the expert in the condition and treatment. This is okay when we are feeling well but who can support us when we are not.”

“There is a lot of negative information and misinformation out there about fibromyalgia. The health professionals should be making sure that the wrong message is challenged.”

“I went to see a physiotherapist about a shoulder problem as I wanted to increase the mobility. I got a referral through my GP. When I told the physiotherapist that I had fibromyalgia, they said ‘the reason you have been diagnosed with that is because they can’t find anything wrong with you.’ When I got tearful by his attitude (this was not the only disrespectful comment) he responded by saying, ‘I don’t do crying especially in women I will leave you for a moment whilst I get you some information’ and he left the room. These were shocking comments to hear and comes from ignorance of the condition.”

“For many years I had good support from all the staff at my GP surgery. I moved to a town nearby and had to move to a GP there. The level of support and knowledge of my condition is very low in comparison. How can it be so different when it is not that far away?”

Some members of the support group felt that there was a lack of knowledge of fibromyalgia in more newly qualified GPs and that this should be addressed as part of their training.

“A specific doctor at the surgery has helped me so much. They are very knowledgeable about fibromyalgia and they are doing a talk on it to improve the knowledge of the other clinicians.”

Dignity and respect is not always given to patients

Some participants commented that they were not always treated with dignity and respect by health professionals when talking to them about fibromyalgia or their health issues.

For example:

“I just was told to lose weight by my GP. I was not treated with any dignity or respect.”

“You get labelled as a nuisance by the doctors and the surgery as you need to see or speak to someone quite regularly about how you are. We should not be made to feel guilty about this.”

“My doctor was more concerned about whether I was at work or not. I worked for almost 25 years in a school but I left on ill health grounds as my body could no longer manage with the role. I thought it was wrong for him to challenge me on this.”

“I went to the doctor in a lot of pain. He just sat there and just said: ‘I will wait until you stop rocking’. I was shocked by what they said as I was moving as it reduces the pain slightly. It was a bad experience and they were patronising throughout the appointment.”

“It is very hard to get an appointment at the surgery. When I spoke to a specific GP I felt they were not listening or interested in what I was saying. Eventually I was able to get a referral to the rheumatologist.”

“We understand that GPs cannot be experts in fibromyalgia but a bit of knowledge and a not being judgemental makes a big difference when talking to us.”

“The doctor did not know much about fibromyalgia but she was honest about it with me. They listened and responded to my concerns; this makes a difference to know you are being listened to.”

“I think they have been quite supportive [the GPs]. They did listen to me and sent me for tests to try and identify the reason for my tiredness and other symptoms.”

Fibromyalgia diagnosis

Many participants commented that they had struggled to get a diagnosis. Some people had had issues for many years before they were taken seriously.

For example:

“As well as awareness, there is a big gap in getting a diagnosis for fibromyalgia. There should be a diagnosis pathway. This would speed up diagnosis and treatment and would mean we would not have to suffer for many years not knowing what is wrong with us or thinking it is all in our heads.”

“You can get on a referral carousel as you are referred to different specialists to see if they can help you. It is good that they do the referrals but they need to be better co-ordinated and the results linked. Fibromyalgia can have many symptoms so the different specialists need to work together rather than looking at things separately.”

“I was sent for various tests over the years about my memory, pain and other things. I saw a neurologist and psychologist. I also had an MRI scan but they found nothing abnormal. I had lots of blood tests but nothing came up. As a result of a letter received from one of the specialists, they recommended seeing a rheumatologist as they thought I may have fibromyalgia. I now have a diagnosis but have still not seen a rheumatologist as my GP refuses to refer me. This is after nine years of tests, lots of visits to different specialists and innumerable GP visits.”

Difficult to access rheumatologist

Some participants felt that they had had to repeatedly ask their GP to get a referral to see a rheumatologist over a period of months or even years. In addition there was also concern about the waiting time to see a rheumatologist.

