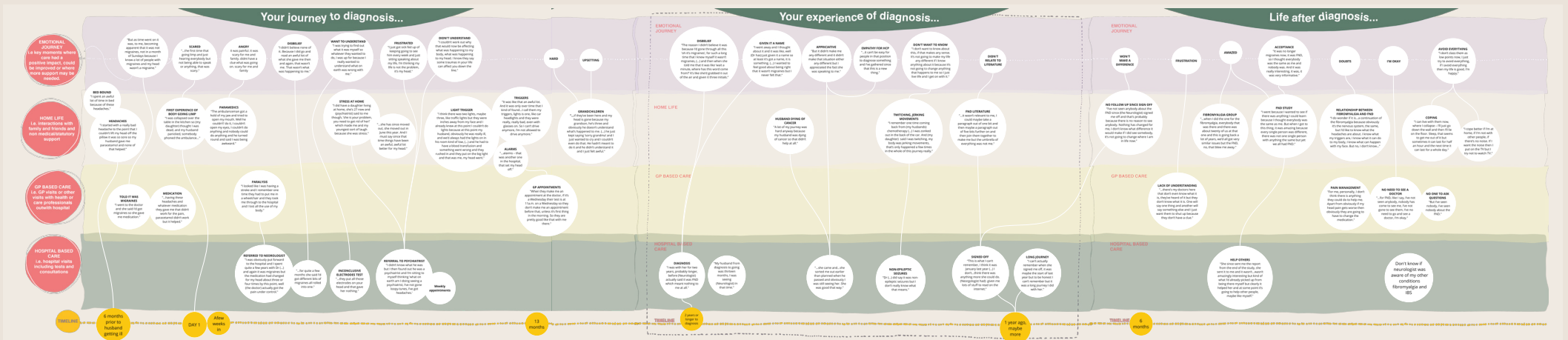


experience map
functional neurological disorder

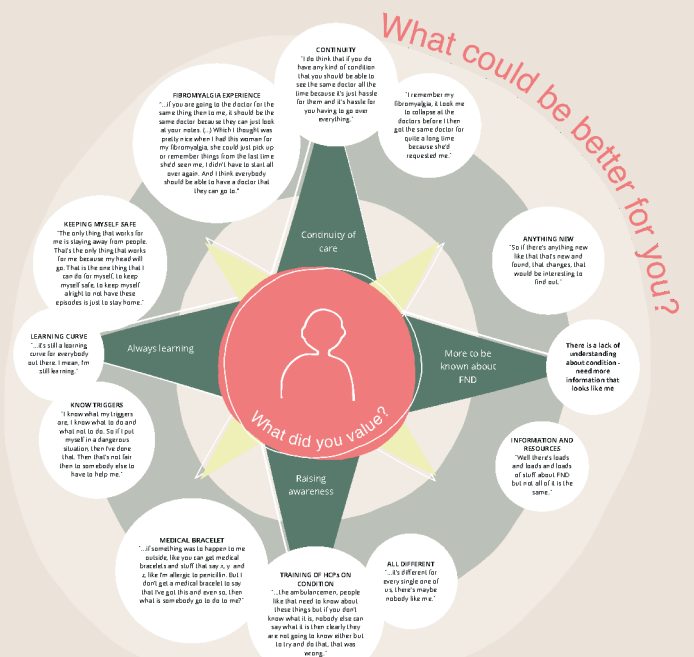


What keeps you well?
See in detail on page 3



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

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



What keeps you well?

About you...

Mental health

"it's not something I've thought about, I try not to think about it. But when I have needed it, there is one doctor down the road...she understands me very well and I really don't have to say a lot."

Wheat intolerant

FND taken over

"I've got IBS, I've got fibromyalgia and I don't want to know about either of them, it's not going to make any difference. The IBS I had to be careful with, I've worked that out and that's easy now, the fibromyalgia the same but what's happening to me now, this FND has just taken over from anything."

Paralysis

IBS

IBS is easier to handle

"I've had the IBS for a long, long time, I even had surgery for that and it turned out to be surgery that shouldn't have happened but I've learnt to live with that."

My condition(s).

Non-epileptic seizures

Memory

"My memory is not the best, that's one thing for sure that this has done."

Headaches

Triggered by noise and light

Fibromyalgia

had for about 15 years. Had a follow up with hospital about 5 years ago since discharge, no change and told to carry on with medication.

