FUNCTIONAL SEIZURES IN WALES

What new research tells us about diagnosis, care and the urgent need for better support

REAL. COMMON. INVOLUNTARY. DESERVING OF PROPER CARE.

A plain-English report from FND Connect

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Free information for patients, families, carers and professionals

AT A GLANCE

The findings in one page

A major event in Wales brought together people living with FND, relatives, neurologists, researchers, therapists and patient organisations. FND Connect reviewed the full presentation in its entirety and produced this report so that patients and families can understand the findings without having to work through medical language.

The central message

Functional seizures are real, common and involuntary. They can be severely disabling, but patients are still too often diagnosed and then left without a clear treatment plan or joined-up support.

2,800 people with functional seizures identified in Welsh health records from 2003 to 2023	**About 50%** of known cases may have been missed because the condition was not coded clearly
90 in 100,000 estimated to be living with recorded functional seizures in Wales in 2023	**Around 30%** of the identified functional-seizure group also had epilepsy
About 5x as many emergency department visits as people without seizures	**About 2x** the risk of death during the study period compared with matched controls

What the research confirms

- **Functional seizures are not deliberate.** People are not choosing, faking or causing their seizures.
- **The condition is under-recorded.** Many patients are missing from official figures because records use vague, outdated or incorrect labels.
- **Diagnosis alone is not treatment.** Hospital use often remains high after diagnosis because suitable follow-up care is not available.
- **The impact reaches far beyond seizures.** Patients face higher levels of long-term sickness, financial hardship, poor mental health and repeated emergency care.
- **Better care should save money as well as lives.** Early diagnosis, clear explanations, emergency plans and specialist support could reduce harmful and expensive crisis care.

UNDERSTANDING THE CONDITION

What are functional seizures?

Functional seizures are episodes in which the brain temporarily loses its usual control over movement, awareness, speech or sensation. They can look similar to epileptic seizures, but they are not caused by the same sudden electrical activity seen in epilepsy.

A person may shake, collapse, become unable to move or speak, lose awareness, stare, freeze, experience vision changes, or feel disconnected from their body. Different people can have very different types of episode.

They are still real seizures

The fact that functional seizures are different from epileptic seizures does not make them less real, less frightening or less disabling. A person cannot simply choose to stop one.

The preferred name matters

The preferred terms are functional seizures or dissociative seizures. Older labels such as “pseudo-seizures” or “hysterical seizures” can wrongly suggest that a patient is pretending. They should not be used.

Some people have both conditions

Functional seizures and epilepsy are not mutually exclusive. Around 30% of the people identified with functional seizures in the Welsh study also had epilepsy. This makes individual emergency plans especially important, because the response may need to be different for each type of seizure.

What may be happening in the brain and body

The presentation described emerging research into the way the brain constantly receives information from the heart, lungs, muscles, stomach and other parts of the body. We are usually not aware of most of these signals.

One speaker compared this system to a volume control. For some patients the volume may become too high, causing a racing heart, sweating, tingling, dizziness or overwhelming body sensations. For others it may become too low, causing a sense of being disconnected, spaced out, heavy, floaty or “unplugged”.

The seizure may then happen like a fuse being tripped or a system automatically trying to reset itself. This is still developing science and it will not explain every seizure in every person, but it supports what patients have long known: something real is happening in the way the brain and body communicate.

Stress is not the whole explanation

Stress, trauma, anxiety or depression may matter for some people, but there is no single cause that applies to everyone. Around one-third of people in earlier FND research had no recorded major stressful event before their symptoms began.

THE WELSH POPULATION STUDY

How common are functional seizures?

Researchers used anonymised NHS records covering most of the Welsh population. They developed a careful method to find people whose records suggested that a neurologist had diagnosed functional seizures.

They identified around 2,800 people during the study period from 2003 to 2023. This is believed to be the first study of functional seizures using health records from an entire national population rather than a single clinic or a small number of hospitals.

