Living with Fibromyalgia - ​ 20th February 2024

**The Workshop:**

The purpose of the workshop was to provide an opportunity for local patients and carers to help shape what future support could look and feel like with the aim of potentially developing a structured self-management programme. During the workshop, we wanted to: ​

* Understand what we could do better
* Provide an opportunity for people to help shape future support systems
* Explore some of the barriers that people feel when they face trying to access care and support

**How we organised the workshop:**

We asked key speakers to join us to provide context to the current services and support available for patients. After setting the scene, we split attendees into break out rooms with a facilitator and worked through some questions whilst allowing opportunity to explore thoughts and opinions​.

Over 80 people joined the workshop all eager to find out more, hear from others and share their experiences.

**Guest Speakers:**

**Dr Rainer Klocke​** - Consultant Rheumatologist**​**

**Halima Bashir​** - Primary Care Network Lead Pharmacist- Brierley Hill and Amblecote​

**Sarah Lee**​ - Clinical Lead Community Dietitian - Adults​

**Alex Deutsch** ​- Advanced Pain Practitioner​

**Jo McGoldrick**​ - Health & Wellbeing Coach, SWL PCN ​

**Richard Tasker**​ - Lived experience expert

**Themes:**

Although we had questions we wanted to ask, the conversation flowed and the following themes came up.

* It feels like we are given a label
* No one really understands it – like it’s a made-up illness and you get fobbed off
* We know it’s our responsibility to manage our health but we need support and advice to do this
* It can feel so isolating and debilitating
* Just because we look okay on the outside it doesn’t mean we are
* We need more than just medication – we need a holistic treatment plan

**What are some of the biggest barriers?**

* Managing our health
* Impact on our mental health
* Accessing the right healthcare
* Other underlying medical conditions that have an impact
* Lack of education for us and others
* Work life balance
* Access to additional support
* Finding motivation

**Motivation**

* Having the motivation and realising that you have to take ownership
* The weather can often increase pain symptoms for some people
* Have to plan way in advance
* Needing rest days and ‘do’ days
* Struggle to set goals
* Starting somewhere new for work/leisure
* Breakthrough pain and feeling that you don’t want to socialise
* You prioritise what you have to do rather than what you want to do

**Personal Health**

* Losing weight is difficult
* Would like to exercise but there are cost implications
* Isolation and struggles due to the symptoms; draining, brain fog and pain
* Difficulty managing unexpected flare-ups whilst trying to get on with day-to-day life and/or working full time
* Lack of sleep
* Having to take time off after doing anything
* Stomach aches

**Mental Health**

* Depression
* Bias that it’s all in your head and the negative effect this has on those suffering.
* Feeling disconnected from other people
* There's a lot of anxiety around this, which causes you to self isolate
* Struggle to be kind to themselves
* Losing your sense of identity as a person
* You get angry because people are dismissive of your condition

**Work life**

* Working full-time and being in pain as well
* Waiting for months for them to do a risk assessment
* Working is hard due to lack of understanding, been told I have had lots of time off, but have chronic fatigue
* Struggling with pain management - currently on morphine patch and work doesn't understand
* Work is so hard now, doing 30 hours, which isn’t a lot but everyday is a struggle.

**Lack of education**

* It’s not recognised by others and can also be seen as a label
* Seems to be aimed at middle aged/older people with no recognition for young people suffering with the condition
* Ignorance towards the illness as it’s “invisible”
* Dismissed - seen as a hypochondriac / several GP appointments
* Confusion about what "healthy eating" and "exercise" mean for individuals with fibromyalgia

**Other underlying medical conditions**

* Dealing with additional underlying medical conditions
* How it morphs with other conditions such as ME and you can end up having several co conditions
* Other conditions which are also aligned to fibro, feeling like you are a burden especially on your children

**Healthcare**

* Accessing GPs and changes to medication
* Not being heard or listened to by healthcare professionals
* Co-morbidities relating to the fibromyalgia and diagnosis takes so long to obtain, sent to different experts with no clear answers- The whole process was just over 18 months long
* Fibromyalgia diagnosis could have been earlier, however healthcare professionals opted to investigate the possibility of other long-term conditions first
* Some GPs are referring out of the Dudley area and this has an impact on travel time/accessing appointments, particularly during work time.
* Even when simple referral options exist, uptake depends on GP engagement
* Lengthy waiting times for some services
* Feel like a burden to healthcare providers
* Treatment is gendered as the majority of people with fibro are women