For example:

“After a long struggle with my GP to get a referral I then waited eight months for an initial appointment with the rheumatologist. When the letter came through I had been given an appointment in Swadlincote which is over 25 miles away from my home. After contacting the department I was able to change it but do not understand why it had taken so long to get an appointment or why I was not given one at Royal Derby which is much nearer to where I live and easier to get to. The communication and administration could be improved to make the system more efficient.”

“My GP finally agreed (after many visits to the GP over a long period of time) to do a referral to the rheumatologist. I later found out that the hospital had contacted the GP to see if it was urgent and the GP said not. I was upset about this as I had wanted to attend the rheumatologist for many years. They had disrespected my wishes and not considered it as urgent.”

“My GP did an urgent referral for me in November; I got an appointment for the end of March. I was not happy that I had to wait this long.”

Lack of on-going support from rheumatologists at hospital

Participants spoke about the lack of follow on and on-going support from rheumatology.

For example:

“When I got my diagnosis that was it. I have never been back to them to see how I am, or if there is anything else they can do.”

“You just get your diagnosis from the rheumatologist but then you are referred back to the GP to prescribe your medication. They do not have the specialist knowledge on the condition and they are not always supportive.”

“Once you get diagnosed there is no follow on except to pain management, if you are lucky.”

Fibromyalgia treatment - no consistency or personal choice

Participants gave mixed reports about treatment. Some were referred to physiotherapists, some to pain clinics or to rheumatologists. None were referred to other wellbeing options, yoga, gentle exercise, meditation, mindfulness etc.

For example:

“There is a lack of consistency in treatment for us in this area (Erewash) among the GP surgeries so just think what it is like across the county. I think it depends on surgeries funding which is not right.”

“I think there is a gap in knowledge as there is help out there. I have used the counselling services and the voluntary sector has activities and courses that can help. The doctors should know about them and tell people.”

“One named doctor has been very supportive and understanding of my condition.”

“None of the staff at the surgery had any idea about the support group (Fibro Active). I found out about it another way.”

“It is hard to get an appointment at the surgery. The GP who I like to see, who understands about fibromyalgia, works part time. It takes such a long time to get things resolved.”

“The help I received from the staff at the Royal Derby Hospital CFS chronic fatigue syndrome/ME team has been wonderful. The physiotherapy was particularly helpful.”

Medication

Some participants spoke about their experience of receiving medication to relieve symptoms of fibromyalgia.

For example:

“I have only been told to take paracetamol. It does not even touch the pain.” Members of the support group were shocked that this person had not been prescribed any medication. They advised the participant to return to the GP to enquire about more effective pain relief.

“I went to the practice nurse for a mediation review. I felt quite challenged as she was questioning why I was on anti-depressants and that I should stop taking them. I told her that I took them because of my fibromyalgia and not because of depression. They help to relax my muscles and help therefore to aid sleep. The lack of knowledge in the people carrying out the reviews needs to be improved so people do not have to justify the medications that they are on.

“I have been asked by my GP to reduce the tablets I am on as they are expensive. I have a good relationship with my doctor and after discussion I have altered the dosage; rather than taking the tablets three times a day I now take stronger ones twice a day. This is cheaper but it still provides the pain relief I need.”

“It has worked well for me with the surgery. Fibromyalgia is different for everyone and one medication does not suit everybody. Over time I have worked with my GP to find out which combination of tablets are right for me.”

“Getting medication to help me with the pain is almost impossible. I had two heart attacks last year which means I cannot take tricyclics (Tricyclic antidepressants (TCAs) are chemical compounds used primarily as antidepressants but are frequently used to treat fibromyalgia). I am in lots of pain most of the time but there is nothing I can take that helps.”

“You get labelled as a fat person by the doctors and the public, but a lot of the medications that you need to take to help with the symptoms can cause you to gain weight. I gained three stone with one medication.”

Members of the group agreed that there was a great variation in prescribing medication for fibromyalgia. It can depend on the knowledge of the GP of the condition and the relationship with the patient. Participants spoke of requesting specific medication as they had knowledge of it. There was concern in the group that there were also issues of funding for medicines that each surgery has and this can have an effect on what medicines are prescribed.

