

FND

PUTTING IT ON THE MAP

Functional Neurological Disorder (FND) is a disorder relating to the way the brain sends and receives signals, in which the symptoms range from muscle spasms and movement disorders, to seizures and blackouts. With the condition having been mired in controversy, and for decades often dismissed as being of purely psychological origin, Tom Plender, a musician, pens the continuation of his journey – and the lessons which line the FND road.



Tom Plender

In my previous article for Northern Ireland Healthcare Review last year, I discussed the struggles I had obtaining a FND diagnosis and getting doctors to take me seriously. I eventually had the good fortune of being referred to a leading expert in the field, Professor Mark Edwards, who was at that time practising at The National Hospital for Neurology and Neurosurgery in London, where I was successfully treated and regained my ability to function. FND research has moved forward rapidly in the last few years, and in this article I wanted to expand and go into detail about some of the new theories and treatment concepts.

A PARADIGM SHIFT

At the current time, FND is experiencing something of a paradigm shift. Previous theories were largely based on the ideas of Sigmund Freud, believing that FND is a form of ‘Conversion Disorder’ – the idea that the patient is converting psychological trauma into physical symptoms. As I stated in my previous article, there has never been

any definitive evidence to back up this idea, therefore it is little more than an unproven theory. ⁽¹⁾

Recent studies also don’t support this view, revealing that a significant amount of FND patients don’t have any history of psychological trauma. The Freudian view is now being challenged and superseded by a new set of ideas, the most prominent of which is the concept of the ‘Bayesian Brain.’ ⁽²⁾ This theory suggests that FND stems from the way the brain processes data and is the result of that process going wrong.

An example of how this can be applied is the following:

You are sitting at a table about to pick up a glass of water: your brain has a pre-existing internal model or set of expectations about what will happen when you pick up that glass of water based on the fact you have done this hundreds of times before. This pre-existing model is actually stronger than the feedback you will receive through your hand, and other senses. The brain doesn’t control movement by feedback and by constantly checking the weight of the glass etc., instead it actually controls movement by making an expectation based on previous events. In FND, it seems that the brain’s internal model of movement somehow goes wrong, setting up a kind of ‘rogue representation.’ ⁽³⁾ These events or faulty representations take place at very low levels of the nervous system beneath the patient’s conscious control.

HOW DOES FND GET TRIGGERED AND WHAT CAUSES THIS FAULTY OR ROGUE REPRESENTATION TO TAKE PLACE?

The most common triggering factors seem to be events, such as accidents, serious

illness or some kind of physical trauma, but it can also be triggered in some instances by psychological trauma. Essentially, there is some kind of shock or overload to the brain and nervous system, causing it to crash a bit like a computer. Where some of the previous confusion may have arisen is that doctors have often confused risk factors with root causes. Psychological trauma is certainly a risk factor for developing FND, but it is just one of many potential risk factors. Another potential risk factor is already having an underlying neurological condition.

A situation where a patient may develop FND on top of a pre-existing neurological condition, for example, MS or epilepsy, is often referred to as ‘FND overlay’. FND is probably a spectrum, so for some addressing psychological trauma as a component of the treatment may be helpful, for others it will be irrelevant.

SO HOW DO YOU TREAT FND?

During my inpatient treatment at The National Hospital for Neurology, it was explained to me that I had a problem to do with the way my brain controlled movement and that conscious parts of my brain had become over-involved in what should be automatic movement. ⁽⁴⁾

This often happens to patients with FND, and also people who experience long-term chronic pain. The brain’s response to the pain is to distort or start ‘smudging out’ that area, possibly as a kind of survival response; it then tries to find a way round this by diverting the signals that engage movement to other parts of the brain that should not be involved.

Through physiotherapy, I had to learn how to move automatically again. For me

at that time all movement caused pain and muscle spasm that could last days and sometimes weeks. The idea was that by re-engaging my old automatic movement patterns these would then override the new faulty movement patterns in my brain. This was very challenging and hard to do as it involved many repetitions and to some extent breaking through a kind of pain barrier, but over weeks and months in a supportive environment of daily specialised neuro-physiotherapy and movement retraining it began to work. CBT or Cognitive Behavioural Therapy was also added in addition at a later stage. This can be used to alter attentional processes and expectations relating to movement and also to challenge and inhibit the faulty motor responses.