**Additional support**

* Financial support
* Lack of research and support for those around people living with Fibro
* Self-management programmes exist but lack referrals from GPs. More awareness is needed about available resources
* Was diagnosed when I was 17/18 years old, so I look young and healthy which is hard when suffering, had issue with working due to the inconsistency of symptoms and being unwell

**Tell us about some of the positive experiences:**

* Personal techniques
* Support services
* Work life support
* Friends and family support
* Peer support
* Healthcare
* Fibromyalgia workshop

**Personal tactics**

* Goal setting
* Laughter, proper laughter
* To keep living, to keep pushing yourself, to keep saying yes even though you know you're going to struggle tomorrow or the week after because of it but to keep going
* To build in a confidence to say no I can't do that no I'm not going to do that or that doesn't work for me. To build confidence to put in boundaries when you meet with family or friends or work, and you say I will be finishing early today, or I won't be going on that walk, or I will need to sit down
* Mindfulness looking for the joy and the positive experiences in life helps reduce the anxiety
* Something for me like a bath, or a film but taking guilty pleasures
* Going to the gym once you push through the initial pain/tiredness barrier
* Low energy workout classes and aqua classes
* Going on holiday and lying in the sun is brilliant for the bones
* Reading
* Developed a routine for activity and diet – little and often
* Forcing myself to socialise

**Support Services**

* Thrive into work have been helpful and talking therapies
* Expert patient programme
* Pain management clinics for additional support
* Some GPs have been supportive but not all.
* Lots of discussion about self-management programmes and how they have been beneficial in helping people set small, achievable goals.
* I’m going to set up a workplace support group, which will hopefully help

**Work Life Support**

* Beneficial having supportive employers, option to work from home has made a significant impact for lots of people, particularly in pain management.
* Now retired, had regular reviews with health and safety person, company put in lots necessary equipment to support work.
* Pandemic bringing a change to work dynamic/being able to work at home
* Fellow colleagues have been supportive with the move to working from home

**Friends and Family support**

* Working with family and friends to get that support
* Having a good support network around you
* Being around grandchildren or children or loved ones who understand and get it and believe you it's very healing
* Good family support
* Loving family/support network

**Peer Support**

* Being able to engage and form friendships with those who are also suffering and fully understand it
* Allowed the ability to feel heard and understood
* Peer-led support provides useful education on managing symptoms
* Having people around who are ‘non-judgemental’
* Interaction with others is key as it can be a very lonely condition to live with
* Peer support and learning from others experience

**Healthcare**

* Seeing healthcare professionals that offer empathy, time and understanding of the impact of living with fibromyalgia
* Seeing the same healthcare professional
* Some GPs are very engaged, knowledgeable doing the appropriate referrals. One person shared that she felt ‘lucky’ to have the GP that she has.
* Exploring other options such as acupuncture and CBD
* Just having conversations with professionals who understand the struggle

**Fibromyalgia Workshop**

* Sessions like today to find out more and meet others who suffer – it can be quite lonely

**What would help you overcome barriers?**

* Support groups
* Access to exercise
* Self-care/ self-care courses
* Support services
* Education and training
* Healthcare

**Support groups**

* Advice on where to go or what to do if you have a flare-up - there is no support
* Fitness groups with fibro in mind, love a team sport/activity helps with motivation, but don't want to let the team down lol. But also, as a young man, it is a little embarrassing as they seem to be for an older group (32yr old)
* This session is a step in the right direction for others who don’t have fibro, to see how debilitating it is
* More local support e.g. support groups

**Access to exercise**

* Online exercise classes
* Having discounts available for local leisure centres/swimming pools so that exercise can be more suitable and accessible.
* Access to a hydrotherapy pool
* Allocated times for swimming sessions (like autism hour) to avoid crowds, noise, etc.
* Clearer guidance on pacing, diet, and exercise specific to fibromyalgia
* Walking pad at home for exercise/movement

**Self-care/self-care courses**

* Availability of a structured self management programme
* A monthly check-in with people 6 weeks after attending any self-care courses
* Knowing and understanding your own body, not overdoing it, pacing yourself
* Positive self-talk
* Prioritising and making time for the things that make you happy, focusing on the positives where possible etc.