PET

Cat - A rare black Bengal, 17 years old

READING

"I love to read, that's about it really."

HOBBIES

"I enjoy gardening in the warmer months, (...) Formula 1."

HOME

"Keeping me well is staying at home."

SAFE

"It's not been a nice journey but I'm now - I kind of know what's safe and what's not and I'm just safe at home because I can't - I'm not allowed out on my own anyway (...), car lights if it's night-time or bumpy roads, they just set my head off and just people in general, talking."

Things I do...

CHALLENGING FAMILY RELATIONSHIPS

"None of us speak to my son, em...and...my eldest daughter is not too bad, it's the one that lived at home, the one that's 27, she thinks it's all made up."

GRAND- CHILDREN TRIGGER

"I've got two grandchildren, sadly that I can't see. They set my head off."

People and values

FAMILY SUPPORT

Youngest daughter is a great support "has been on this journey with me."

HAPPY PLACE

"I'm in a happy place again now. Yes, I'm happy. And I never actually thought after I'd lost my husband that I'd ever be with anybody else again, I thought that was it, you know."

LOSS OF HUSBAND

"I'm a widow, two years past. My husband died of cancer."

NEW RELATIONSHIP

"I'm now in a new relationship with somebody that I was with years ago."

Where I Live...

QUIET & REMOTE

"I'm actually out in the countryside, (...) nice and quiet."

"I need to be actually, it's kind of...it's pretty weird that I am here because in my head now I need this quiet."

MOVING

"I'm actually looking to move because this place is too much for me now, there's a lot of land with it but if I move I'm going to have to go somewhere that's quiet as well."

"I'm English, I've lived in Scotland for forty years, most of my life."

SAFE AT HOME

"I'm just safe at home."

Live alone

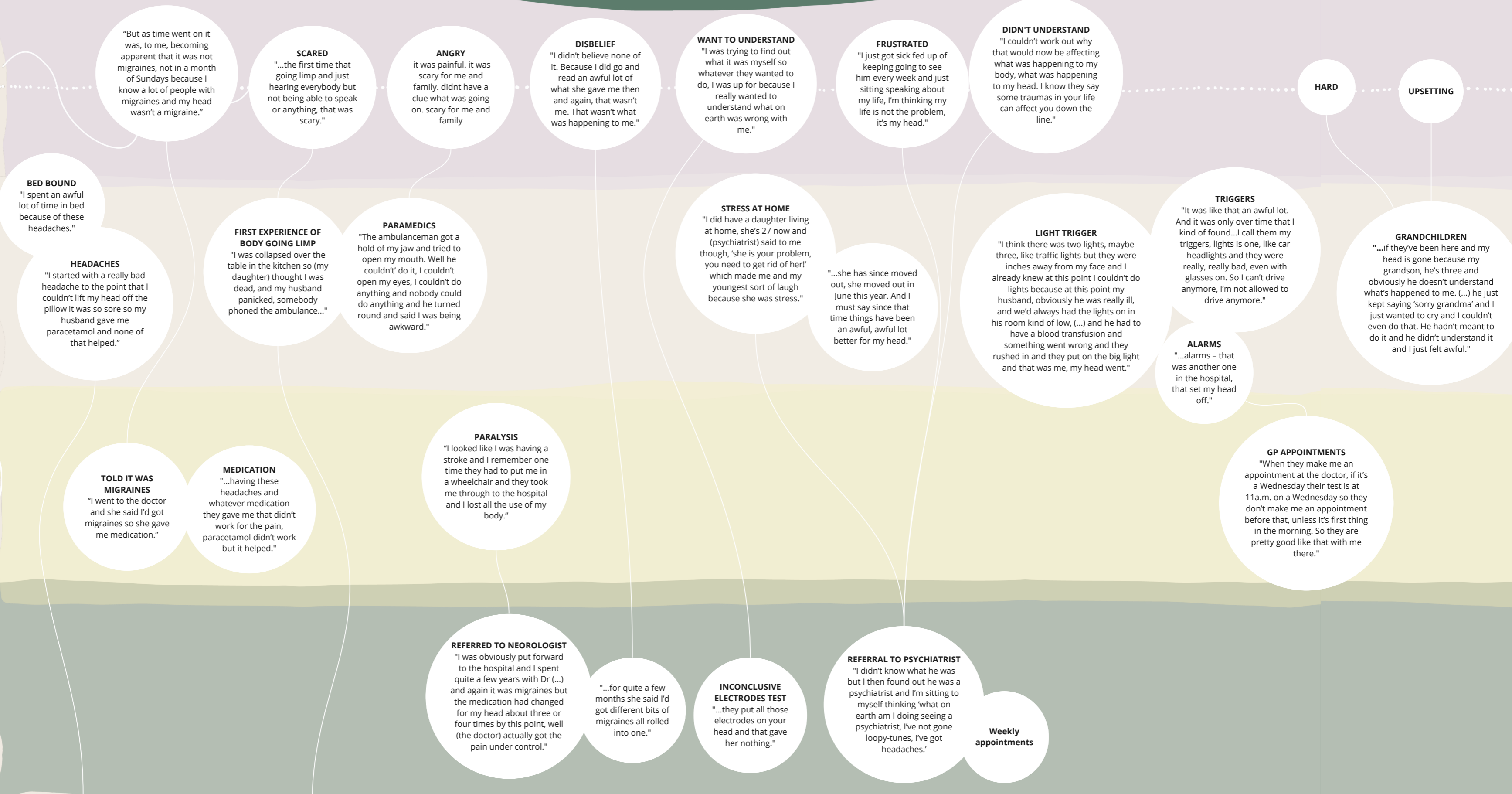
Your journey to diagnosis...

