

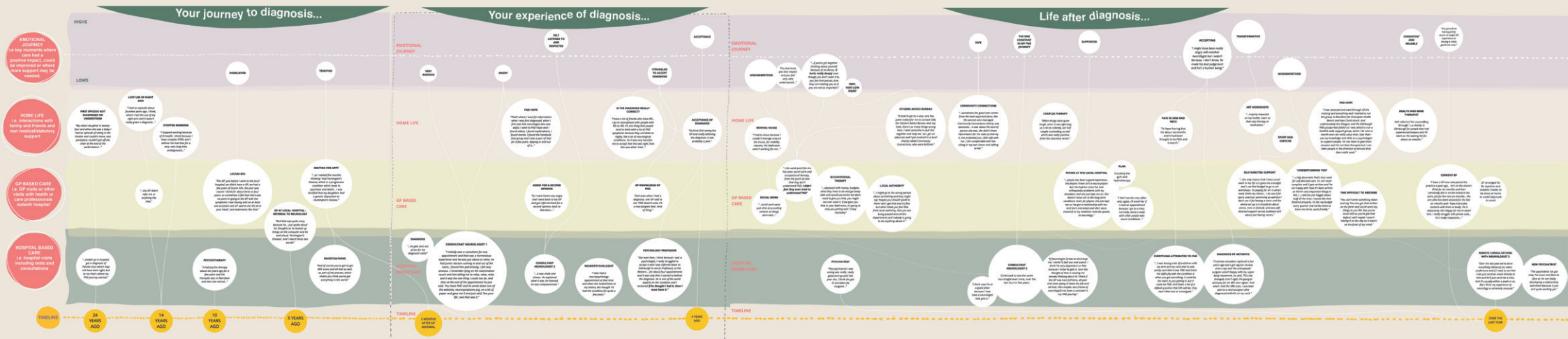
experience map

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 in the NHS as a Psychologist

"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."

OTHER CONDITIONS

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

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"

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."

LIVING ON AN ISLAND

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

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."

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."

Where I live...

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'."

Things I do...

HELPING OTHERS THROUGH VOLUNTEERING ROLES - USING MY EXPERTISE

STRUCTURE & ROUTINE

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

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."

NETWORK OF FRIENDS

From school and through my different interests and activities

FAMILY

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

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

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."

FAITH

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

"I think I ask questions that, as a psychologist, 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."

People and values...

My Condition(s)...

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

24 YEARS AGO

14 YEARS AGO

10 YEARS AGO

5 YEARS AGO

FIRST EPISODE NOT DIAGNOSED OR UNDERSTOOD

"My oldest daughter is twenty-four and when she was a baby I had an episode of sitting in the theatre and couldn't move, was paralysed, couldn't get off the chair at the end of the performance..."

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."

DISBELIEVED

TERRIFIED

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!"

PSYCHOTHERAPY

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

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."

Your experience of diagnosis...

EMOTIONAL JOURNEY

VERY ANXIOUS

ANGRY

FELT LISTENED TO AND RESPECTED

ACCEPTANCE

STRUGGLED TO ACCEPT DIAGNOSIS

HOME LIFE

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..."

IS THE DIAGNOSIS REALLY CORRECT?

"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..."

ACCEPTANCE OF DIAGNOSIS

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

GP BASED CARE

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..."

GP KNOWLEDGE OF FND

"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

"But even then, I think because I was a psychologist, 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

5 MONTHS AFTER GP REFERRAL

4 YEARS AGO

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..."

CITIZENS ADVICE BUREAU
"It took to get to a very, very low point indeed for me to contact CAB, the Citizen's Advice Bureau and say, 'look, there's so many things wrong here, I need someone to pull this together and help me.' So I got an advocate and I got involved in a local charity called Community Connections, who were brilliant."

COMMUNITY CONNECTIONS
"...sometimes the good care comes from the least expected place, like the woman who managed Community Connections charity was awesome... It was about the kind of person she was, she didn't share information for the sake of sharing it, she protected you, I felt safe with her, I felt comfortable with her, sitting in my own home and talking to her."

COUPLES THERAPY
"When things were quite tough, when it was affecting us a lot as a family, we had couple counselling as well which was really positive, from the voluntary sector."

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..."

CONSULTANT NEUROLOGIST 2
Continued to see the same neurologist ever since, over the last four to five years.

"I think now I'm in a good place because I now have a neurologist that gets it."