**Healthcare**

* A GP with a specialist interest
* It can be too medicine driven and we are too reliant on it. What about the help that vitamins and alternative therapies can offer
* Advice on vitamin D – what doses do we take and what are the contraindications
* We didn’t know about health coaches before we did the workshop and that they could help
* Access to a good osteopath
* To get definite answers because the not knowing is very difficult to live with
* Quicker diagnosis
* Increase in GP engagement in referring patients to available support groups.
* Annual check-up, including blood tests.
* Better understanding and knowledge from primary care on inflammatory markers
* A holistic treatment plan for fibro can mask other symptoms.
* Managing medication – giving my own thoughts on what I think I need
* Honest conversations about medication and the management of this with GP’s/doctors

**Support services**

* Accessing support services like – Just Straight Talk and Dudley Community Information
* Having options of face-to-face or online would be helpful.
* Introduction of fibromyalgia advocates/navigation for patients in GP settings
* Workplace events within the community
* A special phone line for when I have a flare-up
* The mental health side of fibro needs to be better and more timely – there needs to be a variety of support

**Education and training**

* Acknowledgement that fibro is real
* Knowing what is out there and where to go and it being better promoted.
* To not only have informed staff dealing with us but also empathic staff dealing with us so more empathy an understanding and less dismissive attitude
* Improving education for health care teams and easier access
* Education for employers and managers – understanding of impact both physical and brain fog symptoms
* Education available for family, carers to access both written and online materials
* Overall promotion of fibromyalgia services available across Dudley plus increased awareness and education for both patients and healthcare professionals.
* An information pack that I can give to my work to help them understand
* Other issues have an impact on fibro, so help with them - minor illnesses like a cold etc, flares up fibro.
* Having a manager who has a real understanding of the condition and how it can affect your work
* More awareness forums – increase the awareness and understanding of the condition - encouraging GP’s to attend

**What could we do better?**

* Public education
* Research
* Alternative/holistic
* Visibility/accessibility of services
* Healthcare training and awareness
* Healthcare
* Support services
* Support groups

**Public education**

* Spread the word better to help with the loneliness aspect
* Sharing of studies such as King’s College – Fibro study (2021)

**Research**

* Having a questionnaire at the start and end of the project to measure its success depending on objectives.

**Alternative/Holistic**

* Natural supplements on prescription / Self-help techniques

**Visibility/accessibility of service**

* Make support groups more known as well as health coaches
* Have an interpreter for those who may also be deaf
* Talking therapies specific to fibro
* Create more accessible educational resources to help individuals self-manage their condition effectively.
* The dietetic update was enormously helpful

**Healthcare training and awareness**

* More education for medical professionals on fibromyalgia
* Self-management programme; accessible at different times of the day
* The 6-week program sounds good, especially for newly diagnosed people with sessions
* Information about help and support
* Better explanation of what fibro is and what can affect you
* 6 week rolling programme of support

**Healthcare**

* Advocate for more GP/primary care awareness that can increase referrals and engagement in self-management programmes.
* Create more accessible educational resources to help individuals self-manage their condition effectively.
* Help with sleep disturbances and fatigue
* Improvement on referral processes
* Re-instill confidence in the system

**Support services**

* To include MDT (multi disciplinary team) that can support with relevant symptoms
* Strengthen collaboration between support services and healthcare providers.
* Have a 6 week plan outside of work hours
* Benefit from online pathways/sessions such as these
* Help and support to access the services needed, quicker
* 6-week plan is not long enough, not enough time to cover all of the factors that effect the patient’s day-to-day life

**Support groups**

* Support groups both face-to-face and online and hybrid in an accessible space
* Find something you love and a group that does it
* Wellbeing Hub in the community with access for individuals who work during the day
* Peer groups for sharing lived experiences and connection to enhance the sense of belonging, as fibromyalgia can lead to feelings of isolation.
* A physio led exercise class online or in person, and recorded so people can do it in their own time

**Do you know what support is out there for you?**

This question was met with silence and shrugging, basically the answer was no without anybody really saying it. Then they started saying apart from the GP and the pain management there's nothing.

