

# Listening Event

## Luton resident views on Fibromyalgia

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## What are Healthwatch Luton's Listening Events

During the COVID-19 pandemic, Healthwatch Luton continued to gather views online via teams / zoom and surveys to capture people's views. In 2022 we began to also reinstate our face to face engagement, working in the community to gather views and feedback on services.

Our Listening Events are created from subjects or topics raised by Luton residents where they wish to give feedback in this medium

Listening Events are online forums on particular themes or topics and are to provide a space for residents to provide feedback to us on their experience.

They are managed by Healthwatch Luton's Signposting and Communication Officer and Volunteer and Development Officer, and ask the three key questions on NHS / Social Care reform:

- What works well
- What does not work well
- How can it be improved

The Listening Events are managed to ensure people are able to have their voice heard in an inclusive environment, and help to shape the views of residents on topics, themes, issues or subjects.

In 2022 we hope to marry these Listening Events with Information Events similar to these themes. Providing residents with information out to them on various topics. You can see more details on our website.

## Methodology

All views are taken anonymously during the Listening Event, and thematic summaries are provided to report on.

The reports are then provided to an inhouse Peer review under our Advisory Sub Group to the Board of Directors to ensure the information is able to be published and adheres to Data Protection Laws.

## What were the themes of people's experiences of Fibromyalgia in Luton?

People attended our Fibromyalgia Listening Event on the 26<sup>th</sup> May 7-8pm 2022.

Overall the themes of people's experiences of this condition in Luton were:

- Individuals with fibromyalgia in general were diagnosed with multiple conditions, for example diagnosed with rheumatoid arthritis in addition to fibromyalgia. But they weren't given any medication for it. Some individuals self-medicate with pain killers but find that morphine is the only thing that helps, however it is addictive. Having other conditions alongside makes symptoms of fibromyalgia worse and they are in constant pain. However taking pain killers makes it difficult to have a life. Sleep is difficult due to constant pain.
- Individuals feel differently everyday and no two days are the same so cannot predict and plan life.
- Consultants specialising in different conditions do not take into account other conditions for example the diabetic consultant at hospital didn't want to know anything about arthritis. However the rheumatoid specialist asks about everything.
- Some individuals struggled to get diagnosed and took years for the symptoms to be recognised.
- Once diagnosed there were no offers of help or support. There is no information available and Individuals have to do their own research.

## What has worked well?

- Helped to join a Fibromyalgia support group and it helps to listen to other people. However there monetary constraints for a meeting room and it needs to be accessible.
- Having a hospital bed, which is electric and has a memory foam mattress helped to improve sleep a little bit.
- Gabapentin medication for pain helps but the side effects makes individuals become overweight.
- Keeping a food diary helps some individuals find the triggers for a flare of symptoms of fibromyalgia.
- Keeping away from stressful situations helps as stress can be a trigger.

## What has not worked well?

- GP appointments aren't very long which isn't very helpful and due to multimorbidity issues, need to see the same doctor who knows and understands the individual.
- Seeing a GP who knows about fibromyalgia and knows your case history would understand the side effects of taking pain killers and other medication.
- One individual was prescribed a pain killer that was not meant to be given and there was a lack of communication.
- There should be understanding about an individual's condition and needs.
- Most individuals diagnosed with Fibromyalgia also experienced menopause, IBS, blood pressure and cholesterol issues.

## What could be better and improved?

- Individuals need to be listened to and believed and not be told that it is all in the patients head.
- GP's should receive training on Fibromyalgia.
- Having a fibro clinic and pain management programmes could be helpful
- Medication for everyone that works
- Hope is that long covid research will help fibro as well as symptoms are similar and no two days are the same. Each day is different and one can't predict so difficult to plan life.
- A specific contact at surgeries who should be educated on particular subjects, all interlinked- like menopause, fibro: otherwise individuals have to research on their own
- All information and details of support for long term conditions should be in one place that one can pick up. Information should be made simple- easy terminology.
- Need to know the role of the person they are getting care from.
- Better access to appointments- one participant mentioned waiting for three weeks, have to call on the dot at 8:30. Then the wait times make you forget what you are ringing for.
- Consultants need to ask about other conditions, treat the person as a whole.
- Back and knee specialists don't talk to each other- consultants could all meet together, all link up and discuss condition. Person centred

care, not condition centred care. Having medical teams together would help.

## What can Healthwatch Luton do?

We will share your experiences and themes with the health and care system, publishing anonymously your experiences, for the public, providers and commissioners to see.

We will support individuals in signposting providing advice and guidance, and escalating areas of concern.

We will report findings to the integrated care system, who commission services across BLMK for them to raise the experiences in their service planning and design.

We will use these reports to document ongoing experiences of Luton residents, both sharing locally, regionally and nationally to ensure these views are taken into account when planning and delivering services.

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