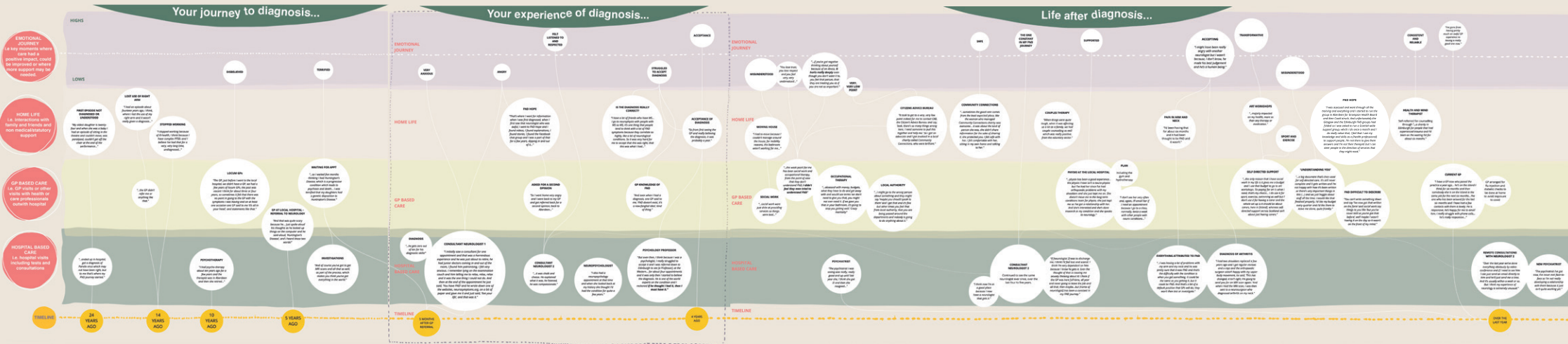


experience map
functional neurological disorder

Overview of all maps

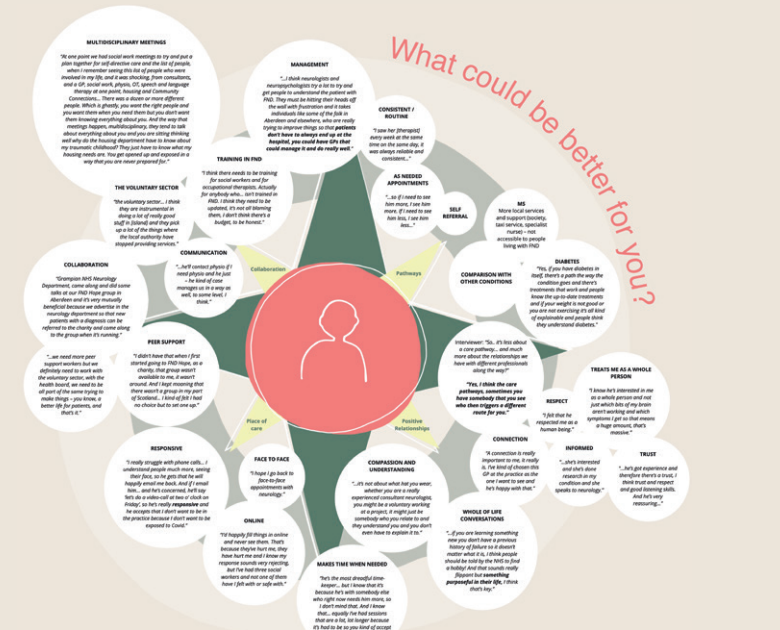


What matters to you?
See in detail on page 3



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...

PROFESSIONAL BACKGROUND

Previously worked as a health professional in the NHS

HELPING OTHERS THROUGH VOLUNTEERING ROLES - USING MY EXPERTISE

STRUCTURE & ROUTINE

"That is fundamental to everything. Without that, life just feels chaotic."

BEING PROACTIVE

"I'm not the kind of person who will just wait for that appointment, I'll find out their email address or their secretary's contact number and I'll ask for help. I didn't used to but I now will say 'I need this'."

"If you are born with a learning disability or you have an early brain injury, you know that's what life is. But I can remember what life was like before and that's massive."

"...making a meal, I'm a disaster, I walk away and I leave the pan, I forget this is on, I forget the ingredients and I used to do that really, really well but I've lost that."

