

FND

Functional Neurological Disorder |

“ THE MOST
COMMON
CONDITION
YOU HAVE NEVER
HEARD OF! ”



FND HOPE
FUNCTIONAL NEUROLOGICAL DISORDER **UK**

2021 Impact report



Mission

To promote awareness, support affected individuals and advance research for the prevention, treatment and recovery of FND

Vision

A world where FND patients can expect to be treated with dignity, care and respect, regardless of the cause of their symptoms.

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| Welcome from Our Chair of Trustees

“ **FND Hope UK** is a vital support for those diagnosed with the condition. With no recognised care pathway within the NHS, something we hope to change as a charity, it can be incredibly difficult to not only get any treatment but to even get a diagnosis, imagine if that was the case for other health conditions?

People already suffering from the symptoms of FND then have to endure the stigma attached to it which stems from beliefs many years ago, not the knowledge that exists in 2022.

As a charity we aim to remove this stigma, support our community with online classes, a telephone helpline, peer support groups and provide information to fill the gap left at present for them in the NHS.

Our trustees have experience with FND, either as a sufferer, carer or parent, we are passionate about the need for change.



Cindy Smulders



| Welcome from Our Patron



FND is the most common condition you have probably never heard of. I am dismayed by the lack of awareness of the condition, even within the medical profession despite it being as common as Multiple Sclerosis. It can affect anyone, your wife, husband, children, friends and family. People diagnosed with FND have to also deal with stigma and misconceptions because of the lack of knowledge surrounding the disorder.

This can result in a lack of compassionate care and effective treatment plans.

This needs to change.

Which is why I will be supporting the campaign for a dedicated FND care pathway, access to the right treatment for everyone, raising awareness and educating medical professionals.

That's why I am pleased to be
FND Hope UK's Patron.



Lorraine Kelly, OBE



Functional Neurological Disorder Patient Healthcare Journey

Onset of symptoms



A&E complete Assessments / Investigations

Potential Outcomes

- Diagnosed with Stroke or Epilepsy
- Not diagnosed and discharged
- Diagnosed and Discharged
- Admitted to Hospital
- Hospital refers to Neurology

OR

GP Appointment



Potential Outcomes

- Possible referral to Neurologist
- Possible referral to Community Therapies but are often not commissioned to treat FND patients
- Possible referral to outpatient Psychiatry



Approx 6 to 9 months later

Neurology Appointment



Potential Outcomes

- Diagnosed and Discharged with website
- Referral to FND Specialist outside catchment area due to healthcare services varying greatly depending on location
- Possible referral to outpatient Psychiatry (can take over 6 months for referral)

OR



Psychiatry Appointment

Potential Outcomes

- Suitable treatment offered
- Treatment not indicated
- Possible referral to outpatient Neurology (can take over 6 months for referral)

Ongoing cycle of patients being referred from clinician to clinician

“ I've been accused of faking, its all in my head and malingering. I've lost faith in the healthcare system and I'm feeling really anxious, depressed and suicidal ”



Approx 12 months later if accepted

FND Specialist Appointment



Potential Outcomes

- Positive diagnosis given
- Possible referral to Community Therapies but are often not commissioned to treat FND patients
- Outpatient Multi-disciplinary Therapy
- Inpatient Multi-disciplinary Therapy
- Day Case Multi-disciplinary Therapy
- Referred back to GP
- Not accepted due to being outside catchment area

“ I'm now on a waiting list. I've lost my job and applying for benefits. My symptoms are deteriorating and i'm just given medication ”



Time taken between diagnosis and treatment Around 2 years but can take 4 years



The earlier treatment is provided, the better the quality of care and recovery

What is FND | ?

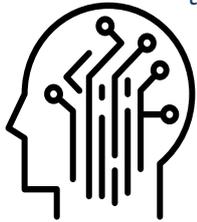
FUNCTIONAL NEUROLOGICAL DISORDER (FND)

Is a problem with the functioning of the nervous system and how the brain and body send and receive signals.

FND has multiple causes and can be triggered by physical injury, psychological or other trauma to the brain and or body.

