

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Cefnogi pobl sydd â chyflyrau cronig](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [supporting people with chronic conditions](#).

CC28: Ymateb gan: | Response from: FND Hope UK England & Wales



1. Introduction

The evidence submitted for this consultation is specifically in relation to the condition: Functional Neurological Disorder (FND) which is the second most common reason for neurology outpatient appointments¹.

Symptoms vary and can include functional seizures, functional limb weakness, functional movement symptoms, sensory symptoms, speech difficulties as well as pain, fatigue and other cognitive symptoms.

Research shows that patients with functional symptoms can experience more disability and distress than patients with neurological conditions like Parkinson's Disease and Multiple Sclerosis².

2. NHS & Social Care Services

2.1

In response to 'The readiness of local NHS and social care services to treat people with chronic conditions within the community'.

In December 2021 and following discussions with the UK Medical Expert Committee which comprises 21 Medical and Allied Health Professionals across the UK, we agreed to send a Freedom of Information request to each CCG and Health Board in England, Wales and Scotland.

To explore issues reported by NHS clinicians and the FND community regarding access to treatment for people with FND. Anecdotal feedback was that some CCG's / Health Boards exclude people with FND from accessing physiotherapy, occupational therapy, speech and language therapy, and/or psychology. A common reason given is that they are not commissioned to treat this condition.

CCG's/Health Boards were asked: 'Does your commissioning agreement within your CCG include treatment for Functional Neurological Disorder'?

- 50% of UK health boards / CCG's had no specific agreement to treat FND or did not treat FND, and almost 10% say that they do not accept referrals for treatment
- Only 35% said they had plans to improve their services for people with FND and only 35% said they were potentially interested in accessing further education or support to improve services.

2.2

In Response to: 'Access to essential services and ongoing treatment, and any barriers faced by certain groups, including women, people from ethnic minority backgrounds and disabled people'.

The survey results from the CCGs/Health Boards, highlights the current patchy and inequitable provision of rehabilitative services for people with one of the commonest causes of neurological disability.

The survey shows access to therapies (including physiotherapy, speech and language therapy, occupational therapy and psychological therapy) for patients with FND in Wales is significantly lower than for those patients living in Scotland and England.

- Between 14% (England), 21% (Scotland) and 43% (Wales) of services said that they did not accept physiotherapy referrals or provide physio for FND. Less than half (43%) said they had neurological physiotherapy services which would accept people with FND.
- Between 22% (England), 21% (Scotland) and 43% (Wales) of services said that they did not accept occupational therapy referrals or provide occupational health for FND and less than half (41%) said they had neurology based occupational therapy services which would accept people with FND.
- Between 17% (England), 14% (Scotland) and 43% (Wales) of services said that they did not accept speech and language therapy referrals or provide speech and language for FND and only 39% said they had neurology based speech and language therapy services which would accept people with FND.
- Between 16% (England), 29% (Scotland) and 43% (Wales) of services said that they did not accept psychology referrals or provide psychological therapy for FND, whilst 42% said they would accept people with FND.

2.3

In response to: 'Support available to enable effective self-management where appropriate, including mental health support'.

The 'My Neuro Survey' results published by the Welsh Neurological Alliance in 2022 reports that 45% of people living in Wales with Neurological Conditions (including people living with FND) felt that their mental health needs were not being met at all.

63% of respondents said they would find counselling helpful but had not been offered it. For those that had, it not always been accessible. For example, a patient with severe speech difficulties being offered a telephone appointment³.

Feedback from people living with FND in Wales, attending FND Hope UK Peer Support Groups is that they are often discharged from neurology services after diagnosis and directed to a website without further guidance and support for self-management.

3. Multiple Conditions

3.1

In response to: 'The ability of NHS and social care providers to respond to individuals with multimorbidity rather than focusing on single conditions in isolation'. And: 'The interaction between mental health conditions and long-term physical health conditions.'

Many people with FND have comorbidities, in a survey of over 500 people with FND, half of them reported having at least one other health condition prior to their FND diagnosis. Comorbid conditions included other neurological conditions, psychiatric conditions, other functional conditions such as Fibromyalgia and Myalgic encephalomyelitis (also called chronic fatigue syndrome). After receiving an FND diagnosis 43.3% reported receiving new diagnoses, the commonest being Fibromyalgia and Myalgic Encephalitis.

Additionally, the rate of Obesity in the study population, increased after receiving an FND diagnosis and is higher than the general population average⁴. A holistic, multidisciplinary approach should be applied to help people manage their FND and the resulting psychological and physical challenges this brings.

References

1. J. Stone *et al.*, Who is referred to neurology clinics?—the diagnoses made in 3781 new patients. *Clinical Neurology and Neurosurgery*. **112**, 747–751 (2010).
2. Carson A, Stone J, Hibberd C, Murray G, Duncan R, Coleman R, Warlow C, Roberts R, Pelosi A, Cavanagh J, Matthews K, Goldbeck R, Hansen C, Sharpe M. Disability, distress and unemployment in neurology outpatients with symptoms 'unexplained by organic disease'. *J Neurol Neurosurg Psychiatry*. 2011 Jul;82(7):810-3. doi: 10.1136/jnnp.2010.220640. Epub 2011 Jan 21. PMID: 21257981.
3. Wales Neurological Alliance (2022) *My Neuro Survey Wales Report*, *Wales Neurological Alliance*. Available at: <https://www.walesneurologicalalliance.org.uk/news/my-neuro-survey-wales-report/> (Accessed: 23 May 2023).
4. A. Ducroizet *et al.*, Functional neurological disorder: Clinical manifestations and Comorbidities; an online survey. *Journal of Clinical Neuroscience*. **110**, 116–125 (2023).