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



BED BOUND
"I spent an awful lot of time in bed because of these headaches."

HEADACHES
"I started with a really bad headache to the point that I couldn't lift my head off the pillow it was so sore so my husband gave me paracetamol and none of that helped."

TOLD IT WAS MIGRAINES
"I went to the doctor and she said I'd got migraines so she gave me medication."

MEDICATION
"...having these headaches and whatever medication they gave me that didn't work for the pain, paracetamol didn't work but it helped."

FIRST EXPERIENCE OF BODY GOING LIMP
"I was collapsed over the table in the kitchen so (my daughter) thought I was dead, and my husband panicked, somebody phoned the ambulance..."

PARAMEDICS
"The ambulanceman got a hold of my jaw and tried to open my mouth. Well he couldn't do it, I couldn't open my eyes, I couldn't do anything and nobody could do anything and he turned round and said I was being awkward."

PARALYSIS
"I looked like I was having a stroke and I remember one time they had to put me in a wheelchair and they took me through to the hospital and I lost all the use of my body."

REFERRED TO NEUROLOGIST
"I was obviously put forward to the hospital and I spent quite a few years with Dr (...) and again it was migraines but the medication had changed for my head about three or four times by this point, well (the doctor) actually got the pain under control."

"...for quite a few months she said I'd got different bits of migraines all rolled into one."

INCONCLUSIVE ELECTRODES TEST
"...they put all those electrodes on your head and that gave her nothing."

REFERRAL TO PSYCHIATRIST
"I didn't know what he was but I then found out he was a psychiatrist and I'm sitting to myself thinking 'what on earth am I doing seeing a psychiatrist, I've not gone loopy-tunes, I've got headaches.'
Weekly appointments

"But as time went on it was, to me, becoming apparent that it was not migraines, not in a month of Sundays because I know a lot of people with migraines and my head wasn't a migraine."

SCARED
"...the first time that going limp and just hearing everybody but not being able to speak or anything, that was scary."

ANGRY
it was painful. it was scary for me and family. didnt have a clue what was going on. scary for me and family

DISBELIEF
"I didn't believe none of it. Because I did go and read an awful lot of what she gave me then and again, that wasn't me. That wasn't what was happening to me."

WANT TO UNDERSTAND
"I was trying to find out what it was myself so whatever they wanted to do, I was up for because I really wanted to understand what on earth was wrong with me."

FRUSTRATED
"I just got sick fed up of keeping going to see him every week and just sitting speaking about my life, I'm thinking my life is not the problem, it's my head."

DIDN'T UNDERSTAND
"I couldn't work out why that would now be affecting what was happening to my body, what was happening to my head. I know they say some traumas in your life can affect you down the line."

STRESS AT HOME
"I did have a daughter living at home, she's 27 now and (psychiatrist) said to me though, 'she is your problem, you need to get rid of her!' which made me and my youngest sort of laugh because she was stress."