CORTICAL MAPPING

More recently I started seeing a new group of medical professionals, including a physiotherapist and a consultant who specialises in complex musculoskeletal pain. After various tests and examinations it was explained to me that their take on my FND was that I had a Cortical Mapping Disorder. This means that my brain's internal map of my body was malfunctioning and sending signals to the wrong parts of my body, for example when I tried to do my hip strengthening exercises my neck would tighten up. My physiotherapist also pointed out that when I raise my hands above my head, my neck and shoulders overreact to this simple movement as if I am lifting weights, a clear example of the faulty movement pattern distortions I mentioned earlier.

Ideas about Cortical Mapping stem from the Australian pain researcher, Professor Lorimer Moseley. He studies pain sensitisation or central sensitisation, a condition where the brain keeps sending the signals of pain a bit like a stuck record even though the cause of the pain has subsided.⁽⁵⁾ Moseley's interest began when he was walking in the outback and noticed a sharp pain in his ankle. He ignored it, kept on walking, and a few minutes later, collapsed unconscious. Upon waking in a hospital bed he was told that he had been

bitten by a venomous snake and was lucky to be alive.

About five years later, after summoning the courage to go walking in the outback again, Moseley experienced a scratch on the ankle. He collapsed in absolute agony and, looking at his ankle, realised that it was just a small twig protruding from a bush that had scratched him but that his brain had sent him a colossal signal of pain as a kind of protective survival response because of previous events. This led him to realise how easily the brain can distort our perceptions of pain and how our fight or flight response can go wrong. Pain is generated in the brain, in response to signals from the injured limb, not in the actual limb itself.

As Moseley's story demonstrates, it is the brain that makes a decision about the degree of pain you will experience depending on its perceived level of threat. He also started to notice that a lot of his central sensitisation patients went on to develop Cortical Mapping Disorders, implying that pain sensitisation can be another risk factor for developing Cortical Mapping or FND type issues.

FINDING THE RIGHT PATH

FND, FND overlay, Cortical Mapping Disorders and central sensitisation are all part of a cluster of conditions that can all feed into each other. I hope this article demonstrates how once something like this goes wrong in the brain and nervous system, if left untreated, it can over time end up triggering many more problems, leading to a downward spiral of cascading symptoms. This highlights the importance of taking these conditions seriously and getting people into targeted treatment.

Hopefully, I have also made clear why applying the Freudian paradigm has, in my view, been so damaging to patients. Spending a huge amount of time trying to root out some hidden psychological trauma really does not address the core issues. The brain is the most complex machine ever studied by man and our knowledge is minimal at best. Overly-simplistic ideas like Freudian Conversion Disorder are simply not fit-for-purpose in the 21st Century. With regards to FND, instead of seeing the

brain in Freudian terms, it is much more helpful, in my view, to view it as a series of interconnected systems. It is when these different systems start to malfunction that you get conditions like FND.

It was the philosopher of science, Thomas Kuhn, who coined the term 'Paradigm Shift'. Kuhn's view of science was that it is not 'The Truth', it is simply the best theory we have at the moment to describe reality. If you look at the history of science it is clear that scientific theories are continuously upgraded, refined and, in some cases, discarded and replaced with new and better ones. Science, because it is done by human beings, is often flawed and subjective; science can't avoid subjectivity when considering evidence. Flawed ideas can be very seductive and convincing when presented in scientific language, they also often reflect cultural biases rather than scientific fact, making them harder to shift. Because of this, new paradigms are rarely accepted easily and without a fight.

The medical profession is still currently split in two about FND, with many stubbornly clinging to the old Freudian paradigm despite mounting evidence to the contrary. The Victorian scientist TH Huxley famously said, 'Irrationally held truths may be more harmful than reasoned errors'. Wise words, and after everything I've been through with FND, I suspect he was right.

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

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