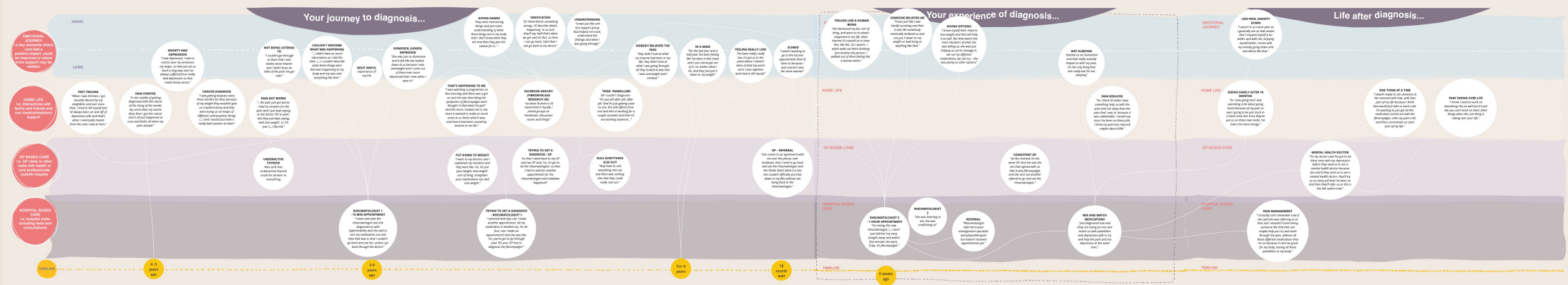


experience map
fibromyalgia

Overview of all maps

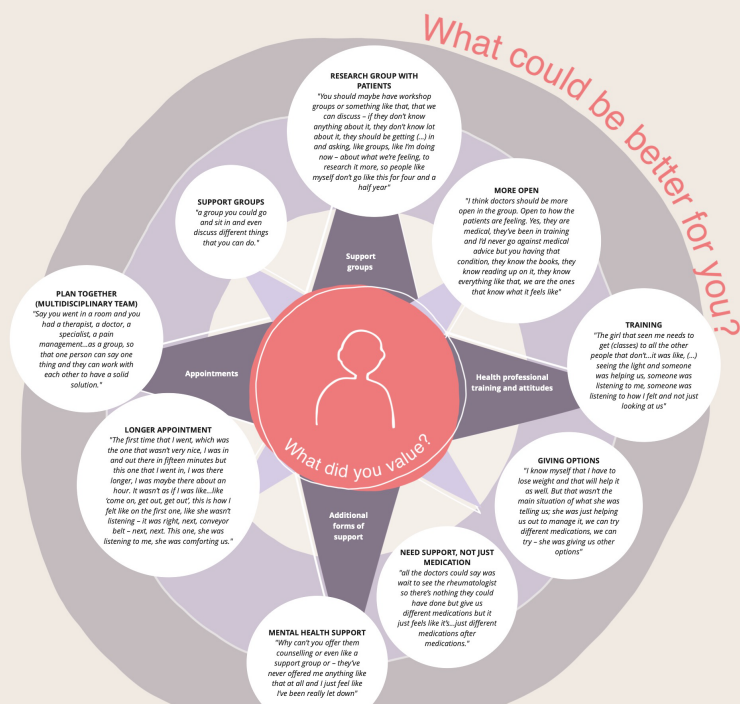


What matters to you?
See in detail on page 3



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?

About you...

My condition(s)..

MANAGING WEIGHT
"I used to be about thirty-two stone and I had weight loss surgery and I got down to about twenty-one stone and I kind of found my life again..."

CANCER
Of lining of womb

HERNIA
On tummy, size of football

UNDERACTIVE THYROID

GALLBLADDER REMOVED

ANXIETY AND DEPRESSION

MEMORY LOSS

BRAIN FOG

SORE EYES

BRAIN ZAPS
"funny things in my head and it was like I was getting electrocuted but then I found out they are called brain zaps"

"Couldn't lift my arms"

NOISE SENSITIVITY

ATTENTION SPAN NOT VERY GOOD

Where I live...

LIVE ON MY OWN
Moved to Aberdeen 16 years ago

How I spend my time...

DON'T DO MUCH NOW
"...at the moment, apart from the weekend I've been away, I don't really go out much or do much."

"At the moment I'm not really doing anything I like to do because of my pain situation and anxiety."

INTERESTS
Spending time with friends and family, going to the bingo, reading

People in my life...

CLOSE FRIEND
"I've got a friend (...) and he helps me with everything. Like, bathing and things like that. (...) he's my best friend in the whole entire world and he helps me with everything."

