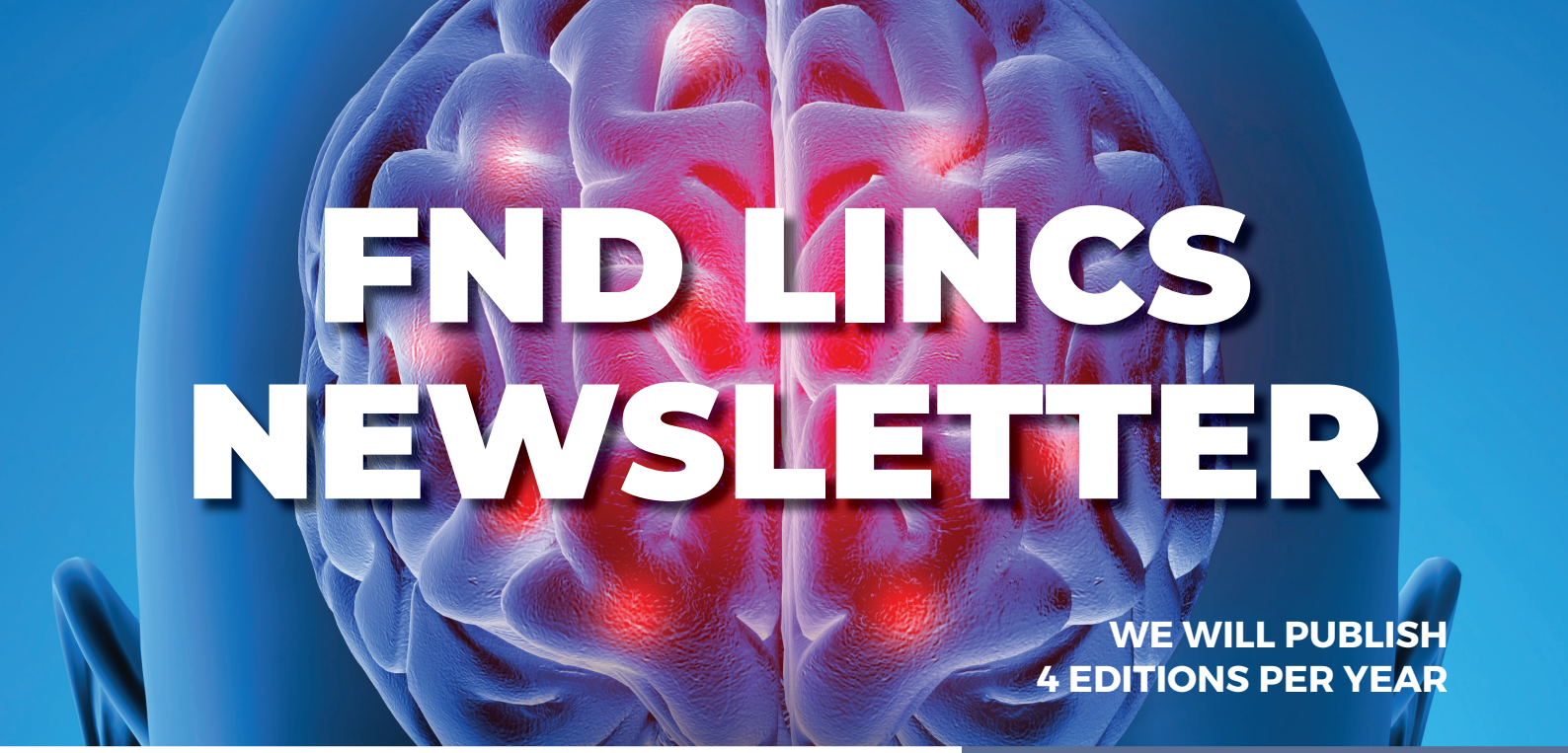

# FND LINCS NEWSLETTER

**WE WILL PUBLISH 4 EDITIONS PER YEAR**

Functional Neurological Disorder (FND) is one of the most common reasons for people to see a neurologist, yet it is still often misunderstood. In Lincolnshire we know there are hundreds of people living with FND, along with their families and carers, who face daily challenges with symptoms, diagnosis, treatment, and stigma. Many have told us they feel isolated or "lost in the system," unsure where to turn for support.

We are producing a regular newsletter to improve awareness, share information, and give people a stronger voice. This newsletter will provide updates on the work being done locally with the NHS Lincolnshire Integrated Care Board (ICB) and partners to improve care pathways, raise awareness among professionals, and strengthen community and voluntary support. It will highlight new developments, share personal stories, and point people to useful resources and support groups.

Most importantly, the newsletter will help connect people. It will create a space where patients, families, professionals, and community organisations can learn from each other and work together for change. By keeping everyone informed and engaged, we aim to build understanding, reduce stigma, and improve outcomes for people with FND in Lincolnshire.