COGNITIVE DIFFICULTIES

"...it affects my memory, it affects my facial recognition, it affects lots of cognitive things, it affects pain, it affects movement - I have uncontrolled movement jerking and things which is very embarrassing when you are out and about. It affects how I control my feelings and how good I control my feelings. Every single functioning that we have as human beings, FND lets you down because it basically really just means that the messages from your brain to your body and your body to your brain, don't go on the normal pathways..."

UNPREDICTABLE

"...waking up in the morning, I do not know whether I can get out of bed myself and sometimes I can perfectly fine and I can walk about or even go faster and some days I'm paralysed and I have to use a wheelchair or stay in bed."

INCONTINENCE

"I think the incontinence is quite a big problem which is quite a difficult one to manage."

DISINHIBITION

"...I think having FND, it breaks down a lot of barriers and you spill yourself into different areas and share things in a different way"

OTHER CONDITIONS

Periodic limb movement disorder, small vessel disease in frontal lobe, complex post-traumatic stress disorder, diabetes, arthritis, nodular prurigo

Things I do...

ART - TRANSFORMATIVE

"...majorly impacted on my health, more so than any therapy or medication."

"...a space to express everything. And a feeling of success and purpose."

LEARNING

"I really believe you can learn something new and if you are using a different part of your brain that you haven't used before, it really strengthens."

THE VOLUNTARY SECTOR

"...for me has been pretty huge."

FAMILY

Very supportive husband, and three wonderful daughters who are all in the medical profession

"...knowing that they try and understand..."

My Condition(s)...

Where I live...

FLYING TO APPOINTMENTS

"It was a secondary benefit for me, from having appointments south in that I got to see my children, I got off-island, which I think is a good psychological thing. I love [the island] and my family would like me to move south but I'm the one wanting to stay here."

People and values...

FAITH

"I guess my religious faith is also quite fundamental."

EVERYONE KNOWS BUSINESS

"...it felt like people are going to know all our business, people know my business and it took me a long time to open up to local services. I was happy to go to Aberdeen and speak to specialists but not to speak to people here. Remote and rural is hard, it's tough. You can't be anonymous."

LIVING ON AN ISLAND

"I think being on an island is quite relevant to my pathway as well, access to things is different."

NETWORK OF FRIENDS

From school and through my different interests and activities

VALUES - EVERYONE IS EQUAL

"Yes, I guess I've always believed, and I think it may come down to my faith, is that everybody is equal so nobody is scary and nobody is any better or any more important or less important than me. So if I need to ask somebody for something then there's nothing wrong in that or being ashamed in that."

"I think I ask questions that, as a [health professional], I want to know the answer as well as just the choice. And because you used the language that is professional, part of the language of that speciality, you have different kinds of consultations. I think I can be - well, I know I can be pretty challenging."

NO SPECIALISTS

"...in Aberdeen I would see a neuro-based OT and a neuro-based physio, so that's the challenge I think [islanders] need to accept where they get it wrong and where they need help and support in ongoing training."

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.

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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

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i.e. hospital visits including tests and consultations

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14 YEARS AGO

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LOST USE OF RIGHT ARM

"I had an episode about fourteen years ago, I think, where I lost the use of my right arm and it wasn't really given a diagnosis..."

STOPPED WORKING

"I stopped working because of ill-health, I think because I have complex PTSD, and I believe I've had that for a very, very long time, undiagnosed..."

"...the GP didn't refer me or anything like that."

LOCUM GPs

"The GP, just before I went to the local hospital, we didn't have a GP, we had a few years of locum GPs, the post was vacant I think for about three or four years, so sometimes it felt that there was no point in going to the GP with the symptoms I was having and on at least one occasion one GP said to me 'it's all in your head', and statements like that."

WAITING FOR APPT

"...so I waited five months thinking I had Huntington's Disease, which is a progressive condition which leads to psychosis and death... I was terrified that my daughters had a genetic disposition to Huntington's Disease."

GP AT LOCAL HOSPITAL - REFERRAL TO NEUROLOGY

"And that was quite scary because he... just spoke aloud his thoughts as he looked up things on the computer and he said aloud, 'Huntington's Disease', and I heard those two words!"

INVESTIGATIONS

"And of course you've got to get MRI scans and all that as well, as part of the process, which makes you think you've got everything in the world."