FND Hope UK is part of the first and only global patient-led charity for people with Functional Neurological Disorder

FUNCTIONAL DISORDERS, of which FND forms a part, account for up to **16%** of diagnoses in new neurology outpatients – double the combined number for Parkinson's disease (**5%**) and MS (**3%**). ^[1]



FND patients live with life-changing symptoms, similar to Parkinson's Disease and long-term disability comparable to that with MS. More than **70%** of FND patients experience continuing or deteriorating symptoms after one year and over **70%** are the same or worse after 10 years. ^{[3] [4] [5] [6]}



FND impacts considerably more women than men; they account for between **60%** and **75%** of patients. ^[2]

For people of working age in England, the **NHS** spends an estimated **£3 BILLION** each year attempting to diagnose and treat medically



unexplained symptoms, of which **FND** forms a major part, and over **£14 billion** per year is lost in sickness absence and impaired

quality of life. ^[7]

FND in Scotland cost **£1.3 million** per year for out-patients, **£6 million** for in-patients and **£4.01 million** for primary care



Source Information

[1] Stone J et al. Who is referred to neurology clinics?—The diagnoses made in 3781 new patients. *Clinical Neurology and Neurosurgery* 2010;112(9):747-751.

[2] Current Concepts in Diagnosis and Treatment of FND Espay - *JAMA Neurology* 18.

[3] Anderson KE, Gruber-Baldini AL, Vaughan CG, et al Impact of psychogenic movement disorders versus Parkinson's on disability, quality of life, and psychopathology. *Mov Disord.* 2007 Nov 15;22(15):2204-9. PubMed PMID: 17876850.

[4] Stone J, Sharpe M, Rothwell PM, Warlow CP. The 12 year prognosis of unilateral functional weakness and sensory disturbance. *J Neurol Neurosurg Psychiatry.* 2003 May;74(5):591-6. PubMed PMID: 12700300; PubMed Central PMCID: PMC1738446.

[5] Sharpe M, Stone J, Hibberd C, et al Neurology out-patients with symptoms unexplained by disease: illness beliefs and financial benefits predict 1-year outcome.

[6] Gelauff J, Stone J, Edwards M, Carson A. The prognosis of functional (psychogenic) motor symptoms: a systematic review. *J Neurol Neurosurg Psychiatry.*

[7] Bermingham S, Cohen A, Hague J, Parsonage M. The cost of somatization in England for the year 2008-2009. et al 2010. *Ment Health Fam Med.* 2010 Jun;7(2):71-84. PMCID:PMC2939455;PMID:22477925.

[8] Carson et al. Disability, distress and unemployment in neurology outpatients with symptoms unexplained by organic disease. *J Neurol Neurosurg Psychiatry* 2011 (82) 7:810-13.



Our Mission

Our mission is to promote awareness of FND, support those affected by the condition and advance knowledge and research for the prevention, treatment and recovery from FND. We are looking forward to a world where FND patients can expect to be treated with the dignity, care and respect they deserve, regardless of the cause of their symptoms.



Supporting those affected by FND

Research suggests that FND is the second most common cause for a neurological outpatient visit, after headache/migraine. However, access to specialist support and appropriate therapy is a 'postcode lottery', with people waiting for up to 4 years for a visit and being referred to places well outside of their local area.

FND Hope UK, together with FND Hope International, is making a real difference in the lives of people experiencing FND, their families and carers, by providing expert support, advice, and therapy.

FND Hope UK developed strong links to FND experts, who provide their advice and expertise, which is then shared with the community through online resources and webinars. We have also built an extensive network of peer-support groups, facilitated by our trained volunteers, which provide a safe space for people to talk and share their experiences in a positive and supportive environment.

Lastly we deliver online therapy sessions, which can be joined free of charge, on a weekly basis. Activities ranging from Yoga, Pilates, Mindfulness Meditation and Art Journalling, provide support and needed respite, allowing people to better manage their symptoms while awaiting medical treatment.

| Diagnosis & access to treatment

It is estimated that between 50,000-100,000 adults and up to 20,000 children and young people under the age of 16 live with FND in the UK³. In addition there are estimated 10,000 new cases per year.

With access to specialist medical support being dependent on geographical location and the knowledge of how to diagnose and treat the disorder varying amongst the medical and allied health professionals, FND Hope UK is forging a way for people experiencing FND to be able to receive the support and treatment they deserve.

In collaboration with FND Specialists, National Neuro Advisory Group (NNAG) and the Neurological Alliance, we have developed an optimum clinical pathway which will provide a much needed resource for the medical community to deliver better informed and more suitable services to people experiencing Functional Neurological Disorders. (For more information on the pathway, please read p. 16).

| Raising awareness in the general & medical communities

With every resource or post that we produce, we are allowing our communities to improve their knowledge and understanding of FND - transforming lives for the better and removing historical stigma linked to the condition.