CIRCLE OF FRIENDS AND FAMILY
"I've got a close circle of friends and my family down the road, which I stay in touch with through Facetime."

FRIENDS NOTICED CHANGE
"five, six years ago you were this bubbly outgoing person, (...) and then from that, I've become like a hermit. I don't go out, I hardly contact them. (...) but they've noticed so much of a difference in me."

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

TIMELINE

4-5 years ago

3-4 years ago

For 4 years

18 month wait

ANXIETY AND DEPRESSION
"I was depressed, I had no control over my emotions, my anger, so that just set us back a long way and I've always suffered from really bad depression so that made things worse."

PAIN STARTED
"In the middle of getting diagnosed with the cancer of the lining of the womb, my uncle died, my auntie died, then I got the cancer and it all just happened at once and that's all when my pain started."

CANCER DIAGNOSIS
"I was getting biopsies every three months for that, because of my weight they wouldn't give us a hysterectomy and they were trying us on heaps of different contraception things (...) and I would just have a really bad reaction to them"

NOT BEING LISTENED TO
"I couldn't get through to them that I was twelve stone heavier and I didn't have an inkle of the pain I've got now."

PAIN GOT WORSE
"... the pain just got worse, I had no answers for the pain and I just kept saying to the doctor 'I'm in pain', and they just kept saying, 'well lose weight', or 'it's your (...) thyroid.'"

UNDERACTIVE THYROID
Was told that underactive thyroid could be answer to everything

COULDN'T DESCRIBE WHAT WAS HAPPENING
"...I didn't have as much information as I did this time. (...) I couldn't describe what these things were that was happening to my body and my ears and everything like that."

MOST AWFUL
experience of my life

DISMISSED, JUDGED, DEPRESSED
"She was just so dismissive and it felt like she looked down at us because I was overweight and I come out of there even more depressed than I was when I went in"

RHEUMATOLOGIST 1 - 15 MIN APPOINTMENT
"I went and seen the rheumatologist and she diagnosed us with hypermobility and she said to sort my medication out and then that was it. And I couldn't go back and see her, unless I go back through the doctor"

THAT'S HAPPENING TO ME
"I was watching a programme on this morning and there was a girl on and she was describing her symptoms of fibromyalgia and I thought 'is that what I've got?' And the more I looked into it, the more it seemed to make so much sense to us that's what it was, and how it had been caused by trauma in my life."

PUT DOWN TO WEIGHT
"I went to my doctors and I explained my situation and they were like, 'no, it's just your weight, lose weight', sort of thing, straighten your medications out and lose weight."

TRYING TO GET A DIAGNOSIS - RHEUMATOLOGIST 1
"I phoned and says can I make another appointment, all my medication is levelled out, I'm all fine, can I make an appointment? And she was like, 'no, you've got to go through your GP, your GP has to diagnose the fibromyalgia'"

GIVING NAMES
"they were mentioning things and just more understanding of what these things are in my body that I don't know what they are and then they give the names for it..."

VERIFICATION
"If I think there's something wrong...I'll describe what's happening to us and they'll say 'well that's what we get and it's this', so then I can go back, I feel that I can go back to my doctor"

UNDERSTANDING
"it was just like sort of a support group that helped me more, understand the feelings and what I was going through."

NOBODY BELIEVED THE PAIN
"they didn't look at what my trauma had been in my life, they didn't look at what I was going through; all they looked at was that I was overweight and I smoked."

IN A MAZE
"For the last four and a half year I've been feeling like I've been in this maze and I just canna get out of it, no matter what I do, and they just put it down to my weight"

FEELING REALLY LOW
"I've been really, really low, it's got us to the point where I haven't been at that low point since I was eighteen and tried to kill myself."

SCARED
"I wasn't wanting to go to the second appointment that I'd been to because I was scared it was the same woman"

FACEBOOK GROUPS (FIBROMYALGIA RESEARCH UK)
"so what I'd done is I'd researched it myself, I joined groups on Facebooks, discussion rooms and things"

TRIED PAINKILLERS
GP couldn't diagnose - "it's just pill after pill, after pill. And it's just getting used to one, the side effects from one and then it working for a couple of weeks and then it's not working anymore..."

RULE EVERYTHING ELSE OUT
"they have to rule everything else out but there was nothing else that they could really rule out."

TRYING TO GET A DIAGNOSIS - GP
"so then I went back to my GP and my GP said, 'no, it's got to be the rheumatologist', so then I had to wait for another appointment for the rheumatologist and lockdown happened"

GP - REFERRAL
"she comes to an agreement with me over the phone, over lockdown, that I need to go back and see the rheumatologist and she thinks that's what it is but she couldn't officially put that down in my files without me being back to the rheumatologist."