The official numbers are probably too low

When the researchers tested their method against groups of patients whose diagnoses were already known, it found only about half of those with functional seizures. The problem was not mainly the search method. The diagnosis was often missing or unclear in the original medical records.

- Functional seizures may be recorded simply as “seizures”.
- An old or inconsistent term may be used.
- The original epilepsy diagnosis may never be corrected in the record.
- A clinician may suspect the condition but avoid recording a firm diagnosis.
- There is no single clear code used consistently across services.

What 90 in 100,000 means

For 2023, the researchers estimated that around 90 people in every 100,000 in Wales were living with recorded functional seizures. Because the method may have missed roughly half of known cases, this should be treated as a minimum rather than a complete count.

Why are recorded cases increasing?

The number of newly recorded cases rose over time, particularly from around 2011 onwards. This could mean that doctors are recognising and recording the condition more often. It could also mean that more people are developing functional seizures. The study cannot yet tell us which explanation is correct.

This study relates to functional seizures, not every form of FND

FND can also cause weakness, tremor, walking problems, speech changes, tics, cognitive symptoms and many other difficulties. The figures in this report relate specifically to functional seizures. They cannot be used to count everyone living with any form of FND.

WHAT HAPPENS AFTER THE LABEL

The biggest gap: diagnosis without treatment

Healthcare use was highest around the time of diagnosis for both epilepsy and functional seizures. After an epilepsy diagnosis, hospital use generally began to fall. After a functional-seizure diagnosis, emergency visits, admissions and outpatient use often remained much higher.

A diagnosis is only the starting point

Telling someone what they have, then discharging them without explanation, follow-up or treatment, does not solve the problem. It can leave the patient more frightened and more dependent on emergency services.

Patients may be left with no clear next step

- No proper explanation of what functional seizures are.
- No written treatment or recovery plan.
- No individual emergency-care plan.
- No rehabilitation or therapy referral.
- No support for family members or carers.
- No named professional coordinating care.
- No route back into services if symptoms worsen or change.

How the diagnosis is explained matters

A patient should never be told only, “You do not have epilepsy,” and then sent away. A clear explanation should confirm that the seizures are real, involuntary and recognised; that the patient has not caused them; and that improvement or recovery may be possible with the right support.

Research discussed at the event suggests that a respectful explanation and at least some follow-up may reduce later hospital use. Poor communication can increase fear, confusion and mistrust.

Why patients still end up in A&E

The study found that people with functional seizures were receiving large amounts of emergency care but relatively little planned care. This does not mean that patients are choosing to use emergency departments unnecessarily.

- A relative, carer, member of the public or professional may call an ambulance.
- There may be no suitable service to contact instead.
- A seizure may be new, unusual, prolonged or linked with injury.
- Patients with both epilepsy and functional seizures may be difficult to assess safely without a clear plan.

Other patients avoid hospital altogether because previous visits involved disbelief, stigma or poor treatment. The recorded figures may therefore miss people who are struggling at home without care.

HEALTHCARE, WORK AND FINANCIAL PRESSURE

The wider impact on people's lives

Healthcare use and cost

For 2023, the estimated NHS hospital cost was around £3,000 per person with functional seizures, compared with around £700 for a similar person without seizures. People with both functional seizures and epilepsy had even higher estimated costs.

4.9x more emergency department visits	**3x** more likely to arrive by ambulance
5.2x as many days admitted to hospital	**2.6x** as many outpatient appointments

The strongest pattern is clear: the system is paying for repeated crises because planned, specialist and community care is not consistently available.

Employment and long-term sickness

Only around one-quarter to one-third of people in the functional-seizure and epilepsy groups were recorded as working, compared with about half of those without seizures.

Around 21% of people with functional seizures reported being on long-term sick leave, compared with around 4% of the comparison group. People with functional seizures were therefore more than four times as likely to be on long-term sick leave.

Deprivation does not mean the condition is the patient's fault

Many patients lived in more disadvantaged households or communities. This does not prove that poverty causes functional seizures. The relationship can run in both directions: disabling symptoms may make work and income harder to maintain, while unsuitable housing, transport problems and lack of access to care can make disability harder to manage.