*The newsletter does not offer clinical advice and should not replace any guidance provided by clinicians working with individuals or their loved ones.*

**Autumn 2025**

**Edition 1**

***"SHINING A LIGHT ON FUNCTIONAL NEUROLOGICAL DISORDER (FND) IN LINCOLNSHIRE"***

FNDLincs.org

## Richie's Research

***As part of our new website we will be sharing information about the latest research and articles associate with FND. This page will be managed by one of our members and will be an opportunity to both share papers and comment. The new web site is currently in development and will be launched in early 2026. Let us know if you want to be involved in any aspect of this exciting development.***

## What is FND?

Functional Neurological Disorder (FND) is a condition where the brain and nervous system aren't working properly, even though their structure is normal. The "wiring" is fine, but the signals between the brain and body get mixed up. Because of this, the body doesn't work as it should. People often compare it to a computer with a software problem—not a broken machine, but a system that isn't running smoothly. This can cause issues like problems with movement, concentration, seizures, or changes in sensation.

## What is FND Lincs?

FND Lincs is an informal group of people with a lived experience of FND who live or use health and social care services in Lincolnshire. This may be because we have a diagnosis of FND or because we have a loved one who has FND.

We came together at an FND Awareness Raising Event organised by a local charity called SHEAC in July 2025. This event was very successful with over 220 people attending and contributing to the discussions.

What was soon realised was that for many people it was difficult to get the support, recognition or help needed following diagnosis. Lincolnshire NHS ICB, have given their support to help develop a FND strategy for Lincolnshire and this newsletter is part of the process of communicating with local people. We are grateful for their support in creating and distributing this newsletter.

### MONTHLY ONLINE COFFEE AND CHAT

**Are you interested in having a monthly informal catch up via Whatsapp? This would be for anyone diagnosed with FND or their families. Tea and coffee not supplied**

**If this is of interest send FND CHAT and first name via Whatsapp to 07507 713817**

*'over 18's only this is an open group which may entail sharing contact details'*

## Our Work with the ICB and System Partners

# "Co-Producing a Strategy for Better FND Care"

## What is Co-Production?

Co-production is about people working together to make things better! It means bringing together people with lived experience — individuals, families, and carers — alongside professionals from health, social care, and the wider community. Together we share ideas, decisions, and responsibilities, to design and improve the services that help shape their lives.

Rather than services being planned for people, they are created with them. Co-production values the unique insight that lived experience brings and blends it with professional knowledge to create support that is more relevant, effective, and fair. In Lincolnshire, this approach ensures that people with FND have a genuine voice in shaping the care and support they receive.

## Why Co-Production Matters?

Co-production matters because it recognises people as partners in shaping the services that affect their lives. By combining professional expertise with lived experience, it leads to better outcomes — ones that are more sustainable, meaningful, and responsive to real needs.

It also builds stronger relationships and trust between those that provider services and the people they support. This shared ownership encourages accountability, creativity, and innovation, while reducing the gap between what services offer and what people truly need. Ultimately, co-production is about shifting power — supporting people to be more than passive recipients to being active contributors, helping to create fairer, more connected systems for everyone in our community.

*"Co-production isn't just about consultation — it's about shared ownership,"* says **Vicky Thomson, Chief Executive of Lincolnshire-based Charity, Every-One**.
*"When we truly work alongside people with lived experience, we design services that reflect real lives, real challenges, and real solutions."*

## Why a Strategy Matters to Lincolnshire ICB?

For Lincolnshire Integrated Care Board (ICB), having a clear strategy for Functional Neurological Disorder (FND) is essential to improve outcomes and make the best use of resources. Many people with FND experience long delays, fragmented care, and repeated hospital visits. A joined-up approach helps ensure that support is timely, effective, and person-centred. The strategy enables the ICB and its partners to plan services more efficiently, reduce unnecessary costs, and tackle health inequalities. It also strengthens co-production, ensuring that people with lived experience shape decisions, helping to create a fairer, more coordinated health and care system for everyone.

## A FND strategy for Lincolnshire

Functional Neurological Disorder (FND) affects hundreds of people in Lincolnshire, yet many face delays in diagnosis, stigma, and gaps in care. Services are often not joined up, leaving people feeling “bounced around” the system. This leads to poorer health, higher hospital use, and greater costs. A clear county-wide strategy will bring partners together to improve awareness, build consistent care pathways, and ensure people with FND get timely and supportive help. By working with patients, families, professionals, and communities, we can improve quality of life, reduce inequalities, and make better use of local health and care resources.