"...she has since moved out, she moved out in June this year. And I must say since that time things have been an awful, awful lot better for my head."

LIGHT TRIGGER
"I think there was two lights, maybe three, like traffic lights but they were inches away from my face and I already knew at this point I couldn't do lights because at this point my husband, obviously he was really ill, and we'd always had the lights on in his room kind of low, (...) and he had to have a blood transfusion and something went wrong and they rushed in and they put on the big light and that was me, my head went."

ALARMS
"...alarms - that was another one in the hospital, that set my head off."

TRIGGERS
"It was like that an awful lot. And it was only over time that I kind of found... I call them my triggers, lights is one, like car headlights and they were really, really bad, even with glasses on. So I can't drive anymore, I'm not allowed to drive anymore."

GP APPOINTMENTS
"When they make me an appointment at the doctor, if it's a Wednesday their test is at 11a.m. on a Wednesday so they don't make me an appointment before that, unless it's first thing in the morning. So they are pretty good like that with me there."

GRANDCHILDREN
"...if they've been here and my head is gone because my grandson, he's three and obviously he doesn't understand what's happened to me. (...) he just kept saying 'sorry grandma' and I just wanted to cry and I couldn't even do that. He hadn't meant to do it and he didn't understand it and I just felt awful."

HARD

UPSETTING

TIMELINE

6 months prior to husband getting ill

DAY 1

A few weeks in

13 months

Your experience of diagnosis...

EMOTIONAL JOURNEY

DISBELIEF

"The reason I didn't believe it was because I'd gone through all this 'oh it's migraines', for such a long time that I knew myself it wasn't migraines, (...) and then when she told me that it was like 'wait a minute, where has this word come from?' It's like she'd grabbed it out of the air and given it three initials."

GIVEN IT A NAME

"I went away and I thought about it and it was like, well (Dr has) just given it a name so at least it's got a name, it is something. (...) I wanted to feel good about being right that it wasn't migraines but I never felt that."

APPRECIATIVE

"But it didn't make me any different and it didn't make that situation either any different but I appreciated the fact she was speaking to me."

EMPATHY FOR HCP

"...it can't be easy for people in that position to diagnose something and I've gathered since that this is a new thing."

DON'T WANT TO KNOW

"I don't want to know about this, if that makes any sense. It's not going to make my life any different if I know anything about it because it's not going to change anything that happens to me so I just live life and I get on with it."

DIDN'T RELATE TO LITERATURE

HOME LIFE

HUSBAND DYING OF CANCER

"A lot of my journey was hard anyway because my husband was dying of cancer so that didn't help at all."

TWITCHING, JERKING MOVEMENTS

"I remember one time coming back from (my husbands) chemotherapy (...) I was zonked out in the back of the car. And (my daughter) said I was twitching, my body was jerking movements, that's only happened a few times in the whole of this journey really."

FND LITERATURE

"...it wasn't relevant to me, I could maybe take a paragraph out of one bit and then maybe a paragraph out of five bits further on and then join them together to make me but the umbrella of everything was not me."

GP BASED CARE

HOSPITAL BASED CARE

DIAGNOSIS

"I was with her for two years, probably longer, before (Neurologist) actually said it was FND which meant nothing to me at all."

"My husband from diagnosis to going was thirteen months, I was seeing (Neurologist) in that time."

"...she came and...she sorted me out earlier than planned when he passed and obviously I was still seeing her. She was good that way."

NON-EPILEPTIC SEIZURES

"Dr (...) did say it was non-epileptic seizures but I don't really know what that means."

SIGNED OFF

"This is what I can't remember, I think it was January last year (...) I don't...think there was anything more she could do. (Neurologist had) given me lots of stuff to read on the internet."

LONG JOURNEY

"I can't actually remember when she signed me off, it was maybe the start of last year but to be honest I can't remember but it was a long journey I did with her."

TIMELINE

2 years or longer to diagnosis

1 year ago, maybe more

Life after diagnosis...

EMOTIONAL JOURNEY

WON'T MAKE A DIFFERENCE

NO FOLLOW UP SINCE SIGN OFF
"I've not seen anybody about the FND since (the Neurologist) signed me off and that's probably because there is no reason to see anybody. Nothing has changed for me, I don't know what difference it would make if I did see somebody, it's not going to change where I am in life now."

