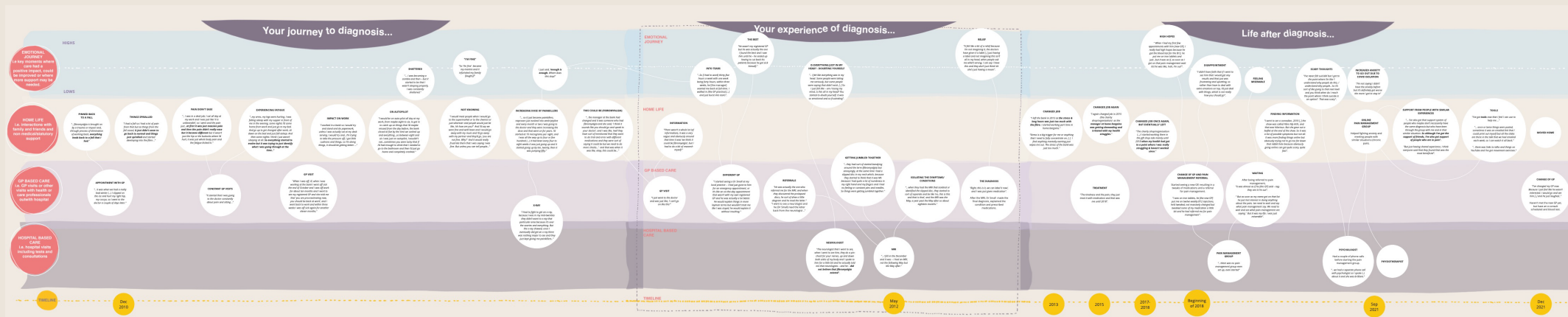


experience map  
*fibromyalgia*

# Overview of all maps



**What matters to you?**  
See in detail on page 3



**Your journey**  
See each panel in detail on pages 4-6

**What could be better for you?**  
See in detail on page 7



# What matters to you?

## GOT MORE AND MORE DIFFICULT

"I used to be quite outgoing, like working with the public, but I haven't worked for about three years.  
(...) I was off work and then I ended up changing my job and went part-time ..."

## USED TO BE MORE SOCIABLE

"I used to go to aerobics and Pilates, maybe once, twice a week for each. I used to walk everywhere, I used to go out with work friends, I used to go out with friends, be a bit more sociable and just all of that stopped."

## UNDERACTIVE THYROID

For about 20 years, and needs checked once a year.

## My condition(s)..

## How I spend my time...

### AT HOME

"My days are just really spent doing bits and pieces at home, obviously cleaning and things spread out over the week, as opposed to a day or two like way before illness."

### READING

"I like reading when I don't feel too tired to concentrate (...)"

### QUITE QUIET

"I've got quite a small circle, just family and friends orientated."

## People in my life...

### SUPPORTIVE FRIENDS

Best friend 'A' and friend 'T' are very supportive.

"I worked with 'T' in a job before I worked at the bank when I got ill. So I'd known her and I just became part of the family, it was like my second home, 'T' was my salvation at that time".

"Mum (...) My little sister, she put her dog down to live with me, so there's just me and the dog (...) I see my boyfriend (...)"

## Where I live...

### LOVELY VIEW AND PEACEFUL

"I live in (...) a little flat by the harbour.

(...) been in the building for coming on for three years but I've just moved (...) to the flat above where I've lived before, just a couple of weeks ago."

## About you...

# Your journey to diagnosis...

HIGHS

LOWS

**EMOTIONAL JOURNEY**  
i.e. key moments where care had a positive impact, could be improved or where more support may be needed.

**HOME LIFE**  
i.e. interactions with family and friends and non medical/statutory support

**GP BASED CARE**  
i.e. GP visits or other visits with health or care professionals outwith hospital

**HOSPITAL BASED CARE**  
i.e. hospital visits including tests and consultations

**SHATTERED**  
"... I was becoming a zombie and then - but it started to be that I wasn't sleeping properly, I was constantly shattered."

**"I'M FINE"**  
"So 'I'm fine' became my mantra and it infuriated my family [laughs]!"

I just said, 'enough is enough. Where does this stop?'

**PINNED BACK TO A FALL**  
"... fibromyalgia is brought on by a trauma or impact and, through process of elimination of working back, **everything leads back to a fall that I had.**"

**THINGS SPIRALLED**  
"I had a fall so I had a lot of pain from that but as things from the fall eased, **it just didn't seem to go back to normal and things just spiralled** and started developing into the fibro ..."

