# A QUEST FOR CLARITY

**Functional neurological disorder (FND) is a disorder of the functioning of the nervous system that involves a problem with the way the brain sends and receives signals – yet for far too long the condition has been cloaked in mystery and misunderstanding. To help us wade through the complexity, Tom Plender, as a musician and FND patient, shares his journey to the outer reaches of neurology, and why FND is the most common condition you have never heard of.**

Tom Plender

FND is responsible for about one-third of neurology outpatient appointments and is the second most common reason for neurological consultation after migraine. It is also by some estimates more common than Parkinson's and MS. So why have so few people heard of it and why is there no national treatment service available on the NHS?

The answers to this question are complex but are partly due to a lack of research and understanding about the condition. Historically there has also been a view among many medical professionals that the condition is of psychological origin, and is a form of conversion disorder – Freud's theory that repressed psychological trauma is converted into physical symptoms and once the trauma is uncovered the symptoms disappear. There has never been any definitive scientific evidence to prove conversion disorder, meaning that it is little more than a theory – nevertheless this idea has been extremely influential for over a century, pointing researchers in the wrong direction. This has had a very negative impact for FND patients, often leaving them without treatment and with doctors unwilling to take responsibility for their condition. In fact, at the present time there are only a tiny number of over-subscribed NHS FND treatment programmes whose services are already at breaking point.

## MY FND STORY

I was a successful professional musician throughout my 20s when I first got FND. I played the drums and piano and mostly worked in the field of jazz and was fortunate to get to work with some of the best jazz musicians in the UK. I had also played almost every conceivable style of music from rock, funk, hip-hop and drum and bass to contemporary classical.

I became ill while I was studying for a postgraduate at the Guildhall School of Music in London and developed overuse injuries in my wrists and knees; these then seemed to trigger FND, resulting in debilitating pain and muscle spasm in my neck and shoulders that over several years resulted in a complete deterioration of my ability to function.

In my struggle to obtain a diagnosis I was shunted backwards and forwards between neurologists and psychiatrists, none of whom seemed to be able to find out what was wrong with me and who mainly resorted to the conversion disorder theory as an explanation. I was frequently told it was all in my head and I needed to get over it.

I tried many treatments – both conventional and nonconventional – and I saw countless doctors, all with little success. I spent time in psychotherapy but there simply was no underlying trauma and as the years went by my disability increased to such an extent that I eventually had to be looked after by carers who would assist me with the basic functions of life like getting dressed, showering and cleaning my teeth etc.

## PROGRESS AT LAST

After 12 incredibly difficult years and at near breaking point I was finally referred to Professor Mark Edwards at the National Hospital for Neurology and Neurosurgery who diagnosed me with FND. He explained that the latest research implied that FND was not necessarily of psychological origin and was in fact a disorder to do with the way the brain controls movement. I was admitted for four months of inpatient rehabilitation, mostly consisting of specialist neurological physiotherapy, but later on occupational therapy and cognitive behavioural therapy, which helped me regain my functioning and allowed me to live without carers and be independent for the first time in years. It also allowed me to begin to play my instruments again after many years of not being able to do music.

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# FND

FND is a very complicated condition and is not yet fully understood, but in the last 10 years there have been significant developments in research that would seem to take a different view to Freudian conversion disorder and indicate new directions for treatment based on the following theory – brain scans of FND patients appear to demonstrate that conscious parts of the brain have become over-involved in movement. (1)

Ideally, movement should be unconscious – when you walk, for example, it's not something you think about, it is an automatic movement. FND patients seem to have lost the ability to move normally and automatically. Many patients with FND also experience a great deal of pain and muscle spasm and as a result often develop central sensitisation, a chronic pain condition where overactivity of neurotransmitters causes the patient to experience a heightened sensation of their pain. In fact, it could be argued that FND seems to be a kind of hyper-sensitised nervous system disorder and cortical disinhibition is an important factor.