## Timeline (subject to change)

**July 2025**
**1st FND Awareness Event**

**August 2025**
**FND Working Groups Established**

**September 2025**
**1st Self-help group meeting**

**October 2025**
**Lincolnshire wide FND Questionnaire**

**December 2025**
**Evaluation of findings and further consultation**

**January 2026**
**Initial Draft Strategy for discussion**

**March 2026**
**Final Draft Strategy Available**

**April/June 2026**
**System Scrutiny and Adoption**

**7th July 2026 - Launch of Strategy at 2nd FND Awareness Event**
**HOLD THE DATE**

## Focus on People & Services

# “Voices of Experience: What People Have Told Us So Far”

We have already received a lot of information and heard from many people about their experiences of getting help and support in Lincolnshire. 5 Key Themes have emerged that we want to investigate further and get more views on through a consultation process.

| | | |
|---|---|---|
| **1. Getting a Diagnosis** | People with FND need a clear and supportive diagnosis as early as possible.<br><br>Diagnosis should be based on positive signs that doctors can see during examination. | The earlier FND is recognised, the sooner care and support can be put in place.<br><br>At the point of diagnosis, plans for treatment and support should begin straight away. |
| **2. Working Together** | FND care works best when different specialists come together.<br><br>This should include neurologists, neuropsychiatrists, physiotherapists, occupational therapists, and speech and language therapists. | Care should be based on the best available evidence and tailored to the person’s needs.<br><br>Links should also be made with voluntary, community, and social organisations for extra support. |
| **3. Training and Education** | GPs and primary care staff need training about FND and what can help to make sure people are referred quickly and positively.<br><br>Wider health and social care staff should know how to respond well, especially when the specialist pathway is not needed. | Families, carers, and people with FND should be supported with clear information about living with the condition.<br><br>Digital tools and technology should be explored to see how they can improve care and outcomes. |
| **4. Joined-Up Pathways** | Develop a clear pathway for FND in Lincolnshire, with access to the right care at the right time.<br><br>Create a single point of access or panel to direct people to the most suitable support. | Improve recording and data collection to understand how many people have FND and what services they use. |
| **5. Community and Voluntary Support** | Reduce inequalities so everyone with FND gets fair access to care.<br><br>Improve communication and information, using digital tools, printed guides, and clear signposting. | Strengthen community support groups across Lincolnshire, making sure they are accessible to all.<br><br>Build peer support systems so people with FND can share experiences and advice. |

NHS
Lincolnshire
Integrated Care Board

# Have your say on Functional Neurological Disorder (FND)

## Are you affected by FND as a patient, carer or family member? We want to hear from you!

Your voice can help improve care, support, and understanding of FND.

## Take our short survey

**Scan this QR code or visit our website at https://lincolnshire.icb.nhs.uk/fnd-survey**

## Spotlight on support and services

This will be a regular feature in our newsletter and will be a place to highlight support and services that are available across Lincolnshire to help people and families, professionals and our wider community. If you know of a great service or support provider please let us know by emailing **info@fndlincs.org**

### Help for Carers?

A carer is anyone, adult or child, who gives unpaid help to a family member, partner, or friend who cannot manage on their own. This may be due to illness, disability, mental health, addiction, or ageing. Support can include practical help with daily tasks or emotional support and companionship. Many people don't see themselves as carers, because caring often feels like a natural part of being a parent, partner, or friend. Carers may juggle work, school, and family commitments, and some remain hidden. Every caring role is different, but all carers are vital to our communities.

Lincolnshire County Council have resources at https://www.lincolnshire.gov.uk/support-carers

### Looking for help?

We have highlighted some services below where you can begin your search

**H.A.Y. Lincolnshire** - an online directory with over 600 local groups, support services, educational courses, and self-help resources. https://haylincolnshire.co.uk/

**Wellbeing and Recovery College** - free educational courses focused on mental health and wellbeing. https://www.lpft.nhs.uk/recovery-college

**Let's Move Lincolnshire** - is here to help you get active in a way that works for you. https://letsmovelincolnshire.com/

### Are you a Professional with an interest in FND?

The Allied Health FND Networking Group is for NHS Professionals who work with patients that have FND. They meet online 3 or 4 times a year.

To find out more visit
https://www.ahpfndnetwork.org/


### FND Support Group

The next support group meeting will be at
**PINCHBECK COMMUNITY HUB (PE11 3RU)**

**THURS 11TH DEC 2025**
**3pm - 5pm & 6pm - 8pm**
**EVERYONE WELCOME**

FNDLincs Facebook page
Have you followed and liked our facebook page?
https://www.facebook.com/share/14KL9UJMcfQ/


Thank you for reading our newsletter. We will publish 4 editions per year to help keep everyone informed of progress towards our aspirations to improve services, support and quality of life for all those impacted by FND. If you want to get involved or help please get in touch.

If you have any items for inclusion in future editions, then please contact us at **info@fndlincs.org** or give us a call on **07507 713817.**