FRUSTRATION

AMAZED

FIBROMYALGIA GROUP
"...when I did the one for the fibromyalgia, everybody that was there and there was about twenty of us at that one and this is going back a lot of years, we'd all got very similar issues but the FND, no, that blew me away."

ACCEPTANCE
"It was no longer migraines now, it was FND, so I thought everybody was the same as me and nobody was. And it was really interesting, it was, it was very informative."

FND STUDY
"I went because I wanted to see if there was anything I could learn because I thought everybody was the same as me. But when I got to this thing, it was amazing because every single person was different, there was not one single person with anything the same but yet we all had FND."

DOUBTS

RELATIONSHIP BETWEEN FIBROMYALGIA AND FND
"I do wonder if it is...a continuation of the fibromyalgia because obviously it's the nervous system, the same, but I'd like to know what the headaches are about. I know what my triggers are, I know what it can do to my body, I know what can happen with my face. But no, I don't know..."

I'M OKAY

AVOID EVERYTHING
"I don't class them as low points now, I just try to avoid everything, if I avoid everything then my life is good, I'm happy."

COPING
"I can live with them now, where I collapse - I'll just go down the wall and then I'll lie on the floor. Sleep, that seems to get me out of it but sometimes it can last for half an hour and the next time it can last for a whole day."

"I cope better if I'm at home, if I'm not with other people, if there's no noise. If I want the noise then I put on the TV but I try not to watch TV."

GP BASED CARE

LACK OF UNDERSTANDING
"...there's my doctors here that don't even know what it is, they've heard of it but they don't know what it is. One will say one thing and another will say something else and I just want them to shut up because they don't have a clue."

PAIN MANAGEMENT
"For me, personally, I don't think there is anything they could do to help me. Apart from obviously if my head pain gets worse then obviously they are going to have to change the medication."

NO NEED TO SEE A DOCTOR
"...for FND, like I say, I've not seen anybody, nobody has come to see me, I've not gone to see them, I've no need to go and see a doctor, I'm okay."

NO ONE TO ASK QUESTIONS
"But I've seen nobody, I've seen nobody about the FND."

HOSPITAL BASED CARE

HELP OTHERS
"She since sent me the report from the end of the study, she sent it to me and it wasn't...wasn't amazingly interesting but kind of what I'd already picked up from being there myself but clearly it helped her and at some point it's going to help other people, maybe like myself."

Don't know if neurologist was aware of my other conditions fibromyalgia and IBS

TIMELINE

6 months

What could be better for you?



CONTINUITY

"I do think that if you do have any kind of condition that you should be able to see the same doctor all the time because it's just hassle for them and it's hassle for you having to go over everything."

"I remember my fibromyalgia, it took me to collapse at the doctors before I then got the same doctor for quite a long time because she'd requested me."

Continuity of care

FIBROMYALGIA EXPERIENCE

"...if you are going to the doctor for the same thing then to me, it should be the same doctor because they can just look at your notes. (...) Which I thought was pretty nice when I had this woman for my fibromyalgia, she could just pick up or remember things from the last time she'd seen me, I didn't have to start all over again. And I think everybody should be able to have a doctor that they can go to."

KEEPING MYSELF SAFE

"The only thing that works for me is staying away from people. That's the only thing that works for me because my head will go. That is the one thing that I can do for myself, to keep myself safe, to keep myself alright to not have these episodes is just to stay home."

LEARNING CURVE

"...it's still a learning curve for everybody out there. I mean, I'm still learning."

Always learning

KNOW TRIGGERS

"I know what my triggers are, I know what to do and what not to do. So if I put myself in a dangerous situation, then I've done that. Then that's not fair then to somebody else to have to help me."

More to be known about FND

There is a lack of understanding about condition - need more information that looks like me

INFORMATION AND RESOURCES

"Well there's loads and loads and loads of stuff about FND but not all of it is the same."

Raising awareness

MEDICAL BRACELET

"...if something was to happen to me outside, like you can get medical bracelets and stuff that say x, y and z, like I'm allergic to penicillin. But I don't get a medical bracelet to say that I've got this and even so, then what is somebody go to do to me?"

TRAINING OF HCPS ON CONDITION

"...the ambulancemen, people like that need to know about these things but if you don't know what it is, nobody else can say what it is then clearly they are not going to know either but to try and do that, that was wrong."

ALL DIFFERENT

"...it's different for every single one of us, there's maybe nobody like me."