

A brain disorder stopped me walking and using my arms – it is common in the UK, but medics often miss it

Former jazz musician Tom Plender was suffering from functional neurological disorder, a common neurological disorder that goes undiagnosed





By Paul Dinsdale

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When Tom Plender was in his early 20s, he looked set for a career as a successful jazz pianist. He was studying at one of the leading music schools in the country, the Guildhall in London, and doing regular gigs as a drummer in the evenings with a jazz group.

One day, he started to experience recurring pain in his arms, and then in his legs, and shortly afterwards, began to have mobility problems in all his limbs. His GP referred him to a neurology consultant, who was unable to diagnose the condition, and despite further referrals, other consultants were mystified by his health issues. He was told it was probably ‘psychological’, and that it was all in his mind.

“I was considered to be one of the most promising young jazz musicians in the country, but during my studies at the Guildhall, I developed what I now know to be **functional neurological disorder** (FND),” says Tom, now 48.

“I deteriorated very quickly and lost the use of my arms and my ability to walk. Eventually, I ended up housebound and being looked after by carers, and virtually every doctor I saw said my condition was ‘psychological’. What they really meant was, they didn’t know what was wrong with me and they just looked for an easy explanation by saying it was all in my own mind.”

After 12 exhausting years of investigations and appointments with neurologists, Tom – almost at an emotional breaking point – was referred to Mark Edwards, now professor of neurology and interface disorders at [King’s College London](#), who had a special interest in the condition.

“He didn’t think it was just psychological and finally diagnosed me with FND, and offered me a course of treatment. I was admitted to hospital for around three months for intensive rehabilitation. Since then, I have been in recovery and I’ve started to be able to play music again, so it’s been wonderful.”

Astonishingly, Tom's case is not unusual, as FND is classed as the second most common reason for consulting a neurologist after severe migraine, but patients are frequently dismissed by doctors and only given information on support groups for psychological issues.

Many are left to suffer alone without treatment, and have to give up working, so they survive on disability benefits or universal credit, at a huge cost to the welfare system, despite the fact it is a highly treatable condition.

Recent studies show that between 50 to 100,000 adults in the UK are living with FND and that 10 to 20,000 children and young people in the UK under 16 develop the condition every year. About 8,000 new adult cases are diagnosed each year.

Shockingly, most of these will not receive any treatment, due to a lack of specialist training among neurologists, lack of resources in some areas and poor funding for services. Despite research confirming FND to be a complex brain network disorder, there is currently no national service for patients once diagnosed in the NHS, although it's more common than Parkinson's disease and multiple sclerosis (MS). Recently the condition was described as "a crisis for neurology" by a world-renowned neurologist, [Dr Mark Hallett](#), of the National Institute for Health in the US.

The condition has a fascinating history. In early medicine, and until the 19th century in Britain, it was simply called 'hysteria', and doctors regarded it as some form of aberration or temporary madness on the part of the patient. As there was no understanding of neural networks, this blanket term seemed apposite – Sigmund Freud also termed it 'conversion disorder' in his research.

Once neurology became established as a specialty, after soldiers in the First World War were diagnosed with 'shell shock' – what we know today as post-traumatic stress disorder (PTSD) – a range of psychological conditions became more distinguishable. But FND appears to still be a 'Cinderella' service as far as the NHS is concerned.

“The condition is at the interface between physical and mental health, and although we understand the range of symptoms it produces, we still don't know what causes it,” says Professor Edwards.

“There is some evidence that childhood trauma could be a link to the condition appearing in later life, but this is only true in a number of cases, and many other patients may not have experienced any trauma in their early lives. The incidence is higher in women than men, with the split being around 70-30 in favour of women.

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“The symptoms can range from loss of movement in arms or legs, muscle spasms, slurred or slow speech and in some cases small seizures, similar to epileptic fits, so it can vary widely from one person to another. The treatment depends on the individual and usually involves a combination of physiotherapy, occupational therapy and physical exercise routines. There is no drug treatment available for the condition, which is another reason it has fallen under the radar in the NHS.”

Professor Edwards has now developed a clinical pathway for FND, as there is currently no national guidance from NICE, which evaluates medical treatments, and has produced guidelines for other conditions, such as heart disease, stroke and diabetes.

The guidance for clinicians says: “The long-term outlook for patients is poor with most remaining with long-term disabling symptoms. A successful pathway for people with FND requires a range of services available into which people can be referred depending on need and complexity.”

He is also involved with a major study of about 400 patients at 12 sites across the UK to assess the effectiveness of treatments offered to patients by different consultants. This can vary according to their symptoms, and on the services available in their area. For example, patients in West Yorkshire can be referred for treatment at the National Inpatient Centre for Psychological Medicine, based in Leeds, but other areas of the

country may not offer much at all.

Dr Glenn Nielsen, a senior lecturer in neurological physiotherapy at St George's Hospital in south-west London, who is leading the study, says that some of the perplexity about FND lies in our limited understanding of how the brain works.

“There is a difference of opinion among clinicians on the causes, and some of it is linked to defining the difference between the mind and the brain. We know that motor skills are connected to cognitive development, but it's still unclear how this works in dystonia (the recurrence of muscle spasms) and we hope the study will help to identify some of these aspects more clearly.”

The recent Parliamentary meeting was organised by FND Hope, which offers a support network for people with the condition, as does another charity, FND Action. Once diagnosed, many of them feel abandoned by the NHS, and, as Professor Edwards points out, a long series of hospital appointments and tests can be costly in terms of health care.

“We need a better national network of specialist treatment centres for FND, so patients have a clear pathway for their treatment and rehabilitation, to help them recover more quickly and regain their quality of life,” he says. [i](#)