## BUT WHY DO PEOPLE GET FND?

In Professor Mark Edwards' view, there is usually a triggering event, most commonly some kind of accident or physical trauma, but it can in some instances also be triggered by psychological trauma.

The current view is that the brain relies strongly on internal models and expectations when initiating movement. In FND something temporarily triggers the brain to go wrong, thereby setting up a malfunctioning internal model. (2) Some researchers have referred to it as a 'rogue representation' (3), while others have described the effect as a bit like a computer crashing. This can then wreak havoc, resulting in pain, muscle spasm and disrupted movement patterns. FND patients experience the disrupted movements as being out of their control, and research would imply that the disorder takes place at very low levels of the nervous system beneath the patient's conscious control.

For this reason, treatment has to be focused on trying to override this malfunctioning internal model by reengaging normal automatic movement as well as altering attentional processes and expectations about movement which also have a big impact on functioning.

According to a recent study by the charity FND Hope, only about 30 per cent of FND patients have psychological trauma – a similar result to those found in Parkinson's – and if FND is essentially a kind of nervous system malfunction, spending enormous amounts of time trying to root out a psychological trauma, in the hope that once it is uncovered symptoms will magically disappear, is clearly a flawed approach.

For many patients like myself, this has proven to be a diversion and a waste of time. Multidisciplinary treatment consisting of specialist physiotherapy, cognitive behavioural therapy and occupational therapy would appear to be the most effective evidence-based treatment for patients with a severe form of the condition. For others, specialised physiotherapy alone is often sufficient. FND can happen to anyone and is not an indicator of mental illness, weak-mindedness or a lack of motivation to get better. Unfortunately, FND patients are still highly stigmatised within the medical profession which is currently split in two about the condition; one half believing that it is of psychological origin; the other half that it is a brain and nervous system disorder.

In view of recent research into FND, surely it is time that the medical profession moved on from the conversion disorder theory. In criticising conversion disorder I am not saying that stress does not have an impact on people's health – clearly it does as the body and mind are deeply intertwined – but it is also clear that many illnesses would benefit from a more holistic, integrated and nuanced approach.

Since the 17th Century Philosopher Descartes announced that the mind and body are separate, for several centuries Western scientific thinking has been mired in a dualistic paradigm where everything must be separated into the categories of either 'physical or psychological'. Conversion disorder in my view is a continuation of this outdated dualistic thinking in its simplistic and one-sided attribution of all symptoms to psychological causes rather than seeing the mind and body as a complex and integrated system. To add to this, there is also the rarely-discussed fact that Freud falsified results with regards to many of his patients, including in his work 'Studies on Hysteria' – the book in which his conversion disorder theory is presented. (4)

## CALLS FOR GREATER RECOGNITION

There is currently no national service for FND on the NHS, and a desperate need for more research into the condition and for new and innovative treatments. Until FND is recognised as a legitimate and complex neurological disorder, rather than being of purely psychological origin, there will be little treatment and sympathy for a community of people who have been neglected for decades. Things are moving forward with a Parliamentary meeting this April organised by the recently-founded charity, FND Hope, in conjunction with leading figures in FND research, such as Professor Mark Edwards, Dr Glenn Nielsen, Professor Eileen Joyce and Dr Tim Nicholson. There has also been a successful campaign to include FND in both the neurological and psychiatric sections of the DSM with the recognition there does not necessarily need to be a psychological stressor. However, with the soon-to-be-published ICD 11 the panel backtracked and rejected the inclusion of FND in favour of the slightly farcical 'functional neurological dissociative symptom disorder' with an emphasis on psychiatric and Freudian interpretations as justification. As a result of this it is clear that there is still a long way to go and much to be done in creating more awareness and understanding about this complex condition.

***For more information about FND Hope, visit www.fndhope.org.***

## REFERENCES

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4. Unauthorised Freud – Frederick Crewes