**PAIN DIDN'T EASE**  
"... I was in a desk job; I sat all day at my work and I was just like 'it is unbearable', so I went and the pain just... **at first it was just massive pain and then the pain didn't really ease but it became different** but it wasn't just the hip or the buttocks where I'd hurt, it was just whole body pain and the fatigue kicked in."

**EXPERIENCING FATIGUE**  
"... my arms, my legs were hurting. I was falling asleep with my supper in front of me in the evening, some nights I'd come home from work and just go to my bed. And go up to get changed after work, sit down on the bed and just fall asleep. And then some nights I think I just wasn't sleeping at all. **So everything started to evolve but it was trying to just identify what I was going through at the time.**"

**IMPACT ON WORK**  
"I worked in a bank so I would try and stand and do paperwork, unless I was actually sat at my desk serving. I would try and... I'm trying to take the pressure off. I got little cushions and things, so I'm doing things, it should be getting better ..."

**ON AUTOPILOT**  
"I would be an auto-pilot all day at my work, from maybe eight to six, to get in to catch up on things that I'd maybe missed from the day before, the bank closed at five by the time we cashed up and everything... so between eight and six I was just on autopilot, I wouldn't eat... sometimes you were lucky that if I'd had enough to drink that I needed to go to the bathroom and then I'd just go home and completely crashed."

**NOT KNOWING**  
"I would meet people when I would go to the supermarket or to the chemist or just wherever and people would just be like, 'oh how are you?' And I'd say we were fine and we'd leave and I would go away with my mum and I'd go away with my partner and they'd go, 'you are not fine. Why?' And it would really frustrate them that I was saying I was fine. But unless you can tell people..."

**INCREASING DOSE OF PAINKILLERS**  
"... so it just became painkillers, naproxen just evolved into amitriptyline and every month or two I was going to the doctor and they were increasing the dose and that went on for years. I'd started at 10 micrograms per night, and I was all the way up to four or five hundred (...) it had been every four to eight weeks it was just going up and it started going up by ten, twenty, then it was jumping fifty."

**THIS COULD BE (FIBROMYALGIA)**  
"... the manager at the bank had changed and it was someone who had fibromyalgia and she said, 'I think it sounds like you should go and speak to your doctor', and I was like, 'well they have sort of mentioned that they want to do trial and error with different medications and they were sort of saying it could be but we need to do more checks...' and that was when it was like, okay, this could be..."

**APPOINTMENT WITH GP**  
"... it was when we had a really bad winter (...) I slipped on the ice and hurt my right hip, my coccyx, so I went to the doctor a couple of days later."

**CONSTANT GP VISITS**  
"It started that I was going to the doctor constantly about pain and sitting ..."

**GP VISIT**  
"When I was off, ill, when I was working at the bank I went off sick the end of October and I was off work for about ten months and I went to see my registered GP and she told me that 'you are procrastinating now, you should be back at work', and I went back to work and within three weeks I was off sick again for another eleven months."

**X-RAY**  
"I had to fight to get an x-ray, because I was in my mid-twenties they didn't want to x-ray that particular area because it's over the ovaries and everything. But the x-ray showed, once I eventually did get an x-ray there was nothing major to see and they just kept giving me painkillers..."

TIMELINE

Dec 2010



# Your experience of diagnosis...

## EMOTIONAL JOURNEY

### INTO TEARS

"...So [I had to work] thirty-five hours a week with one week being forty hours, within three weeks, he [the manager] wanted me back at full-time. I walked in [the GP practice] [...] and just burst into tears".

### THE BEST

"He wasn't my registered GP but he was actually the one I found the best and I saw him until he - he ended up having to cut back his patients because he got sick himself."

### IS EVERYTHING JUST IN MY HEAD? - DOUBTING YOURSELF

".. I felt like everything was in my head. Some people were taking me seriously, but some people were saying that didn't exist. [...] So I just felt like - am I losing my mind, is this all in my head? You started to doubt yourself. It was so emotional and so frustrating".

### RELIEF

"It felt like a bit of a relief because I'm not imagining it, the doctors have given it a label [...] just having a label and not imagining this isn't all in my head, when people ask me what's wrong, I can say I have this and they don't just think 'oh she's just having a moan'".

## HOME LIFE

### INFORMATION

"There wasn't a whole lot (of information), it was a very vague and obviously around that time it was 'we think it could be fibromyalgia', but I had to do a bit of research myself."