One of the most common experiences that many of our members face is the lack of information and understanding of the condition amongst the general population and within the medical community.

Through our work with our members, FND Warriors and FND experts, we are able to provide medically-reviewed advice, create factsheets and letters, that people experiencing FND can use in their home and work, and deliver a campaign which shared FND stories. Between July and December 2021, our #FNDandUS Campaign, which featured 6 FND Service User journeys, saw over 800k video views to raised awareness of FND.

Through our work in raising awareness we are actively removing the stigma, which is so strongly attached to an FND diagnosis. By informing medical and allied health professionals on better diagnosis and treatment of the condition, we are improving patient experience for all of our community members and their families.

³Raper J, Currigan V, Fothergill S, et al., Long-term outcomes of functional neurological disorder in children, Arch Dis Child., (2019)



Impact story: Andy

FND Hope UK has meant that I was finally able to understand what was happening to me. After years of being told “it was all in my head” and “it will get progressively worse”, I discovered a community who not only believed me, but shared my experiences and was able to offer advice and guidance.

My FND journey began 5 years ago, when a scaffold collapsed and I fell four metres onto a concrete floor - dislocation, bashed head, all the things that you would expect. Two weeks later I started having seizures and experiencing stroke-like symptoms. It led to me losing my job, my home and becoming homeless for 5 months.

FND is like an animal, it constantly evolves. I was in and out of hospital for a long time with no more help than when the symptoms started. As tests came back clear, I was told that “there was nothing wrong, it was all in my head” and I was struggling to get people to believe me. It was all about managing the pain - there was nowhere to go, I would zombie out all the time. At my lowest, I did not want to be here anymore and I stepped in front of a car. I stumbled on FND Hope UK when my partner

“The charity made me realise that I was not on my own”



and I were looking for support. The charity made me realise that I was not on my own and that everybody has been told the same story.

It helped us understand a lot about the condition and, through connecting with people, I was able to consider alternative ways to manage my symptoms while I was waiting to be diagnosed (I was on a waiting list for 2 years, as there was no one in the local area who could diagnose me).

Ultimately, they saved my life. If it wasn't for them, I would have probably just listened to the doctors, when they said it would get progressively worse, I would never be able to work and I would spend the rest of my life in a wheelchair. And I did, for a while. I think it was because I believed what I was told. But then I decided that, if it was in my head, I could make a difference. And here I am now, climbing mountains and working by supporting other people in crisis and setting up a mental health cafe in my local area.

I am passionate about raising awareness of FND, connecting with people to share my story and spreading the message that FND is real and that people experiencing it are not alone.

Andy is one of our Ambassadors, inspiring us with his positivity, energy and drive to challenge the everyday.



“
Ultimately,
they saved
my life”



Supporting our community

FND Hope UK is a **fully volunteer-led** charity and our key driver for all of our activities is our unwavering commitment to create a better world for children, young people and adults who experience FND.

In order to support our community, in 2021 we have



Delivered **125 online classes**, including Yoga, Dance, Pilates, Mindfulness,

Meditation and Art Journaling for Wellbeing

In a 3-month period, over **600 people** attended our online classes



Sent **3,300 FND Patient Booklets** to our community and medical professionals



Linked with over **19,600 people** through our social media channels



Published **9 virtual newsletters**, read by over 5000 people

Supported over **80 peer** support groups to move to virtual delivery

In December 2021, we completed **52 call-backs** through our helpline



Responded close to **900 emails** to help support our FND community with questions, signposting and advice

Reached **94.7k views** on our FND Hope YouTube Channel



“ I absolutely could not have coped with what was happening without them. ”

