

Functional Neurological Disorder Awareness Day UK 25th March 2021



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We invite everyone to be involved in raising FND Awareness on the 25th March 2021, from sharing your 'lived experience' of 'Functional Neurological Disorders', to showing your support for the cause and joining in our shared #Voices4FND

Given we are still in lockdown, we will again be focusing our efforts in raising awareness across social media sites and also getting our service users engaged in activities such as sharing experiences and also their creativity, highlighting that they are more than disability in our theme this year of a 'GREAT DAY IN'. You are welcome to join us in any way you can!

The COVID lockdown has affected everyone in some way, but for those with an FND diagnosis and its' related symptoms, lockdown is often a way of life. Specialist care and services are still poorly lacking, and with your support in helping raise our #Voices4FND we know it will help towards making a difference to hundreds of adults and children who are living with FND in the UK.

"After months of what were for me, symptoms out of the blue, I was finally diagnosed with FND. The biggest shock was my prescription which came in the form of being given a website to go and look at and told don't worry you'll get over it." (1)

Functional Neurological Disorder (FND) presents with motor, sensory and/or cognitive neurological symptoms such as an inability to walk, tremors, paralysis, seizures, involuntary movements, blindness, bowel and/or bladder issues, speech and/or swallowing symptoms, along with pain and severe

fatigue.

FND is common, and is the second most common reason for referral to Neurology worldwide [2]. FND is associated with significant morbidity and healthcare costs. It causes disability and impaired quality of life in the long term similar to that seen in people with multiple sclerosis or Parkinson's disease [3]. Misdiagnosis and inappropriate treatment carries a significant risk of iatrogenic injury, morbidity and cost to patients and healthcare systems. Despite this, services specifically designed to help people with FND are very limited [3]. People with FND suffer from high levels of stigma and discrimination due to poor understanding of the disorder by both clinicians and people in the community [4]. Many people 'fall' into the "black hole" and "great divide" between neurology and psychiatry [5].

Functional disorders have been described as a 'crisis for neurologists' [6]. Traditionally medical care lies at the interface between neurology and psychiatry. Presently we know FND is not caused by disease or damage to brain or body. The brain networks are not communicating with the central nervous system causing serious dysfunction with the body. FND symptoms are debilitating, distressing and disabling. Very little research, worldwide, has been undertaken on what is a very common and disabling disorder that can be life-long for sufferers and their carers.

The UK FND Awareness Day is held every year on the 25th March. 2020 marks our fourth Awareness Day with collective voices joining us from around the globe. From UK to Australia, we are uniting voices across oceans and borders in raising our #Voices4FND. The theme #Voices4FND encourages people with lived experience to share their experiences of FND to help drive awareness, knowledge and research centred on experiential wisdom. To get involved see fndawarenessday.org.uk

For more information see the contacts and websites below.

2. Stone, J., et al., Who is referred to neurology clinics?—The diagnoses made in 3781 new patients. *Clinical Neurology and Neurosurgery*, 2010. 112(9): p. 747-751.

4. Rommelfanger, K.S., et al., Disentangling stigma from Functional Neurological Disorders: conference report and

roadmap for the Future. *Frontiers in neurology*, 2017. 8: p. 106.

5. Perez, D.L., et al., Bridging the Great Divide: What Can Neurology Learn From Psychiatry? The Journal of Neuropsychiatry and Clinical Neurosciences, 2018. online ahead of print: p. [appi.neuropsych.17100200](https://doi.org/10.1177/0951375817100200).

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