Understanding My FND

A Guide for Family, Friends, Colleagues and Professionals

If someone has shared this with you, it means they trust you and want to help you understand a little more about what life with Functional Neurological Disorder (FND) can be like for them.

FND is a condition that affects how the brain and nervous system function. The symptoms are real, involuntary, and can have a significant impact on everyday life.

While you may not always be able to see what is happening, your understanding, patience, and support can make a huge difference to someone living with FND.

What I Wish People Knew

Living with FND can be confusing, exhausting, and frustrating.

Some days I may seem able to do things quite easily. Other days, the very same tasks can feel overwhelming or impossible. This inconsistency is one of the most challenging parts of living with the condition.

My symptoms are not a choice.

I am not being lazy, dramatic, or seeking attention.

I am not making symptoms happen, and I cannot simply switch them off through willpower or positive thinking.

Many people with FND spend a lot of energy trying to hide symptoms, push through difficulties, or appear well. What you see on the outside does not always reflect what is happening on the inside.

I am often working much harder than it appears just to get through everyday tasks, conversations, appointments, work, or social activities.

Being believed, listened to, and treated with kindness can make a bigger difference than you may realise.

What FND Can Feel Like

FND affects people in different ways, and no two experiences are exactly the same.

Some people may experience:

- Functional seizures or dissociative episodes
- Limb weakness
- Tremors, spasms, or tics
- Difficulties with walking or balance
- Fatigue and exhaustion
- Dizziness or feeling lightheaded
- Speech and communication difficulties
- Brain fog, memory, and concentration problems

Symptoms can vary from day to day, or even hour to hour.

One of the most difficult aspects of FND is not always knowing how I will feel from one day to the next.

I may wake up feeling relatively well and then experience a sudden increase in symptoms later in the day. Plans can change unexpectedly, and activities that seem simple may require much more energy than people realise. This unpredictability can be frustrating, disappointing, and sometimes isolating.

Living with FND can sometimes feel like trying to use a phone with a poor signal. The device is there, but the messages are not always getting through properly.

My body may not respond in the way I expect. My legs may suddenly feel weak or heavy. My hands may shake. I may struggle to find words, concentrate, or remember things. I may feel exhausted after activities that once felt simple.

Sometimes symptoms can appear suddenly and without warning. What you see on the outside may only be a small part of what I am experiencing.

Even on days when I look well, I may be working hard to manage symptoms, conserve energy, and get through everyday tasks.

FND Symptoms Often Fluctuate

One of the most misunderstood parts of FND is that symptoms can change.

I may be able to do something one day and struggle with it the next. I may manage an activity for a short time but then need significant rest afterwards.

This does not mean symptoms are imagined, exaggerated, or under my control. Fluctuation is a recognised and common feature of FND.

The most helpful thing you can do is understand that my abilities may vary from day to day, while continuing to trust and support me.

Please Don’t Judge My Good Days

When I have a good day, it doesn't mean I am cured.

When I have a difficult day, it doesn't mean I am not trying.

Symptoms can fluctuate from hour to hour, day to day, and week to week. This can be confusing for the people around me, but it can be just as confusing and frustrating for me too.

I may be able to attend an event, go to work, spend time with family, or enjoy a hobby one day, then need significant rest afterwards or struggle to do the same thing again the next day.

Good moments are important and should be celebrated, but they do not always reflect the challenges happening behind the scenes.

The best thing you can do is trust what I am telling you about my experience.

How Can You Help?

You do not need to have all the answers. Often the most helpful things are the simplest things. Listening without judgement, being patient, and understanding that symptoms can change can make a bigger difference than you may realise.

Asking what support I need, rather than making assumptions, helps me feel respected and understood. FND affects everyone differently, and my needs may change from day to day. Some days I may need practical help, while on others I may simply need a little extra time, flexibility, or understanding. Gentle encouragement can be helpful, but so can recognising when I need to slow down, rest, or approach things differently. Supporting me does not mean pushing me beyond my limits. Often, it means helping me find a balance between maintaining independence and managing my symptoms safely.

Above all, believing me matters. Feeling understood, accepted, and supported can reduce the stress and isolation that often come with living with a misunderstood condition. Sometimes, knowing that someone is willing to listen, learn, and stand beside me can be just as important as any practical help.

A Final Message

I am still me. FND is something I live with, but it is not all that I am.

There may be difficult days, setbacks, and frustrations along the way, but kindness, patience, understanding, and support can make a real difference.

Thank you for taking the time to learn more about my condition. It means more than you may realise.