PE2165/C: Raise awareness of and provide educational resources and training for Functional Neurological Disorder (FND)

Minister for Public Health and Women's Health written submission, 21 October 2025

Petition PE2165 asks 2 questions:

1. for a response to the questions raised by the petitioner in her additional submission

The additional submission contains several questions. These have been separated and answers to each question provided in italics:

Regarding the government's response I would like to know if patients with FND will be consulted regarding the approaches to improving awareness to GPs.

It is the responsibility of NHS Boards to in Scotland to plan and deliver services at a local level, including for FND. The Advice and guidance published by the Scottish Government, Health and social care - Planning with People stipulates "NHS Boards and Integration Joint Boards have a statutory duty to involve people and communities in the planning and development of care services, and in decisions that will significantly affect how services are run."

We are working with statutory sector and third partners to improve the delivery of services for people with neurological conditions, including involvement of people with lived experience.

I also understand that Practice Based Small Learning modules is an online learning opportunity for various medical conditions. Will this become mandatory regarding FND and be made available to GPs, A&E staff, paramedics and call handlers?

As more and more people are diagnosed with FND and unaware of who to turn to when their own GP cannot support them, neither can NHS 24 or 999 call handlers understand and neither do paramedics. Therefore should the training modules not be mandatory rather than voluntary?

Practice Based Small Group Learning (PBSGL) modules are nominated by PBSGL members. The process is outlined by NHS Education for Scotland on their website CPD Connect incl. PBSGL Scotland - PBSGL - Did you know Given the competing number of potential modules it is not possible to mandate the development of these.

Will the information collated via NHS Lothian be available for the public once it concludes in Autumn 2025?

Yes. NHS Lothian will publish the outcomes of their FND co-ordinator programme this autumn. This can be requested from the Scottish Government by contacting Clinical_Priorities@gov.scot

Also, any further data collected from NHS Grampian be shared publicly? What are the next steps once this ended?

The final report for NHS Grampian's work is available from the Scottish Government by contacting Clinical_Priorities@gov.scot

NHS Grampian has used the knowledge from the GP training developed in the project to inform a successful bid to improve health and wellbeing of people with Functional Disorders (including FND) in NHS Grampian to help them be heard, held, and empowered. This includes identified practitioners that co-develop care plans with patients providing ongoing support and signposting, and running initial diagnosis specific education sessions.

We will continue to work with all statutory health and social care providers to promote models of care that lead to successful patient outcomes.

In creating a social and face to face support group of over 200 members not one person has been made aware of the FND care pathway nor of the Dissociative Seizures app or site. Why is this information not more widely shared?

It is the responsibility of the individual's clinician to refer people with FND to appropriate resources. The Scottish Government will continue promote the Dissociative Seizure app to NHS boards. For example we are running a national seminar for health and social care providers, 'FND in Focus' in November 2025. This will include a presentation on the app. The FND care pathway is aimed at clinical staff and has been widely promoted by the Centre for Sustainable Delivery who developed it. The Care co-ordinator project Scottish Government funded NHS Lothian to develop is an example of the Pathway being used to improve the care of people with FND.

Receiving a diagnosis and given a website to read is not enough support, and furthermore to get any further support or information patients are having to search through the internet to find these very valuable resources. Furthermore, out of the 200+ members none have heard of or been signposted to these sites by any medical practitioners and have not heard of NHS Right Decisions either. Why is none of this shared more publicly within GP practices, hospitals, etc?

Neurosymptoms.org was developed by a group of leading experts in FND with significant patient and clinician involvement. It is an internationally recognized source of patient and clinician information and includes links to patient support groups and other websites on FND. We are sorry that the petitioner has not found this helpful.

Going forward, why are individuals such as myself, those in the support group we have created and those who are living daily with FND having to fight for information to be shared, when we have felt dismissed, medically gaslit and left to fend for ourselves?

We recognise that there is still a long way to go in raising awareness and understanding of FND. Work to do this is ongoing. As well as the seminar referred to above, other NHS boards are considering models of care that they can adopt long-term. For example NHS Lothian recently provided training to colleagues in NHS Highland that was over-subscribed and attended by around 150 people.

In regards to raising awareness in workspaces and in the wider community, what opportunities are there for this to be done other than ourselves raising awareness on social media and in our local communities? NHS England are using the NHS app which is a free app where patients can see their medical appointments, test results and any diagnosis they have. Will this be available on NHS Scotland? This would be beneficial for those with FND and other health conditions for showing and sharing with paramedics, A&E staff etc if for example speech or cognition is impaired due to functional symptoms. It would also benefit the individual and employers as information regarding appointments and medications can also be shared. Due to the app showing historical appointments, referrals, medications and diagnosis it would also be beneficial for the individuals to understand their FND diagnosis and possibly pinpoint a potential risk or cause for FND.

On 26 September, the Cabinet Secretary updated Parliament via a statement on the rollout of MyCare.scot and the associated plan that details the approach and delivery of the service. The new online service will be rolled out across Scotland from April 2026, following an initial launch in Lanarkshire in December. This will help ensure that the service is robust, safe, secure and meets people's needs.

MyCare.scot is a key enabler in the journey of digital transformation and will revolutionise people's access to health and social care information and services. https://www.digihealthcare.scot/our-work/digital-front-door/

2. what preliminary assessment it has made of the pilot projects in NHS Lothian and NHS Grampian, including in terms of their potential to be expanded on a national level.

Both projects have been asked to submit final reports outlining what they have done and how their impact has been measured. The NHS Lothian FND co-ordinator report is due by November 2025. The NHS Grampian project is available on request from Clinical_Priorities@gov.scot

It is the responsibility of NHS Boards in Scotland to plan and deliver services at a local level including whether to adopt the innovative approaches to service delivery funded through Neurological Care and Support: A Framework for Action 2020-2025. Statutory providers should consider adoption of the approaches tested through these projects based on the data that has been presented in the project reports and on local assessment of need and available resource.

NHS boards self-evaluated against the General Standards for Neurological Care and Support in 2024. This helped them identify local strengths and weaknesses and to prioritise areas for improvement. All are progressing improvement plans for neurology services as a result of this. Many of these include actions related to improving services for people with FND. Improvement plan progress updates were submitted to the Scottish Government in 2025.

I hope you find the above responses helpful.

Yours sincerely

Jenni Minto MSP