Mental health and emotional wellbeing

Anxiety, depression and other mental health difficulties were recorded more often among people with functional seizures. This does not mean the seizures are "just mental health". Living with unpredictable symptoms, losing independence, being unable to work and repeatedly not being believed can severely affect emotional wellbeing.

Both sides of the problem deserve care

Patients should be offered mental health support when they need it, without having their neurological symptoms dismissed or every difficulty automatically blamed on stress.

A SENSITIVE BUT IMPORTANT RESULT

The mortality finding must be taken seriously

The study found that people with functional seizures had around twice the risk of death during the study period compared with similar people without seizures. The risk remained higher even after the researchers allowed for several other health and social factors.

This is not a prediction for an individual

These are findings across large groups of people over many years. They do not tell any one patient how long they will live, and they should not be read as saying that a person with functional seizures will die young.

Average ages recorded in the study

77 years people without seizures in the matched comparison group	**69 years** people recorded with functional seizures only
59 years people recorded with both functional seizures and epilepsy	**61 years** the matched epilepsy group

The researchers saw higher rates of deaths linked with nervous-system conditions, accidents and other external causes, suicide, and mental or behavioural health conditions. They could not yet fully explain the difference.

Possible reasons that need further research

- Poor or delayed access to suitable treatment.
- Misdiagnosis or incorrect emergency treatment.
- Other physical or neurological conditions.
- Mental health crises and suicide risk.
- Financial hardship, poor housing and reduced access to support.
- Repeated emergency admissions without coordinated follow-up.

Prolonged seizures and treatment-related harm

A prolonged functional seizure can be mistaken for a prolonged epileptic seizure. The patient may then receive strong emergency medication that affects breathing or heart function, and some people may be admitted to intensive care or ventilated unnecessarily.

This is why an individual emergency-care plan is essential. It should describe the person's usual episodes, what helps, what should be avoided, when emergency assessment is needed, and how to respond if the person also has epilepsy.

Urgent safety note: New, sudden, severe or unusual symptoms should not automatically be assumed to be FND. Seek urgent medical help when an episode is different from the person's usual pattern, involves injury, or causes immediate concern. In an emergency, call 999.

THE PROPOSED PATHWAY FOR WALES

What good FND care should look like

A national pathway has been developed to describe how FND care in Wales should work. A pathway is a plan for how patients should move through assessment, diagnosis, treatment and longer-term support.

An important limitation

The pathway describes the service patients should receive. It does not mean those services are already available everywhere. At the time of the presentation, Wales did not have a dedicated specialist FND team.

The main parts of the pathway

1. **A timely neurological assessment.** FND should be diagnosed carefully using recognised signs, not simply because other tests were normal.
2. **A clear and positive explanation.** Patients should be told that the condition is real, involuntary and potentially treatable.
3. **Support matched to the person.** Some people may need education and local therapy; others will require more intensive or specialist care.
4. **A joined-up team.** Depending on need, this may include neurology, physiotherapy, occupational therapy, psychology, psychiatry, speech therapy, nursing and rehabilitation.
5. **A named care navigator.** One professional should help coordinate appointments, referrals and communication rather than leaving the patient to connect the system alone.
6. **Access to specialist FND services.** People with complex or severe symptoms should be able to see a team with specific FND knowledge.
7. **A route back into care.** Symptoms can improve, worsen, disappear or return. Patients should not have to start from the beginning after every relapse.

Peer support is valuable, but it is not a replacement for healthcare

Support groups and charities can reduce isolation, share reliable information and help people regain confidence. However, patients should not be left dependent on volunteers because properly funded clinical services do not exist.

A CAUTIOUS NATIONAL COMPARISON

What might the Welsh figures mean across the UK?

The presentation reported a recorded prevalence of around 90 people with functional seizures per 100,000 population in Wales in 2023. The UK population was estimated at about 69.281 million in mid-2024 by the Office for National Statistics.