Member survey respondent

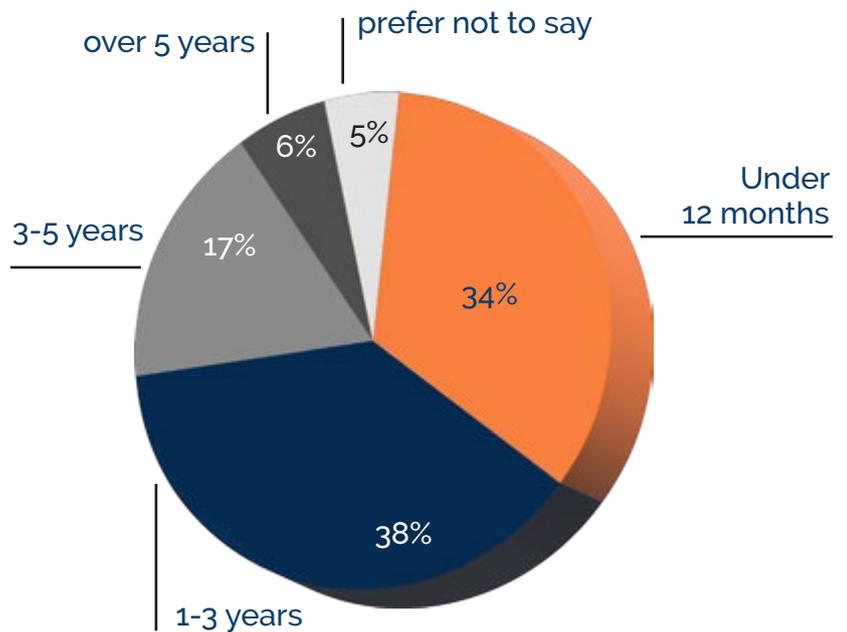


Member survey

To gain a better understanding of our impact on our community, we commissioned an independent researcher to undertake a member research. Our findings were based on responses from 235 individuals who are linked to FND Hope UK.

The research provided insight into how people access support, with the vast majority choosing FND Hope UK as the first organisation they contacted, and how effective and beneficial they see our services to be. We were also able to learn more about our members and benefit from their suggestions on how we can improve.

Who participated How long have you been linked to the charity?



Our most useful resources

71% social media content

69% downloadable resources

68% newsletters

62% FND patient booklets

62% Videos

85% The majority of our members identify as female

f Facebook is the most popular way to initiate contact with us

Suggestions to improve our services:

- ✓ Evening/weekend classes
- ✓ Different online classes
- ✓ Face-to-face support groups

“ It has been my lifeline since being diagnosed. Thank you. ”

Member survey respondent



Impact story: Cindy

FND Hope UK provided us with knowledge which allowed me and my family to begin to understand what FND is and start taking back a little bit more control.

My daughter has been diagnosed with FND following a head injury when she was 15 years old. She is an accomplished athlete and, at the time, had just become a Great Britain Junior World Champion. After her accident, she suddenly became someone very different. As her mum, I was desperate and I reached out for anything. Eventually I found FND Hope UK.

Initially it was suspected that she had a concussion, then post concussion syndrome. She then collapsed again and during her stay in A&E, we were told that 'there was nothing wrong with her' and 'it was all in her head'. She couldn't speak, she couldn't walk and we were sent home. It was only the following time

“ I felt someone was here to help me and support me, and that was all because of FND Hope UK ”



she was hospitalised that a neurologist suggested it could be FND. We were given a one page leaflet which gives you a summary of what it is, but that was that.

I am quite a strong, confident person and for the first time in my life, I didn't know what to do to help my daughter. Because I had no information, nobody listened to us, nobody could really tell us what was wrong or why. And that feeling of uselessness was awful. I think the effect mentally on me has been worse than it's been on my daughter. I'm not the person I was before she became ill. And that's not because she became ill. It's because of the way we were both treated.

The medical team really tried to take us down the psychological route, which did a lot of damage. Trying to find issues where there were none. It made us question everything. Surely it had to be psychological if they thought it was.

We decided to take my daughter's recovery into our own hands. We got her into private physiotherapy. We were lucky that her school was helpful. I've heard it's often not the case.

Due to my daughter's achievements, she is a minor celebrity in the sporting world. Her story was featured on TV and that's how FND Hope UK got in touch. They were very honest from the start, that they could not offer a solution. What they could do is offer support and help and signpost me to different resources. And I couldn't believe that for the first time there was somebody out there who would talk to me and try to explain what FND was. It made us realise that it didn't have to be psychological, it could also be caused by a physical trauma, injury or illness. That was a huge turning point for us. It was a golden moment where I didn't feel alone anymore. I felt someone was here to help me and support me, and that was all because of FND Hope UK.

Through various treatments and testing we have now learnt that FND is actually one of the symptoms of another underlying condition. It made us realise how important it is that all symptoms are thoroughly investigated rather than being put under the FND label. We just needed someone to listen to us.

