

Briefing for the Citizen Participation and Public Petitions Committee on petition PE2165: Raise awareness of and provide educational resources and training for Functional Neurological Disorder (FND) lodged by Michelle Moir

Brief overview of issues raised by the petition

The petitioner is seeking to raise awareness of and to improve training and resources on Functional Neurological Disorder (FND).

Following diagnosis, the petitioner was signposted to a website – neurosymptoms.org, established by Professor Jon Stone, a Consultant Neurologist with NHS Lothian. Professor Stone has, with colleagues, including Professor Alan Carson, carried out research into functional neurological disorders and their treatment since 1999 'driven by a desire to improve knowledge, understanding and attitudes towards functional disorders'. The website provides a link to the team's research pages on functional disorders – the Centre for Clinical Brain Sciences, University of Edinburgh.

What are functional neurological disorders?

According to the Centre's website:

"Functional disorders are one of the commonest reasons for patients to see a neurologist. They include problems such as dissociative (nonepileptic) seizures, functional movement disorders (such as tremors, spasms or jerks) and functional limb weakness.

Functional Neurological Disorders (sometimes abbreviated to FND) are genuine and often disabling. They relate to a disorder of nervous system functioning, but not brain disease. Other terms used to describe these hidden and stigmatised disorders include conversion disorder and psychogenic disorders."

<u>Information about FND was updated on NHS Inform</u> in February 2025. There is information on the clinical features – distinctive ways that symptoms present that are unique to FND. It is these features that identify FND as distinct from other neurological conditions, with similar symptoms.

Treatments discussed are forms of rehabilitation therapy, to improve the ability to carry out everyday activities. NHS Inform states that many of the these are designed to 'retrain the brain'. Sometimes treatment is successful, sometimes not, and sometimes people go into remission, others do not.

One study carried out in Edinburgh found that 14 years after diagnosis, regardless of any interventions or treatment:

- 20% had completely recovered
- 31% had improved
- 23% were the same
- 14% were worse

FND National Pathway

In May 2024, the <u>NHS Scotland Centre for Sustainability published a 'national pathway'</u> document to provide:

"Benefits to People with FND:

- Recognition that FND is real, common, and disabling
- Better access to evidence-based treatment for FND

Benefits to Services:

- Recommendations to Health Boards and practitioners on the content of an FND service.
- More efficient, sustainable, and cost-effective use of existing services

The document states that FND 'is often suspected in primary care' and can be raised as a possibility by any health professional in any healthcare setting.

However, it is not clear what training is available to primary care medical and nursing staff to assist with diagnosis in primary care, so GPs would have to understand and link a variable set of clinical features. The Royal College of General Practitioners has produced a learning course, which includes a module on recognising and explaining FND.

Training and resources available to clinicians on FND

A short online course on FND for health practitioners

Allied Health FND Networking Group – <u>resources</u>, <u>recommendations</u>, <u>guidance and articles for clinicians</u>

Functional neurological disorders: effective teaching for health professionals

The objective of the study was, somewhat unusually, to create a course designed to develop the skills for diagnosis and management of FND. The experimental course was delivered biannually over 2 days, face to face to small groups of health professionals by experts in multidisciplinary management of patients suffering from FNDs (including a neurologist,

psychiatrists, psychologists, physiotherapists and a clinical nurse. The study concluded:

"It is possible to make real change in the understanding and management of medical and allied health clinicians working with people with FND with a low-cost intervention. Also, the development of educational networks and multidisciplinary collaboration can lead to the creation of therapeutic platforms for the diagnosis, management and advocacy of this patient group.

Other guidance

The National Institute for Health and Care Excellence (NICE) has produced a 'clinical knowledge summary', (CKS) on FND. A CKS provides primary care practitioners with an 'accessible summary of the current evidence base and practical advice on best practice' in relation to certain conditions. This is not a full NICE guideline. There is a full guideline on 'Suspected neurological conditions: recognition and referral. NICE assesses all the evidence available about a disease or condition, and bases its recommendations on the strength of that evidence.

(see also <u>resources</u> indicated above, which contain links to **other guidance**, **from professional associations etc**)

Anne Jepson Senior Researcher, SPICe 10 June 2025

The purpose of this briefing is to provide a brief overview of issues raised by the petition. SPICe research specialists are not able to discuss the content of petition briefings with petitioners or other members of the public. However, if you have any comments on any petition briefing you can email us at spice@parliament.scot

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