"...ended up in hospital, got a diagnosis of Parvilo virus which may not have been right, but to me that's where my FND journey started."

PSYCHOTHERAPY

"I had psycho-therapy about ten years ago for a few years and the therapist was in Aberdeen and then she retired..."

Your experience of diagnosis...

EMOTIONAL JOURNEY

ACCEPTANCE

FELT LISTENED TO AND RESPECTED

STRUGGLED TO ACCEPT DIAGNOSIS

ANGRY

VERY ANXIOUS

HOME LIFE

ACCEPTANCE OF DIAGNOSIS

IS THE DIAGNOSIS REALLY CORRECT?

FND HOPE

"That's where I went for information when I was first diagnosed, when I first saw that neurologist who was awful, I went to FND Hope and I found videos, I found explanations, I found stories, I found the Facebook chat group and I was a part of that for a few years, dipping in and out of it..."

"I have a lot of friends who have MS... I go to neurophysio with people with MS so MS, it's one thing that people tend to think with a lot of FND symptoms because they correlate so highly, like a lot of neurological conditions. So it was very hard for me to accept that this was right, that this was what I had..."

"So from first seeing the GP and really believing the diagnosis, it was probably a year."

GP BASED CARE

GP KNOWLEDGE OF FND

ASKED FOR A SECOND OPINION

"So I went home very angry and I went back to my GP and got referred back for a second opinion, back to Aberdeen..."

"And even when I had a diagnosis, one GP said to me, 'FND doesn't exist, it's a new-fangled idea', kind of thing."

HOSPITAL BASED CARE

DIAGNOSIS

"...he gets zero out of ten for his diagnostic skills!"

CONSULTANT NEUROLOGIST 1

"I initially saw a consultant for one appointment and that was a horrendous experience and he was just about to retire, he had junior doctors coming in and out of the room, I found him patronising, I felt very anxious. I remember lying on the examination couch and him telling me to relax, relax, relax and it was the one thing I could not do. And then at the end of the appointment he just said, 'You have FND' and he wrote down one of the websites, neurosymptoms.org, on a bit of paper and gave me it and just said, 'live your life', and that was it."

CONSULTANT NEUROLOGIST 2

"...it was chalk and cheese. He explained what it was, he listened, he was compassionate."

NEUROPSYCHOLOGIST

"I also had a neuropsychology appointment at that time and when she looked back at my history she thought I'd had the condition for quite a few years."

PSYCHOLOGY PROFESSOR

"...I really struggled to accept it and I was referred down to Edinburgh to see [a Professor], at the Western... for about four appointments and it was only then I started to believe the diagnosis. He is one of the world experts on the condition and I reckoned if he thought I had it, then I must have it."

TIMELINE

4 YEARS AGO

5 MONTHS AFTER GP REFERRAL

Life after diagnosis...

EMOTIONAL JOURNEY

MISUNDERSTOOD
"You lose trust, you lose respect and you feel very, very undervalued..."

"...if you've got negative thinking about yourself because of an illness, it **hurts really deeply** even though you don't want it to, you feel that person, that they are treating you as if you are not as important."

VERY, VERY LOW POINT

HOME LIFE

MOVING HOUSE
"I had to move because I couldn't manage around the house, for mobility reasons, the bathroom wasn't working for me..."

GP BASED CARE

SOCIAL WORK
"...social work were just shite at providing services so things were bad..."

"...the weak point for me has been social work and occupational therapy, from the point of view that they don't understand FND, I didn't feel they even tried to understand FND"