Illustrative calculation - not a UK prevalence study

If the Welsh recorded rate of 90 per 100,000 applied evenly across the United Kingdom, it would suggest roughly 62,000 people living with recorded functional seizures.

The Welsh method appeared to identify only about half of patients whose functional-seizure diagnosis was already known. If that degree of under-recording were also seen across the UK, the true figure could potentially be closer to 125,000 people.

~62,000	~125,000
using the recorded Welsh rate	if roughly half of cases were missed

Why this must be treated cautiously

This is a simple extrapolation, not a measured UK figure. Wales may differ from other nations in diagnosis, coding, population and access to neurology. The study also covered functional seizures only, not every type of FND.

The real point

Even the cautious figure would represent tens of thousands of people. The higher figure would place functional seizures on a scale that should be impossible for health planners to dismiss as rare or niche. And because functional seizures are only one part of FND, the total number of people living with FND symptoms across the UK would be higher still - although this study cannot tell us how much higher.

This is not a number to sensationalise. It is a reason to measure FND properly, code it consistently, fund appropriate services and stop leaving people invisible in the data.

OUR RESPONSE

What FND Connect believes must happen next

The findings provide strong evidence that functional seizures are a major health issue. Patients are not failing to manage their condition. Too many are being left to manage a serious and complex condition without coordinated support.

1. **Faster diagnosis.** People with suspected functional seizures should be assessed promptly by clinicians who understand FND.
2. **Clear explanations.** Every patient should leave diagnosis understanding that the condition is real, involuntary and treatable.
3. **Individual emergency plans.** Ambulance and emergency teams need clear guidance, particularly when epilepsy is also present.
4. **Follow-up after diagnosis.** Patients should not be discharged with a label and no next step.
5. **Access to rehabilitation and therapy.** Care should be based on symptoms and needs, not assumptions about stress.
6. **Named care coordination.** Patients should not have to act as their own case manager while unwell.
7. **Specialist FND teams.** Complex cases require coordinated expertise, not repeated referrals between disconnected services.
8. **Better professional training.** GPs, ambulance crews, emergency departments, neurologists, mental health teams and therapists all need practical FND education.
9. **Accurate medical records.** Consistent coding is essential for safe care, research, service planning and recognition of need.
10. **Support beyond the clinic.** Employment, benefits, housing, education, social care and family support are all part of living with FND.
11. **Patients involved from the beginning.** Research and services should be designed with people who live with the condition, not presented to them after decisions are made.
12. **Urgent further research.** The causes of increased mortality and the most effective treatments must be investigated.

FROM FND CONNECT

Our conclusion

Functional seizures affect thousands of people, disrupt education and employment, place families under enormous strain and lead to repeated emergency care. They are linked with financial hardship, poor mental health and an increased risk of death.

The evidence now supports what patients have said for years: functional seizures are real, disabling and deserving of the same seriousness given to other neurological conditions.

There are reasons for hope

Understanding is improving. Researchers are finding measurable changes in brain-body communication. Patients are increasingly involved in research and service design. Wales now has a written pathway describing better care. The next task is to turn that knowledge into services people can actually access.

People with functional seizures deserve to be believed.
They deserve treatment.
And they should not have to fight through the system alone.

About this report

FND Connect reviewed the full research presentation in its entirety and prepared this plain-English summary for patients, families, carers and professionals. It is an independent summary and does not replace the original research papers, clinical guidance or personal medical advice.

Contact FND Connect

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Sources and notes

- Full functional-seizures research presentation reviewed in its entirety by FND Connect. All study findings and figures in the main report are drawn from that presentation.
- Office for National Statistics: Population estimates for the UK, England, Wales, Scotland and Northern Ireland, mid-2024. UK population used for the illustrative calculation: 69.281 million.
- The UK figures on page 9 are simple illustrations based on the Welsh reported rate and possible under-recording. They are not official UK prevalence estimates.