Since then Cindy has joined us as a Trustee and is the driving force behind our parent support groups and our under 18s support. She is also a passionate spokesperson and her energy is instrumental in our work as a charity.



| Diagnosis & access to treatment

It has been shown that medically unexplained symptoms (which include FND) costs the NHS an estimated £3.1bn per year. When we take into account decreased quality of life and absence through sickness, wider costs to the economy reach £14bn on an annual basis⁵. This does not include the impact FND has on the families of people experiencing it, their places of work and education, support networks and friends. FND Hope UK benefits from a wealth of expertise and lived experience of FND. Through our own journeys and listening to the stories of our members, we know that a quick and informed diagnosis, followed by appropriate treatment and a referral to provide more holistic support can be life-changing. It's not uncommon that an onset of FND is linked to loss or significant changes to employment or skills essential to an individual's chosen career, their ability to lead independent life and the roles and responsibilities they hold in their private life. In addition, an FND diagnosis is often linked to patients experiencing stigma and misunderstanding from the healthcare professionals and the general public (suspicion of malingering or exaggeration of symptoms).

Over the last 12 months, we worked with outstanding FND experts to develop a pathway which could be used by healthcare professionals.



| Pathway

This optimum clinical pathway for adults with FND was designed by a group of specialist clinicians, allied health professionals and charity representatives. It has been recognised that the current long-term outlook for patients is poor with most remaining with long term disabling symptoms. It is common that people with FND face specific challenges in accessing appropriate care and support, which include: stigma and misunderstanding, poor quality or absent explanation of the diagnosis, frequent discharge after diagnosis without treatment plan or follow-up, referral into treatment services (community physiotherapy/occupational therapy, community mental health services) that lack expertise and support (often resulting in early discharge without treatment), lack of coordination between mental and physical health services in assessment and treatment, lack of a clear pathway to access specialist services, lack of availability of specialist services. It has been emphasised that it is of fundamental importance that people with FND receive a swift and well-explained diagnosis. This aspect of care requires a change

in practice in neurology services and related services where people with FND commonly present such as neurosurgical services, A&E, hyperacute stroke services. In some circumstances, diagnosis can be difficult, and therefore a key role for a specialist FND service is to provide expertise in diagnosis in such cases. A successful pathway for people with FND will therefore need a range of services available into which people can be referred depending on need and complexity. Achieving effective triage is therefore a key outcome of an optimum clinical pathway for FND.

Clinical working group membership:

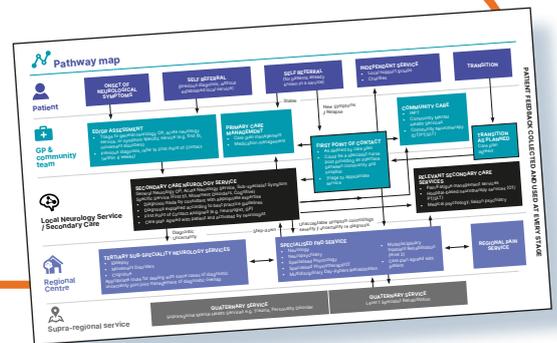
Professor Mark Edwards
Professor of Neurology



Dr Michael Dille
Consultant Neuropsychiatrist



To view the full Pathway map please go to **Page 22**





Impact story: Summer

Hello, my name is Summer and I am an FND Warrior.

FND Hope UK helped me massively. Not just me but my family too. They helped me realise that I am not the only one out there struggling.

I was hospitalised at the end of November 2020 due to becoming paralysed from the waist down after collapsing at school and not being able to move. I was in severe pain and my legs felt like they were on fire - like someone was pouring boiling water on them. A week later, after numerous tests and some intense physiotherapy, I was able to walk again.

Little did I know it was only the beginning of my journey and at the age of 11, I was diagnosed with FND.

Before, I was an active and healthy child who loved dancing and would spend most of the week at dance lessons - dancing is my passion, my life, my happy place. As for many other people, my life came to an abrupt pause in March 2020 due to COVID. It was a tough few months for me as I never got the chance to say goodbye to my friends in primary school, and had to stop dancing. The first few weeks of secondary school were great, however I then started being bullied, first mentally and then physically. My parents and school did everything they could to resolve the situation but it had a massive impact on my confidence and I started to get anxious around people.

Whilst there is no real understanding of what caused my FND, my neurophysiologist believes that with all the change in my life, and unhappiness, on top of my body changes, it's was like a computer with no memory left. It was like my body was buffering. My brain sent the message but the part of my body that needed it, did not receive it and needed time to catch up.