Your experience of diagnosis...

FEELING LIKE A HUMAN BEING

"she dismissed my fat, sort of thing, and went on to what's happened in my life, what trauma it's caused us to have this, like this. So I wasn't...I didn't walk out there thinking 'just another fat person', I walked out of there feeling like a human being."

SOMEONE BELIEVED ME

"It was just like I was hardly surviving and then it was like somebody eventually believed us and not put it down to my weight or bad living or anything like that."

GIVING OPTIONS

"I know myself that I have to lose weight and that will help it as well. But that wasn't the main situation of what she was telling us; she was just helping us out to manage it, we can try different medications, we can try - she was giving us other options"

NOT SLEEPING

"started us on Duloxetine and that really actually helped us with my pain, it's the only thing that has really but I'm not sleeping"

PAIN REDUCED

"So I think I'd rather have something help us with the pain and not sleep than the pain that I was in, because it was unbearable. I would say since I've been on these pills, I think my pain has reduced maybe about 60%."

CONSISTENT GP

"at the moment it's the same GP. And she was the one that agreed with us that it was fibromyalgia and she sent out another referral to go and see the rheumatologist."

RHEUMATOLOGIST 2

"she was listening to me, she was comforting us"

REFERRAL

"Rheumatologist referred to pain management specialist and physiotherapist but haven't received appointments yet."

MIX AND MATCH MEDICATIONS

"just diagnosed now and (they are trying to) mix and match us with painkillers and depression pills to try and help the pain and my depression at the same time."

RHEUMATOLOGIST 2 - 1 HOUR APPOINTMENT

"I'm seeing this new rheumatologist, (...) and I just told her my story straight away and within five minutes she went, 'Lily, it's fibromyalgia' "

6 weeks ago

HOME LIFE

GP BASED CARE

HOSPITAL BASED CARE

TIMELINE

Life after diagnosis...

EMOTIONAL JOURNEY

LESS PAIN, ANXIETY DOWN

"I wasn't in as much pain as I generally am so that meant that I enjoyed myself a lot better and with me, enjoying myself better, comes with my anxiety going down and everything like that."

HOME LIFE

SEEING FAMILY AFTER 18 MONTHS

"So I was going and I was panicking a bit about going home because of my pain or was I going to be just stuck in a hotel room but since they've put us on these new meds, I've had a lot more energy."

GP BASED CARE

MENTAL HEALTH DOCTOR

"So my doctor said I've got to try these ones with my depression before they send us to see a mental health doctor because she said if they send us to see a mental health doctor, they'll try us on every pill that I've been on and then they'll refer us so this is the last option now."

HOSPITAL BASED CARE

PAIN MANAGEMENT

"I actually can't remember now if she said she was referring us to that, but I wouldn't mind seeing someone like that that can maybe help you try and work through the pain, without all these different medications that I'm on because it can't be good for my body, having all these painkillers in my body."

