

PATIENTS & CARERS

After an FND diagnosis — first steps

Being told you have (or may have) FND can feel confusing, validating, or overwhelming — sometimes all at once. This page is a practical starting point while you wait for follow-up or rehab.

What the diagnosis means

FND is a real neurological diagnosis. It does not mean “nothing is wrong”, “you made it up”, or that symptoms are not serious. Normal scans can still fit with FND.

You deserve a clear explanation, a safety plan, and a next step — even if specialist rehab waiting lists are long.

In the next week

- Write down your top questions for the next appointment
- Note main symptoms, flares, recovery time, and impact on work, school, driving, self-care and sleep
- Ask who is coordinating follow-up and what is available locally (physio, OT, psychology, FND pathway)
- Share one clear resource with family so you are not explaining alone
- If you were given mixed messages, ask for the diagnosis and plan in writing

Things that often help (and things that rarely do)

Often help

- Belief and plain-English explanation
- Steady pacing instead of boom-and-bust
- Sleep protection and gentle routine
- Rehab skills when available
- Peer support and practical adjustments

Rarely help long-term

- Endless emergency scans for familiar symptoms (unless new/red-flag)
- “Push through no matter what” on crash days
- Stopping all activity and isolating completely
- Shame, secrecy, or arguing about whether symptoms are “real”

Safety first

Call 999 for a suspected stroke, first seizure, severe breathing difficulty or other medical emergency. For urgent concerns that are not an emergency, contact NHS 111 where available or your local urgent-care service. Do not assume new or different symptoms are FND.

Continue overleaf for practical next steps, a personal plan and sources →

AFTER DIAGNOSIS · NEXT STEPS

Leave with a shared understanding

Ask whether the diagnosis is confirmed or still a working explanation. Request a copy of the clinic letter and an explanation of any positive findings. It is reasonable to need another conversation: taking in unfamiliar information is harder when you are tired, frightened or in pain.

Turn a referral into a practical next step

Write down the service, the reason for referral and who will arrange it. Ask what to do if no appointment arrives, what support is available meanwhile and when your GP will review progress. Availability varies; an information leaflet does not replace an agreed care plan.

Start small while you wait

Choose one manageable routine and one question for follow-up. Keep a brief record of changes that affect daily life rather than checking every sensation. Seek support if uncertainty or low mood is becoming overwhelming. Your need for care remains valid even if recovery is slow or uneven.

My next steps — discuss with your care team

The explanation I want clarified

My agreed next step and follow-up date

Sources and further reading

- NHS: understanding an FND diagnosis
www.plymouthhospitals.nhs.uk/display-pil/pil-fnd-understanding-the-diagnosis-8013
- NHS: GP appointments
www.nhs.uk/nhs-services/gps/gp-appointments-and-bookings/

More practical help: Start here path · Appointment pack · What is FND? leaflet