It was really scary at first and I could not understand why this was happening to me. In time I had learned to accept the temporary paralysis which would come and go. The pain was still there and the paralysis started to move into other areas. After 3 months, I started to develop other symptoms such as ticks, and Tourette-like outbursts, which was really embarrassing.

The scariest symptom of all was the seizures. I have ended up in hospital on numerous occasions, sometimes having to stay overnight. One particular episode was so bad, I temporarily lost most of my short term memory.

Who knows what the future holds for me. But I am pleased to say, I am back doing what I love - dancing. I have turned a corner at school, and am back loving life again. We noticed that my symptoms seemed to occur when I was stressed or anxious, so I am now also getting counselling to help with my anxiety.

I have FND. But FND does not have me. I do not let this disorder define who I am, or what I do. I am me and I will keep on dancing when I can. I am very lucky to have a supportive family around me, whilst this is my fight, they are my army, they are right behind me, helping me when times have been tough.

I want to spread awareness, and get it out there. We shouldn't have to face this alone. More research, funding and support is needed to help all of those who are suffering from this disorder.

FND Hope UK provides so much support to everyone involved in the charity. We are like one big family, always there to help, advise and support each other through the difficult times.

“ FND Hope UK provides so much support to everyone involved in the charity ”





Raising awareness

It has been suggested that FND is as common as Multiple Sclerosis or Parkinson's Disease⁷, however it does not benefit from the same levels of awareness amongst the general public and the medical community. Good levels of understanding and awareness are linked to better diagnosis and treatment, better quality of life, stronger support networks and lower levels/lack of stigma.

FND Hope UK recognises the importance of raising awareness and is putting our resources, expertise and networks to build the knowledge and understanding of the condition. In 2021, in addition to our successful "FND and Us" campaign, we have:

In 2021 we have.....

- Reviewed 12 UK research projects and advertised for our community to get involved
- Created and released "I'm Still Me" FND Awareness Video, which reached over **42,000 views** on social media
- Professor Mark Edwards, Professor of Neurology, St Georges University Hospital alongside Mike Rumsey from Rumsey Films, created **9 different videos to help raise awareness** of FND for the general public, FND Community and Medical Community
- Attended **5 conferences** hosted by medical communities, to share information and patient's perspective

“ FND Hope provides a rewarding, supporting and inclusive environment. It does indeed provide hope. ”

“ It's transformational. I'm in an incredible place and I couldn't have done it without FND Hope UK ”

| The future

We are looking forward to the time when all people experiencing FND will be able to access a quick diagnosis and good-quality healthcare. To the time when communities share a good understanding of the condition and feel empowered to support people experiencing it. We eagerly await the time when medical and allied health professionals diagnose and treat FND patients without stigma and with capacity, knowledge and resources to provide best care.