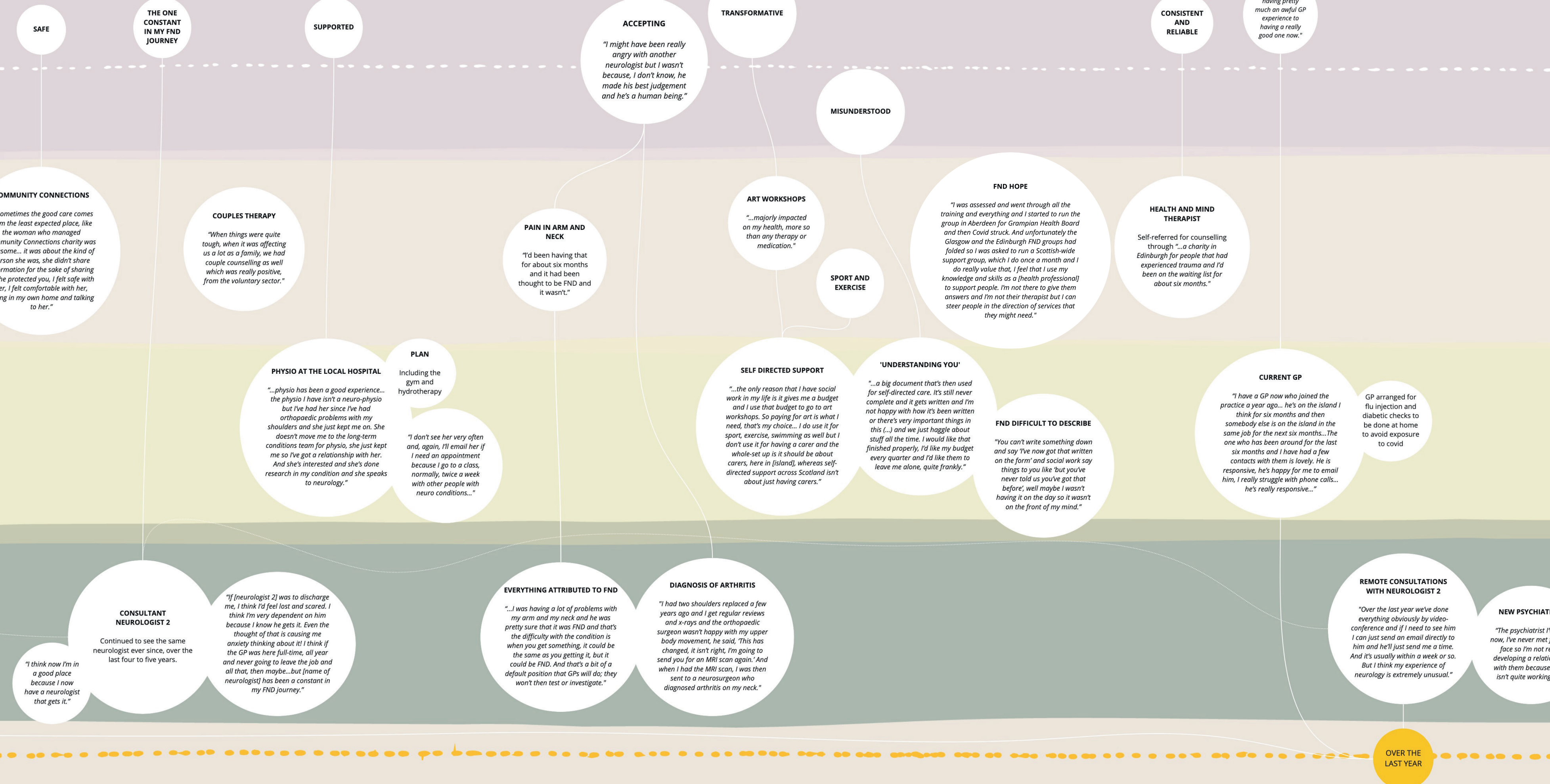
OCCUPATIONAL THERAPY
"...obsessed with money, budgets, what they have to do and get away with and would use terms 'we don't need to give you that, you might not ever need it. If we gave you that in your bathroom, it's going to stop you getting well.' Crazy mentality"

LOCAL AUTHORITY
"...I might go to the wrong person about something and they might say 'maybe you should speak to them' and I get that and it's fine but other times you feel that from local authority, that you are being passed around the departments and nobody is going to do anything about it."

HOSPITAL BASED CARE

PSYCHIATRIST
"The psychiatrist I was seeing was really, really good and up until last year she, I think she got ill and then she resigned..."

TIMELINE



What could be better for you?



MULTIDISCIPLINARY MEETINGS

"At one point we had social work meetings to try and put a plan together for self-directive care and the list of people, when I remember seeing this list of people who were involved in my life, and it was shocking, from consultants, and a GP, social work, physio, OT, speech and language therapy at one point, housing and Community Connections... There was a dozen or more different people. Which is ghastly, you want the right people and you want them when you need them but you don't want them knowing everything about you. And the way that meetings happen, multidisciplinary, they tend to talk about everything about you and you are sitting thinking well why do the housing department have to know about my traumatic childhood? They just have to know what my housing needs are. You get opened up and exposed in a way that you are never prepared for."