"If [neurologist 2] was to discharge me, I think I'd feel lost and scared. I think I'm very dependent on him because I know he gets it. Even the thought of that is causing me anxiety thinking about it! I think if the GP was here full-time, all year and never going to leave the job and all that, then maybe...but [name of neurologist] has been a constant in my FND journey."

TIMELINE

SAFE

THE ONE CONSTANT IN MY FND JOURNEY

SUPPORTED

ACCEPTING
"I might have been really angry with another neurologist but I wasn't because, I don't know, he made his best judgement and he's a human being."

TRANSFORMATIVE

MISUNDERSTOOD

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

SPORT AND EXERCISE

FND HOPE
"I was assessed and went through all the training and everything and I started to run the group in Aberdeen for Grampian Health Board and then Covid struck. And unfortunately the Glasgow and the Edinburgh FND groups had folded so I was asked to run a Scottish-wide support group, which I do once a month and I do really value that, I feel that I use my knowledge and skills as a psychologist to support people. I'm not there to give them answers and I'm not their therapist but I can steer people in the direction of services that they might need."

HEALTH AND MIND THERAPIST
Self-referred for counselling through "...a charity in Edinburgh for people that had experienced trauma and I'd been on the waiting list for about six months."

"I've gone from having pretty much an awful GP experience to having a really good one now."

CONSISTENT AND RELIABLE

PHYSIO AT THE LOCAL HOSPITAL
"...physio has been a good experience... the physio I have isn't a neuro-physio but I've had her since I've had orthopaedic problems with my shoulders and she just kept me on. She doesn't move me to the long-term conditions team for physio, she just kept me so I've got a relationship with her. And she's interested and she's done research in my condition and she speaks to neurology."

PLAN
Including the gym and hydrotherapy

"I don't see her very often and, again, I'll email her if I need an appointment because I go to a class, normally, twice a week with other people with neuro conditions..."

SELF DIRECTED SUPPORT
"...the only reason that I have social work in my life is it gives me a budget and I use that budget to go to art workshops. So paying for art is what I need, that's my choice... I do use it for sport, exercise, swimming as well but I don't use it for having a carer and the whole-set up is it should be about carers, here in [island], whereas self-directed support across Scotland isn't about just having carers."

'UNDERSTANDING YOU'
"...a big document that's then used for self-directed care. It's still never complete and it gets written and I'm not happy with how it's been written or there's very important things in this (...) and we just haggle about stuff all the time. I would like that finished properly, I'd like my budget every quarter and I'd like them to leave me alone, quite frankly."

FND DIFFICULT TO DESCRIBE
"You can't write something down and say 'I've now got that written on the form' and social work say things to you like 'but you've never told us you've got that before', well maybe I wasn't having it on the day so it wasn't on the front of my mind."

CURRENT GP
"I have a GP now who joined the practice a year ago... he's on the island I think for six months and then somebody else is on the island in the same job for the next six months...The one who has been around for the last six months and I have had a few contacts with them is lovely. He is responsive, he's happy for me to email him, I really struggle with phone calls... he's really responsive..."

GP arranged for flu injection and diabetic checks to be done at home to avoid exposure to covid

EVERYTHING ATTRIBUTED TO FND
"...I was having a lot of problems with my arm and my neck and he was pretty sure that it was FND and that's the difficulty with the condition is when you get something, it could be the same as you getting it, but it could be FND. And that's a bit of a default position that GPs will do; they won't then test or investigate."

DIAGNOSIS OF ARTHRITIS
"I had two shoulders replaced a few years ago and I get regular reviews and x-rays and the orthopaedic surgeon wasn't happy with my upper body movement, he said, 'This has changed, it isn't right, I'm going to send you for an MRI scan again.' And when I had the MRI scan, I was then sent to a neurosurgeon who diagnosed arthritis on my neck."

REMOTE CONSULTATIONS WITH NEUROLOGIST 2
"Over the last year we've done everything obviously by video-conference and if I need to see him I can just send an email directly to him and he'll just send me a time. And it's usually within a week or so. But I think my experience of neurology is extremely unusual."

NEW PSYCHIATRIST
"The psychiatrist I've got now, I've never met face-to-face so I'm not really developing a relationship with them because it just isn't quite working yet."

OVER THE LAST YEAR

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."

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

"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."

"...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."

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."

Place of care

Positive Relationships

Collaboration

Pathways

Place of care

Positive Relationships