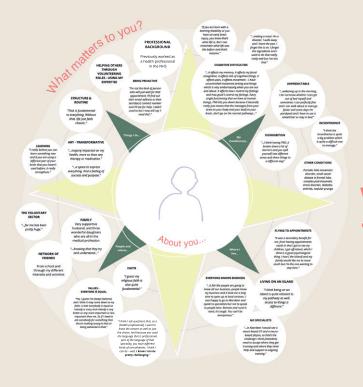
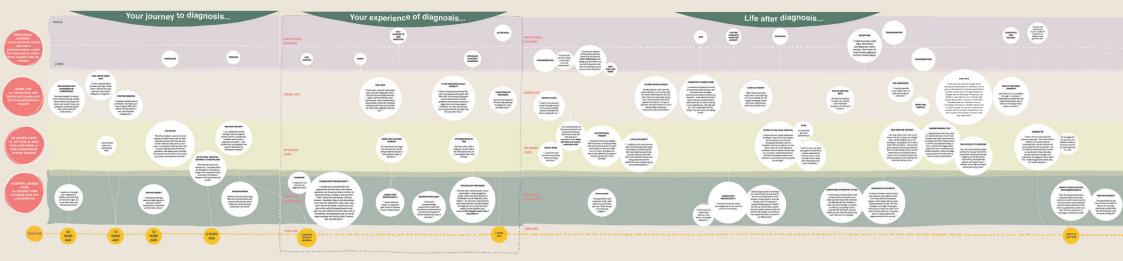


experience map functional neurological disorder

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!

PROFESSIONAL BACKGROUND

Previously worked as a health professional in the NHS

About you...

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'."

COGNITIVE DIFFICULTIES

"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."

"...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..."

Condition(s)..

UNPREDICTABLE

"...wakening 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."

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

INCONTINENCE

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

"...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

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

OTHER CONDITIONS

STRUCTURE & ROUTINE

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

Things I do..

ART - TRANSFORMATIVE LEARNING

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

"...a space to express success and purpose."

SECTOR

"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."

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

THE VOLUNTARY

NETWORK OF FRIENDS

From school and through my different interests and activities

everything. And a feeling of

FAMILY

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

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

People and

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

FAITH

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."

Where I

"...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."

EVERYONE KNOWS BUSINESS

"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."

FLYING TO APPOINTMENTS

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 neurobased 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 **EMOTIONAL JOURNEY** i.e key moments where care had a positive impact, could be improved or where more support may be **TERRIFIED** DISBELIEVED needed. LOWS LOST USE OF RIGHT "I had an episode about FIRST EPISODE NOT fourteen years ago, I think, DIAGNOSED OR **HOME LIFE** where I lost the use of my UNDERSTOOD right arm and it wasn't i.e. interactions with really given a diagnosis..." STOPPED WORKING family and friends and "My oldest daughter is twentyfour and when she was a baby I non medical/statutory "I stopped working because had an episode of sitting in the of ill-health, I think because I support theatre and couldn't move, was have complex PTSD, and I paralysed, couldn't get off the believe I've had that for a chair at the end of the very, very long time, performance..." undiagnosed..." WAITING FOR APPT LOCUM GPs "...so I waited five months thinking I had Huntington's "The GP, just before I went to the local Disease, which is a progressive **GP BASED CARE** hospital, we didn't have a GP, we had a condition which leads to few years of locum GPs, the post was .e. GP visits or other psychosis and death... I was "...the GP didn't vacant I think for about three or four terrified that my daughters had visits with health or refer me or years, so sometimes it felt that there was a genetic disposition to anything like no point in going to the GP with the care professionals Huntington's Disease." symptoms I was having and on at least outwith hospital one occasion one GP said to me 'it's all in your head', and statements like that." 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!" **HOSPITAL BASED** CARE i.e. hospital visits INVESTIGATIONS "...ended up in hospital, **PSYCHOTHERAPY** including tests and got a diagnosis of "And of course you've got to get Parvilo virus which may "I had psycho-therapy consultations MRI scans and all that as well, not have been right, but about ten years ago for a as part of the process, which to me that's where my few years and the makes you think you've got FND journey started." therapist was in Aberdeen everything in the world." and then she retired..." 24 10 TIMELINE -------**5 YEARS YEARS YEARS YEARS** AGO **AGO AGO** AGO

Your experience of diagnosis...