Mental health & depression

Participants spoke about their mental health needs relating to fibromyalgia. This often related to long term pain and no longer being able to carry out tasks that they had previously done; also the effects of ‘mind fog’. However, some people wanted to say that they were not depressed when some health professionals said they were. Other people said that their pre-existing mental health issues were not appropriately addressed.

For example:

“I am not depressed and I do not like it when people say that I am. I take anti-depressants but they help to alleviate the symptoms of fibromyalgia. I do have bad days, but so does everyone. Doctors should not assume that everyone with fibromyalgia is depressed. I know people who are but we are all different and our condition should be treated individually.”

“I have had clinical depression for many years. Because of my mental health, I felt I had to fight even harder to get acknowledgement of my physical pain and wait for many years before I got my fibromyalgia diagnosis.”

Support for carers

Participants mentioned the help they received from loved ones. Their carers did not receive support. Some participants said their partners were their full time carers.

For example:

“Some days I cannot get dressed without support. My husband has to wash my hair as it causes me too much pain to do it myself. My husband now looks after me full time.”

“Sometimes I have no energy to even cut up my food. I do not know what I would do without the support of my partner.”

Financial impact

Some participants raised concerns about the financial impact of fibromyalgia.

For example:

“We struggle to manage financially as my husband cannot work as he cares for me.”

“We have to manage on my husband’s pension and nothing else.”

Participants felt that it is complicated trying to get help with benefits and how the new PIP system works.

Participants felt that some doctors are not willing to support patients in their benefit claims and in signing the relevant forms in a timely manner.

“I was pleased that the surgery sent me for blood tests when I raised my concerns. Unfortunately they have not been as supportive with regard to my ‘fit notes’ to present to the benefits office.”

8. What should happen now?

Services and commissioners should consider:

- Improving awareness among health professional of fibromyalgia
- Being proactive in reducing the stigma of fibromyalgia
- Educate health professionals and the general population of fibromyalgia to improve dignity and respect
- Providing and promoting a diagnosis pathway for fibromyalgia
- Equal access to treatment for fibromyalgia across the county, including on-going access to rheumatologists if required
- Health professionals to work with patients to find correct medication and treatment to manage the condition so they have a good quality of life
- Improved access to mental health support for people with fibromyalgia - not restricted to six sessions
- Support for carers of people with fibromyalgia
- Improved access to and signposting to other wellbeing services that could be of benefit to people with fibromyalgia.

9. Service Provider Responses

Derbyshire Community Health Service NHS Foundation Trust (DCHS)

DCHS is committed to being a system partner in providing high quality care to all patients with chronic pain conditions. Our offer to people living with long term conditions, including fibromyalgia includes physiotherapy, occupational therapy and health psychology. Health psychology enables patients to manage their conditions with less dependence on pharmacological therapy and the associated risks. The service also provides training and consultancy to health care staff working with such patients and their families.

The contents of this report have been shared within the organisation, and will be considered by the Patient Experience and Engagement Group.

Royal Derby Teaching Hospitals NHS Foundation Trust

Many thanks for giving us the opportunity to respond to this report and all our staff who have contributed to this response have indicated that they found it very helpful to hear and understand better the views of patients diagnosed with fibromyalgia.

To commence, it may be of importance to note that presently a specialised or bespoke fibromyalgia service is not provided at the Trust as it is a service that is provided in the Primary Care setting. However, whilst our rheumatology services may not provide a specialised fibromyalgia service, GPs can, and often do, refer their patients to rheumatology in order to rule out other possible conditions that might be causing their symptoms. Fibromyalgia is recognised as being difficult to diagnose as there is no definitive test for the condition; instead it is diagnosed by eliminating any other possible causes of the symptoms. Therefore, if tests are negative for other conditions, the patient is examined for specific tender points in 18 sites of the body. If 11 of the 18 pain points are

positive and certain other reported symptoms are present, fibromyalgia is the assumed diagnosis. Once this diagnosis is made, the patient is usually discharged back to their GP for on-going care as the rheumatology department itself can only provide reassurance and offer further management advice to the GP.