## GP BASED CARE

### GP VISIT

"I just went to the doctor and was just like, 'I can't go on like this'"

### DIFFERENT GP

"I started seeing a Dr Small at my local practice - I had just gone to him for an emergency appointment, or it's like an on-the-day appointment that wasn't with my own registered GP and he was actually a lot better. He would explain things in more layman terms but wouldn't treat me like I was stupid, he would explain it without insulting."

### REFERRALS

"He was actually the one who referred me for the MRI, and when they discovered the prolapsed discs, he sort of drew a little diagram and he read the letter."  
"I went to see a neurologist and he (Dr Small) read the letter back from the neurologist .."

### GETTING JUMBLED TOGETHER

".. they had sort of started bandying around the term (fibromyalgia) but annoyingly, at the same time I had a slipped disc in my neck which, because they started to think that it was MS because I had quite a lot of numbness in my right hand and my fingers and I had no feeling or constant pins and needles. So things were getting jumbled together."

### ISOLATING THE SYMPTOMS/ CONDITIONS

".. when they had the MRI that isolated or identified the slipped disc, they started to sort of separate and be like 'no, this is this and that is that', and the MRI was the May, a year past the May after so about eighteen months."

### THE DIAGNOSIS

"Right, this is it, we can label it now', and I was just given medication".

After the MRI, Dr Small made the final diagnosis, explained the condition and prescribed medications.

## HOSPITAL BASED CARE

### NEUROLOGIST

"The neurologist that I went to see, when I went to see him, they do a pin-check for your nerves, up and down both sides of my body and I spoke to him for a little bit and he actually told me that neurologists - and he - **did not believe that fibromyalgia existed**".

### MRI

".. I fell in the December and it was - I had an MRI, not the following May but the May after."

## TIMELINE

May  
2012

# Life after diagnosis...

## HIGH HOPES

"When I had my first few appointments with him [new GP], I really had high hopes because he got the blood test for the B12, he put me on iron tablets and just...but it was as if, as soon as I got on that pain management wait list he was like, 'nah, I'm out'."

## DISAPPOINTMENT

"I didn't have faith that if I went to see him that I would get any results and that just was frustrating and upsetting, so rather than have to deal with extra emotions on top, I'd just deal with things, which is not really how you should go".

## FEELING MISERABLE

## SCARY THOUGHTS

"I've never felt suicidal but I got to the point where I'm like 'I understand why people do this, I understand why people...so it's sort of like going to that next level and you think when do I reach the point where I think suicide is an option? That was scary'."

## INCREASED ANXIETY TO GO OUT DUE TO COVID ISOLATION

"I'm not saying I didn't have the anxiety before but it's definitely got worse the more I got to stay in"

## CHANGED JOB

"I left the bank in 2013 as the stress & long hours was just too much with the fibro. I started working part time in home bargains."

## CHANGED JOB AGAIN

"I again changed job in 2015 (the charity shop/organisation) as the manager at home bargains was getting demanding and irritated with my health struggles."

## CHANGED JOB ONCE AGAIN, BUT EVENTUALLY LEFT

"The charity shop/organisation (...) I started working there in the gift shop side mainly until 2018 when my health had got to a point where I was really struggling & haven't worked since."

## FINDING INFORMATION

"I went to see a comedian, 2019 [,] the show was called Fibro My Arth, and that was hilarious. But she gave out a leaflet at the end of the show. So it was a list of possible symptoms but not all. It was more finding things online but obviously trying not to go too far down that rabbit hole because obviously going online can get quite scary, quite fast".

## ONLINE PAIN MANAGEMENT GROUP

Helped fighting anxiety and meeting people with similar situations (chronic pain).

## SUPPORT FROM PEOPLE WITH SIMILAR EXPERIENCES

"... I've also got that support system of people who maybe don't necessarily have the same diagnosis but who have been through the group with me and in that similar situation. So although I've got the support of friends, I've also got support of people who are in pain".

"But just having shared experience, I think everyone said that they found that was the most beneficial".

## TOOLS

"I've got tools now that I feel I can use to help me ..."

"... once or twice things were posted, sometimes it was an emailed link that I could print out myself but all the slides are there in the talk that we had emailed each week, so I can watch it all back."

"... there was links to talks and things on YouTube and I've got movement exercises."

## MOVED HOME

## CHANGE OF GP

"I've changed my GP now. Because I just feel like he wasn't interested. I would go and see him [,] and he just laughed."

Haven't met the new GP yet, but have an e-consult scheduled and blood test.

## TREATMENT

"The tiredness and the pain, they just treat it with medication and that was me until 2018".