MANAGEMENT

"...I think neurologists and neuropsychologists try a lot to try and get people to understand the patient with FND. They must be hitting their heads off the wall with frustration and it takes individuals like some of the folk in Aberdeen and elsewhere, who are really trying to improve things so that **patients don't have to always end up at the hospital, you could have GPs that could manage it and do really well.**"

CONSISTENT / ROUTINE

"I saw her [therapist] every week at the same time on the same day, it was always reliable and consistent..."

AS NEEDED APPOINTMENTS

"...so if I need to see him more, I see him more. If I need to see him less, I see him less..."

SELF REFERRAL

MS
More local services and support (society, taxi service, specialist nurse) – not accessible to people living with FND

DIABETES

"Yes, if you have diabetes in itself, there's a path the way the condition goes and there's treatments that work and people know the up-to-date treatments and if your weight is not good or you are not exercising it's all kind of explainable and people think they understand diabetes."

COMPARISON WITH OTHER CONDITIONS

Interviewer: "So... it's less about a care pathway... and much more about the relationships we have with different professionals along the way?"

"Yes, I think the care pathways, sometimes you have somebody that you see who then triggers a different route for you."

TREATS ME AS A WHOLE PERSON

"I know he's interested in me as a whole person and not just which bits of my brain aren't working and which symptoms I get so that means a huge amount, that's massive."

RESPECT

"I felt that he respected me as a human being."

CONNECTION

"A connection is really important to me, it really is. I've kind of chosen this GP at the practice as the one I want to see and he's happy with that."

INFORMED

"...she's interested and she's done research in my condition and she speaks to neurology."

TRUST

"...he's got experience and therefore there's a trust, I think trust and respect and good listening skills. And he's very reassuring..."

WHOLE OF LIFE CONVERSATIONS

"...if you are learning something new you don't have a previous history of failure so it doesn't matter what it is, I think people should be told by the NHS to find a hobby! And that sounds really flippant but **something purposeful in their life**, I think that's key."

MAKES TIME WHEN NEEDED

"he's the most dreadful time-keeper... but I know that it's because he's with somebody else who right now needs him more, so I don't mind that. And I know that... equally I've had sessions that are a lot, lot longer because it's had to be so you kind of accept that, that's okay, and he's flexible."

COMPASSION AND UNDERSTANDING

"...it's not about what hat you wear, whether you are a really experienced consultant neurologist, you might be a voluntary working at a project, it might just be somebody who you relate to and they understand you and you don't even have to explain it to."

FACE TO FACE

"I hope I go back to face-to-face appointments with neurology."

ONLINE

"I'd happily fill things in online and never see them. That's because they've hurt me, they have hurt me and I know my response sounds very rejecting, but I've had three social workers and not one of them have I felt with or safe with."

RESPONSIVE

"I really struggle with phone calls... I understand people much more, seeing their face, so he gets that he will happily email me back. And if I email him... and he's concerned, he'll say 'let's do a video-call at two o'clock on Friday', so he's really **responsive** and he accepts that I don't want to be in the practice because I don't want to be exposed to Covid."

PEER SUPPORT

"I didn't have that when I first started going to FND Hope, as a charity, that group wasn't available to me, it wasn't around. And I kept moaning that there wasn't a group in my part of Scotland... I kind of felt I had no choice but to set one up."

"...we need more peer support workers but we definitely need to work with the voluntary sector, with the health board, we need to be all part of the same trying to make things – you know, a better life for patients, and that's it."

COLLABORATION

"Grampian NHS Neurology Department, came along and did some talks at our FND Hope group in Aberdeen and it's very mutually beneficial because we advertise in the neurology department so that new patients with a diagnosis can be referred to the charity and come along to the group when it's running."

COMMUNICATION

"...he'll contact physio if I need physio and he just – he kind of case manages us in a way as well, to some level, I think."

TRAINING IN FND

"I think there needs to be training for social workers and for occupational therapists. Actually for anybody who... isn't trained in FND. I think they need to be updated, it's not all blaming them, I don't think there's a budget, to be honest."

THE VOLUNTARY SECTOR

"the voluntary sector... I think they are instrumental in doing a lot of really good stuff in [island] and they pick up a lot of the things where the local authority have stopped providing services."

Collaboration

Pathways

Place of care

Positive Relationships

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