FELT

AND

LISTENED TO **EMOTIONAL** RESPECTED **JOURNEY**

ACCEPTANCE

VERY ANXIOUS

ANGRY

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 Aherdeen

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."

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

5 MONTHS AFTER GP REFERRAL

4 YEARS

Life after diagnosis... "I've gone from having pretty much an awful GP THE ONE TRANSFORMATIVE CONSISTENT experience to CONSTANT **ACCEPTING** AND SUPPORTED having a really **EMOTIONAL** RELIABLE IN MY FND good one now." IOURNEY "I might have been really JOURNEY angry with another neurologist but I wasn't because, I don't know, he "...if you've got negative made his best judgement thinking about yourself "You lose trust, and he's a human being." because of an illness, it vou lose respect hurts really deeply even MISUNDERSTOOD MISUNDERSTOOD and you feel though you don't want it to, you feel that person, that VERY, they are treating you as if VERY LOW you are not as important." POINT FND HOPE **COMMUNITY CONNECTIONS** ART WORKSHOPS CITIZENS ADVICE BUREAU "I was assessed and went through all the **HEALTH AND MIND** ..sometimes the good care comes training and everything and I started to run the COUPLES THERAPY "...majorly impacted THERAPIST "It took to get to a very, very low from the least expected place, like group in Aberdeen for Grampian Health Board PAIN IN ARM AND on my health, more so point indeed for me to contact CAB, the woman who managed and then Covid struck. And unfortunately the HOME LIFE "When things were quite NECK than any therapy or Self-referred for counselling the Citizen's Advice Bureau and say, Glasgow and the Edinburgh FND groups had Community Connections charity was tough, when it was affecting medication." through "...a charity in 'look, there's so many things wrong awesome... it was about the kind of folded so I was asked to run a Scottish-wide **MOVING HOUSE** us a lot as a family, we had "I'd been having that Edinburgh for people that had here. I need someone to pull this support group, which I do once a month and I person she was, she didn't share couple counselling as well for about six months experienced trauma and I'd together and help me.' So I got an information for the sake of sharing do really value that, I feel that I use my which was really positive, "I had to move because I and it had been been on the waiting list for SPORT AND advocate and I got involved in a local it, she protected you, I felt safe with knowledge and skills as a [health professional couldn't manage around from the voluntary sector. thought to be FND and about six months." charity called Community her, I felt comfortable with her, EXERCISE to support people. I'm not there to give them the house, for mobility it wasn't." Connections, who were brilliant." answers and I'm not their therapist but I can sitting in my own home and talking reasons, the bathroom steer people in the direction of services that wasn't working for me... they might need." "...the weak point for me 'UNDERSTANDING YOU' has been social work and SELF DIRECTED SUPPORT PHYSIO AT THE LOCAL HOSPITAL Including the occupational therapy, **CURRENT GP** OCCUPATIONAL ...a big document that's then used from the point of view "...the only reason that I have social "...physio has been a good experience... hydrotherapy for self-directed care. It's still never "I have a GP now who joined the that they don't work in my life is it gives me a budget GP arranged for the physio I have isn't a neuro-physio complete and it gets written and I'm understand FND. I didn't LOCAL AUTHORITY practice a year ago... he's on the island I flu injection and and I use that budget to go to art but I've had her since I've had ...obsessed with money, budgets, not happy with how it's been written feel they even tried to think for six months and then diabetic checks to workshops. So paying for art is what I orthopaedic problems with my what they have to do and get away or there's very important things in FND DIFFICULT TO DESCRIBE understand FND" "... I might go to the wrong person somebody else is on the island in the be done at home need, that's my choice... I do use it for shoulders and she just kept me on. She with and would use terms 'we don't this (...) and we just haggle about about something and they might same job for the next six months...The to avoid exposure doesn't move me to the long-term SOCIAL WORK "I don't see her very often sport, exercise, swimming as well but I need to give you that, you might stuff all the time. I would like that "You can't write something down don't use it for having a carer and the conditions team for physio, she just kept and, again, I'll email her if finished properly, I'd like my budget

I need an appointment

because I go to a class,

normally, twice a week

with other people with

neuro conditions...