TIMELINE

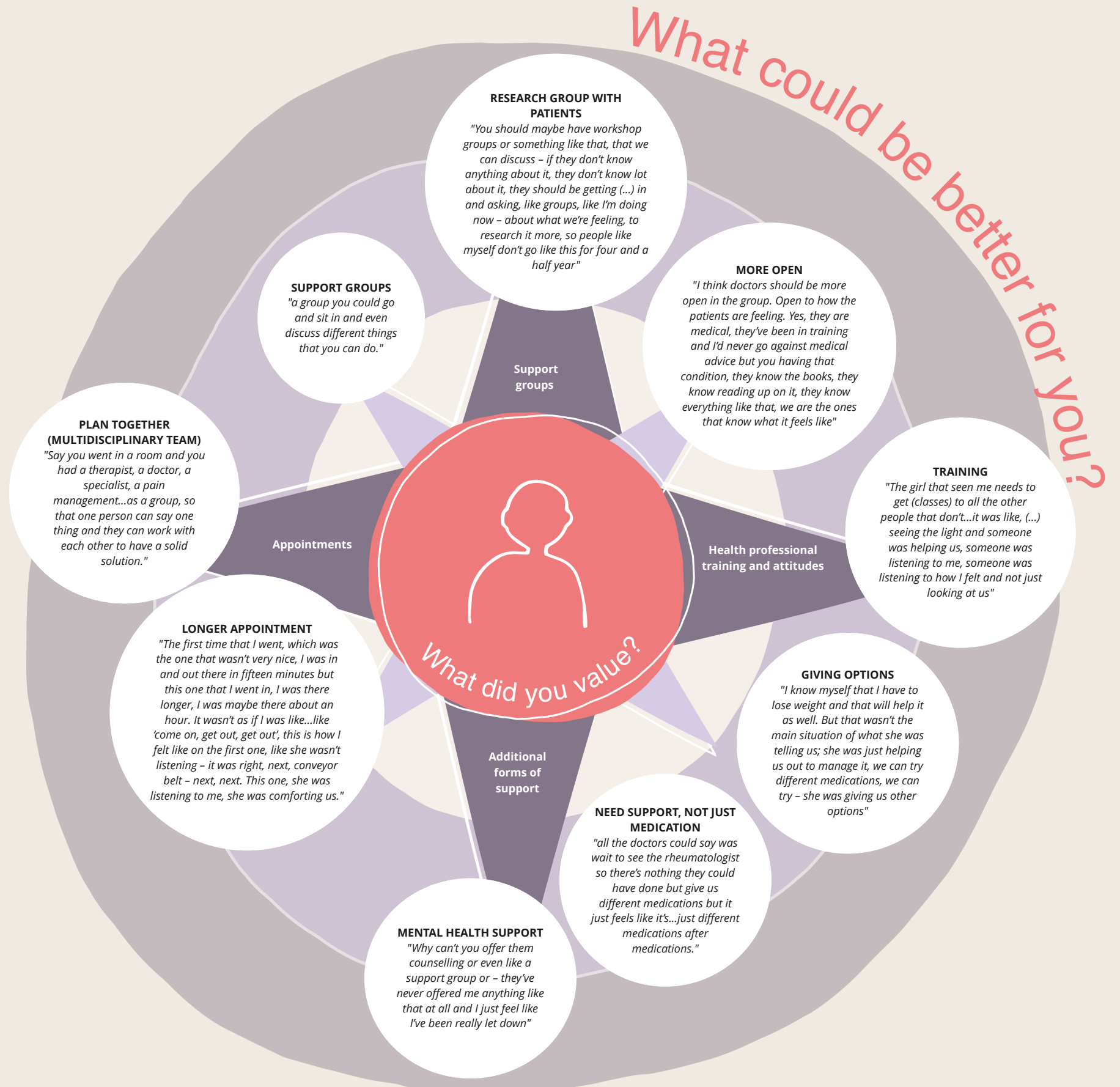
ONE THING AT A TIME

"I wasn't ready to see someone at the moment with that, with that part of my life because I think that would just take us back a bit. I'm wanting to just get all this medication sorted out with the fibromyalgia, calm my pain a bit and then concentrate on each part of my life."

PAIN TAKING OVER LIFE

"I know I need to work on everything else as well but it's just like you can't work on them other things when this one thing is taking over your life."

What could be better for you?



RESEARCH GROUP WITH PATIENTS

"You should maybe have workshop groups or something like that, that we can discuss - if they don't know anything about it, they don't know lot about it, they should be getting (...) in and asking, like groups, like I'm doing now - about what we're feeling, to research it more, so people like myself don't go like this for four and a half year"

SUPPORT GROUPS

"a group you could go and sit in and even discuss different things that you can do."

MORE OPEN

"I think doctors should be more open in the group. Open to how the patients are feeling. Yes, they are medical, they've been in training and I'd never go against medical advice but you having that condition, they know the books, they know reading up on it, they know everything like that, we are the ones that know what it feels like"

TRAINING

"The girl that seen me needs to get (classes) to all the other people that don't...it was like, (...) seeing the light and someone was helping us, someone was listening to me, someone was listening to how I felt and not just looking at us"

Health professional training and attitudes

GIVING OPTIONS

"I know myself that I have to lose weight and that will help it as well. But that wasn't the main situation of what she was telling us; she was just helping us out to manage it, we can try different medications, we can try - she was giving us other options"

NEED SUPPORT, NOT JUST MEDICATION

"all the doctors could say was wait to see the rheumatologist so there's nothing they could have done but give us different medications but it just feels like it's...just different medications after medications."

MENTAL HEALTH SUPPORT

"Why can't you offer them counselling or even like a support group or - they've never offered me anything like that at all and I just feel like I've been really let down"

Additional forms of support

LONGER APPOINTMENT

"The first time that I went, which was the one that wasn't very nice, I was in and out there in fifteen minutes but this one that I went in, I was there longer, I was maybe there about an hour. It wasn't as if I was like...like 'come on, get out, get out', this is how I felt like on the first one, like she wasn't listening - it was right, next, conveyor belt - next, next. This one, she was listening to me, she was comforting us."

Appointments

PLAN TOGETHER (MULTIDISCIPLINARY TEAM)

"Say you went in a room and you had a therapist, a doctor, a specialist, a pain management...as a group, so that one person can say one thing and they can work with each other to have a solid solution."

What did you value?