## CHANGE OF GP AND PAIN MANAGEMENT REFERRAL

Started seeing a new GP, resulting in a tweaks of medications and a referral for pain management.

"I was on iron tablets, he [the new GP] put me on twelve weekly B12 injections, he'd tweaked, not massively changed but tweaked some of my medication a little bit and he had referred me for pain management".

## WAITING

After being referred to pain management.

"it was almost as if he [the GP] said - tag - they are it - I'm out".

"But as soon as my name got on that list he just lost interest in doing anything about the pain, 'we need to wait and say what pain management say. We need to wait and see what pain management are saying.' But it was my life. I was just miserable".

## PAIN MANAGEMENT GROUP

"... there was no pain management group even set up, even started"

## PSYCHOLOGIST

Had a couple of phone calls before starting the pain management group.

"... we had a separate phone call with psychologist so I spoke [,] about it and she was brilliant."

## PHYSIOTHERAPIST

2013

2015

2017-2018

Beginning of 2018

Sep 2021

Dec 2021

# What could be better for you?



## SUPPORT GROUP

"I think the support group and what I've had just in the last three months with the pain management group would have been massively helpful"

## EMOTIONAL AND MENTAL SUPPORT

".. emotional and mental support, because when you are going through it your head goes to some dark places and even just the confusion and uncertainty of it, you are just...it's depressing. (...) more often than not, the mental exhaustion is worse than physical exhaustion. Because when you are physically exhausted, the brain is still going a mile a minute."

## SUPPORT GROUP AT DIAGNOSIS STAGE

"If there had maybe been the support group or just to help make sense of the diagnosis stage, (...) it is a big diagnosis, although it's not life-threatening or terminal or anything but it is, **it's a life-long diagnosis, so just to have that...help to, just to get your head in the right space to take on this diagnosis.**"

## REALISTIC AND SPECIFIC SUPPORT SOON AFTER DIAGNOSIS

"Where do you start? Apart from social media forums, which can be a bit...there's no actual governance. If it's done through the healthcare it's got more of a realistic, specific basis. When you go into social media forums it's just anything and everything and I think it needs that direction of being set up by the healthcare."

## Different forms of support

## MORE INFORMATION AND SIGNPOSTING FROM GP

"It wasn't something that I knew enough about to sort of say 'I think that would be helpful, could I be referred to that', so when I was going through it, I needed...I felt like I would have needed, now looking back, if I'd had more information or direction from GPs, to say 'this is available, would you be interested?' but there wasn't."

## Early support and information

## MORE INFORMATION WHEN WAITING FOR DIAGNOSIS

"Maybe just some sort of more information on the condition, because they sort of say 'we think you could have fibromyalgia', and there's just a very brief description but it was a very brief description of a very widespread and vague condition. So a bit more information there might have helped. Just to sort of say 'this is what we think it might be, this is what that entails.'"

## Supported to take control

## WORKBOOK

"..it would be good to write notes in. But just having shared experience, I think everyone said that they found that was the most beneficial and there is talk of if-maybe in six to eight months, there would be sort of like a catch-up and hopefully when it comes time for that it'll be able to be a face-to-face, so maybe when the next group start up they can have some online, some face-to-face but having the actual workbook in hand, I think that would be of benefit.."

## SUPPORTED SELF MANAGEMENT

Being able to access GP support "just as and when" while having the tools to self manage (pain management) and take control.

## MORE AWARENESS

".. until the GP had said it to me, I'd never heard of it. So it is definitely something that is spoken about more. I think just in terms of through my peers, well I'd never heard of it and I'd only just started hearing it because I was facing it, or possibly, at the time, facing it. I think it is something that is definitely more spoken about now, there was - I've heard of it on TV and things, so it actually seems more real than it did, say, ten years ago."

## Health professional attitudes

## ACKNOWLEDGEMENT AND EMPATHY

"... it was bad enough being in my own head 'is this for real?' without being questioned."

## BEING TREATED SERIOUSLY

"I know with fibromyalgia, it's not a cut-and-paste, every patient will have different experiences and symptoms and not all treatments and medications or anything will work for everyone. But just, I felt like, as an illness, it wasn't necessarily taken very seriously."

## BEING SUPPORTED

"... any sort of support or even just recognition that this wasn't in my head, like I say, there's been a lot of different people that I've seen and there's been a lot of people in my personal life and my work life that treated me like I was making it up, exaggerating but I felt like that was, definitely that was the feeling from some medical professionals too. (...) For a neurologist to say 'we don't believe in that', it was bad enough hearing it from my peers, hearing that from a neurologist, it was kinda crushing.."