Unfortunately the path to diagnosis of fibromyalgia is often prolonged and unfortunately treatments for this condition often fail to fully relieve the symptoms of fibromyalgia. There is however evidence suggesting that certain exercise/physiotherapy therapies, drug treatments and talking therapies can be of benefit to many people. Hence, many patients with fibromyalgia are referred to the Trust's pain clinic (where pain is the main symptom) and in fact 20% of the total patients attending at the pain clinic are patients with a diagnosis of fibromyalgia.

Over the last few years this number has been increasing; this could be in part due to patients finding it easier and quicker to gain a diagnosis or conversely, due to an increase in the actual number of people suffering with fibromyalgia. The pain clinic has over 20 years' experience of using the above approaches to help patients with fibromyalgia and, because we accept individuals with the condition may have spent several years suffering before getting their diagnosis; we therefore aim to see patients referred to the clinic within 18 weeks, in order to put these evidenced based treatments into practice as soon as possible. As part of the holistic approach to care for fibromyalgia that we advocate in the pain clinic, we have experience of helping patients find support for many of the clinical, social and financial challenges that fibromyalgia presents.

As a result of listening to our patients with fibromyalgia, we have recently altered our pathways for treating patients with this condition, allowing us to direct fibromyalgia patients to the correct treatment and care more rapidly following referral to the pain clinic. The doctors and nurses who work in the pain clinic endeavour to educate other health care professionals about fibromyalgia, its impact on the patient and the best treatments available to help with managing this condition. We have done this previously through fibromyalgia awareness days, lectures to GPs and other health professionals within the Royal Derby Hospital, and also through direct communication with doctors in primary care.

The pain team from the Royal Derby Hospital has played an important role in trying to shape the future of pain services in Derbyshire through our inclusion in local commissioning groups and the chronic pain Clinical Interest Group. These forums have allowed us a platform to discuss fibromyalgia and argue for a more comprehensive and coherent approach to chronic pain treatment generally and fibromyalgia care specifically across the region.

For the future, we will continue to try to treat fibromyalgia patients, in line with nationally agreed best practice, within the pain clinic at the Royal Derby Hospital. The pain clinic will also continue to engage with an active programme of education for health care professionals in acute and primary care settings, highlighting the issues surrounding chronic pain and fibromyalgia care.

Other areas who treat patients with fibromyalgia within the Royal Derby Hospital are the Chronic Fatigue Service (where fatigue is the main symptom) or physiotherapy or

occupational therapy for further advice and education on managing the condition. The GPs are also aware of other local support groups and national support groups for this condition, to which patients can be signposted.

Specifically, regarding the issue of the length of wait for GP referred patients to be seen in our rheumatology services; over the past months, the rheumatology department has seen their staffing resources diminished due to consultant sickness and maternity leave. This has unfortunately affected and extended the waiting times for routine out-patient rheumatology appointments beyond the timescale we would ideally want to offer.

However, it is pleasing to note that our Rheumatology Department is presently back up to full medical staffing levels and also a newly recruited additional rheumatologist consultant is to be appointed; this will help reduce the waiting times for our future routine outpatients, to a more acceptable and reasonable length of time.

Reports from patients suffering with fibromyalgia, such as this current report, allow the pain clinic and indeed other affected service areas, to reflect on our practice, consider ways to develop the service and challenge the way we currently work. Without the input of patients who have experienced the workings of the system, this would not be possible.

Your feedback

Fibromyalgia Report

Healthwatch Derbyshire is keen to find out how useful this report has been to you, and/or your organisation, in further developing your service. Please provide feedback as below, or via email.

1) I/we found this report to be: Useful / Not Useful

2) Why do you think this?

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3) Since reading this report:

a) We have already made the following changes:

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b) We will be making the following changes:

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.....
.....

Your name:

Organisation:

Email:

Tel No:

Please email to: karen@healthwatchderbyshire.co.uk or post to FREEPOST RTEE-RGYU-EUCK, Healthwatch Derbyshire, Suite 14 Riverside Business Centre, Foundry Lane, Milford, Belper, Derbyshire, DE56 0RN