CARE

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

not ever need it. If we gave you that in your bathroom, it's going to stop you getting well.' Crazy

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..."

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."

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 it 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."

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."

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

whole-set up is it should be about

carers, here in [island], whereas self-

directed support across Scotland isn't

about just having carers."

"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."

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..."

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

on the front of my mind."

having it on the day so it wasn't

every quarter and I'd like them to

leave me alone, quite frankly."

to covid

REMOTE CONSULTATIONS WITH NEUROLOGIST 2

"Over the last year we've done everything obviously by videoconference 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.

"The psychiatrist I've got now, I've never met face-toface so I'm not really

developing a relationship

with them because it just

NEW PSYCHIATRIST

OVER THE

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."

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."

"... 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."

MANAGEMENT

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."

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."

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."

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."

FACE TO FACE

Place of

Collaboration

"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."

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

CONSISTENT /

What could be better to you? you are not exercising it's all kind of explainable and people think they understand diabetes."

> 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."

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."

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."

RESPECT

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

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

And he's very reassuring...

COMPASSION AND UNDERSTANDING

Positive

Relationships

"...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."

MAKES TIME WHEN NEEDED

"he's the most dreadful timekeeper... 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.'

aren't working and which "I felt that he symptoms I get so that means respected me as a a huge amount, that's human being." massive."

INFORMED

speaks to neurology."

TRUST

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

Your journey to diagnosis... HIGHS **EMOTIONAL JOURNEY** i.e key moments where care had a positive impact, could be improved or where more support may be **TERRIFIED** DISBELIEVED needed. LOWS LOST USE OF RIGHT "I had an episode about FIRST EPISODE NOT fourteen years ago, I think, DIAGNOSED OR **HOME LIFE** where I lost the use of my UNDERSTOOD right arm and it wasn't i.e. interactions with really given a diagnosis..." STOPPED WORKING family and friends and "My oldest daughter is twentyfour and when she was a baby I non medical/statutory "I stopped working because had an episode of sitting in the of ill-health, I think because I support theatre and couldn't move, was have complex PTSD, and I paralysed, couldn't get off the believe I've had that for a chair at the end of the very, very long time, performance..." undiagnosed..." WAITING FOR APPT LOCUM GPs "...so I waited five months thinking I had Huntington's "The GP, just before I went to the local Disease, which is a progressive **GP BASED CARE** hospital, we didn't have a GP, we had a condition which leads to few years of locum GPs, the post was .e. GP visits or other psychosis and death... I was "...the GP didn't vacant I think for about three or four terrified that my daughters had visits with health or refer me or years, so sometimes it felt that there was a genetic disposition to anything like no point in going to the GP with the care professionals Huntington's Disease." symptoms I was having and on at least outwith hospital one occasion one GP said to me 'it's all in your head', and statements like that." 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!" **HOSPITAL BASED** CARE i.e. hospital visits INVESTIGATIONS "...ended up in hospital, **PSYCHOTHERAPY** including tests and got a diagnosis of "And of course you've got to get Parvilo virus which may "I had psycho-therapy consultations MRI scans and all that as well, not have been right, but about ten years ago for a as part of the process, which to me that's where my few years and the makes you think you've got FND journey started." therapist was in Aberdeen everything in the world." and then she retired..." 24 10 TIMELINE -------**5 YEARS YEARS YEARS YEARS** AGO **AGO AGO** AGO