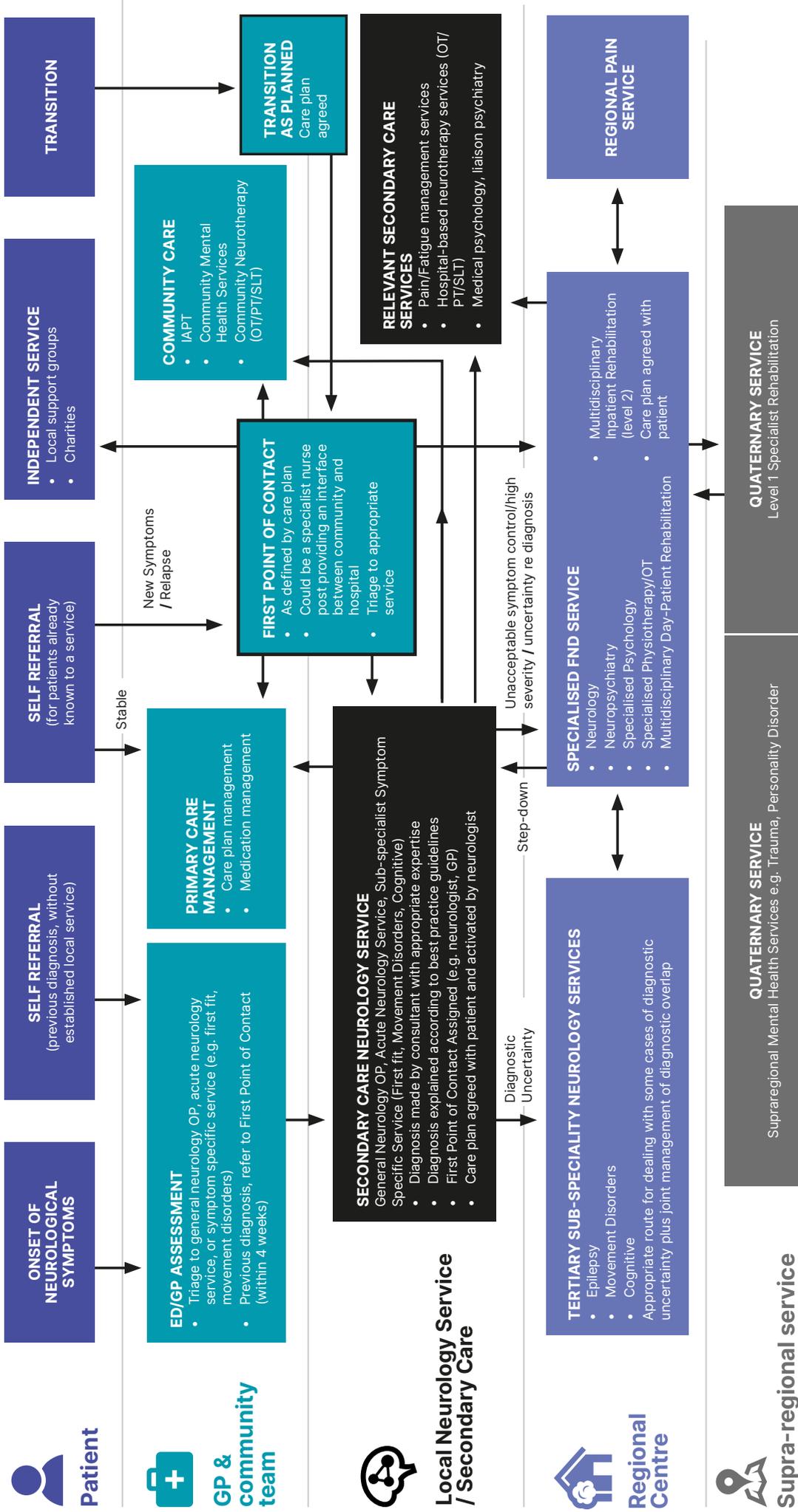
On our journey to that vision, we are planning to:

- ✓ Have a dedicated FND pathway implemented in all counties across England, Wales, Scotland and Northern Ireland
- ✓ To offer FND Masterclasses for those newly diagnosed so they can learn more about their condition, and be the charity medical and allied health professionals refer their patients to
- ✓ Provide Education and awareness to both our community and medical and allied health professionals
- ✓ Offer an annual conference where our community and medical and allied health professionals meet and learn more about research into FND
- ✓ To continue to offer online movement and wellbeing classes while also increasing our offer of support
- ✓ Provide online physiotherapy sessions
- ✓ Continue the improvement of the myFND app to continue to support our community
- ✓ Strengthen our partnerships/relationships with Integrated Care Systems/Boards to ensure appropriate and timely care-support is provided
- ✓ Support the creation of a specific framework for children/Young People that includes sensitive transitional care into adult services
- ✓ Support the creation of a specific healthcare worker training including GPs and A&E staff

Optimum clinical pathway for adults: Functional Neurological Disorder

PATIENT FEEDBACK COLLECTED AND USED AT EVERY STAGE

Pathway map



transformational
 great support
Helpful
Real
 educational
 life-saver
 letting people know they are not alone
life-saver
good resource Helpful
 a place to **non-judgemental**
 feel understood professional
good advice supportive
 relief supportive fab amazing
 dependable





Community

support us through donating



Medical Staff

refer to us for additional support



Members of the public

learn more about FND

Thank *you*

Our Trustees and Patron

Dawn Golder, Cindy Smulders, Abigail Bishop-Laggett, Stephen Betteridge-Sorby, Dr Chris Symeon, Bridget Mildon, Dr Helen Bolter and Lorraine Kelly CBE

Our incredible volunteers

Callum, Kath, Steve, Alex, Alison, Helen, Lindsey, Sarah, Vanessa, Robert, Laura, Charlie, David, Anthony, Henry, Joyce, Kim, Lesley, Chantelle, Kath, Emma, Jemma,

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FND HOPE
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