I asked around community and volunteer groups, and lots of shrugging, but nobody's looked into it or checked it out.

**Post Fibromyalgia Workshop Survey Responses#**

33 survey responses. The key themes were:

* Streamlined provision for a quicker diagnosis
* Raising awareness of fibromyalgia and associated symptoms
* Education for improved symptom management and lifestyle
* Improved education for Healthcare Professionals, in particular GP’s
* Support and provision within the community i.e. low impact exercise classes
* More information and awareness for families and carers
* Workplace support and education for employers

**What three things do you feel are most important to you living with fibromyalgia?**

19% said Being believed. Compassion, acceptance.

19% said Support. Lifestyle, employment, pacing, raising awareness.

15% said Improved Symptom Management. Understanding pain pathways and symptoms.

11% said Understanding from healthcare professionals and family.

10% said Education & Knowledge, Living with fibro, MH, relaxation, exercise.

**Please share a real-life experience that identifies how the current service has aided you:**

Responses to the question were largely negative, with perceived limited support available. Clinicians often offer medications for pain management but demonstrate little understanding of the underlying issues.

“No help or recognition from my GP Practice for fibromyalgia.”

“I don’t feel it (my fibromyalgia) has been recognised yet but maybe after this invitation & professionals out there, things may change now.“

A handful of responses provide positive feedback on their experience.

“I have a wonderful consultant who has supported me through my journey with fibromyalgia.”

“My GP has worked with me to titrate my medications to get the best balance between benefits and side effects listening to me.”

**Do you feel a six-week self-management programme would better enable you to understand and manage your fibromyalgia?**

An overwhelmingly positive response to a six-week fibromyalgia self-management programme, and 87% of participants feel that this additional support would be very beneficial in helping them to navigate their way through:

“Yes, and this would be especially helpful for newly diagnosed. I did a lot of research myself as not supported after diagnosis.”

“I would greatly appreciate any support, information, programme that better educates me regarding my fibromyalgia symptoms.“

**Which one improvement could be implemented to enhance the care pathway for fibromyalgia patients?**

Participants provided some valuable ideas for implementing improvements to current provision:

* Educate and increase the level of understanding for GPs and healthcare professionals
* An exercise programme with fellow sufferers where you could meet weekly or monthly like there’s an exercise class for people with Parkinson’s in certain areas
* Point of contact for medical enquiries and signposting to services etc
* Being made aware of the services out there already and maybe exercise classes?
* Designated Dr who specialises in fibromyalgia
* The multi professional team working seamlessly together in order for a speedy diagnosis
* Educating medical professionals about fibro and dispelling myth that it is "all in their head"
* Fast track clinic
* Having a good contact, i.e. counselling and pain management and especially talking to others who have this condition
* Flexible working options & career adaptations

**Thank you:**

Thank you to all the amazing honest attendees who shared their journeys and experiences with us. We had an overwhelming response for people wanting to join the session which was quite humbling, and it really highlighted the struggles that many are facing on a daily basis. We know we can be stronger together and make the difference that we all need.

‘Thank you for trying to help us feel less alone.’

‘This meeting was fantastic, well done. I'm not expecting sweeping change overnight, just happy to see work being done on it.’

‘I would like to thank everyone for today's workshop. It was enlightening.’

**Next steps:**

We are working with colleagues across health and care to see whether we can develop a self-management programme.

We are exploring what is needed in the programme based on your feedback and seeing which staff can support it.

We may run a pilot/trial and seek feedback, so we know whether the programme is working.

We would like to roll this out as soon as possible and we will update you on what happens next.

**Help groups:**

**Black Country Fibromyalgia Support Group**

Nine Locks Community Centre, Hill Street, Brierley Hill, DY5 2UE

07485 473164 (Helpline: Monday-Friday 10.00am-4.00pm)

**Ideal for All**

(Fibromyalgia Support Group)

2 Independent Living Centre, 100 Oldbury Road, Smethwick, West Midlands, B66 1JE

0121 558 5555

[info@idealforall.co.uk](mailto:info@idealforall.co.uk)

**Fibromyalgia Action UK**

(helpline: 0300 999 3333, Monday to Friday, 10am to 4pm)