



Modernising Patient Pathways Programme:

Functional Neurological Disorder National Pathway

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FND (Functional Neurological Disorder) is one of the most common conditions seen in neurological practice, affecting approximately 10,000 people in Scotland. It can manifest as a range of symptoms including functional seizures, impaired mobility/weakness, speech, and movement disorders.

It is a hidden and stigmatised problem, which often falls between specialities. People with FND experience similar levels of disability to conditions such as Multiple Sclerosis or Epilepsy, and high frequencies of psychological distress.

Services or specialists sometimes 'exclude' people with FND, despite increasingly good evidence for the benefits of multidisciplinary assessment and treatment¹.

This pathway is based on the most recent systematic reviews of the evidence^{2-6,7}, existing consensus recommendations for therapy⁸⁻¹⁰, and other relevant pathways^{11,12}.

What is FND?

FND in this document refers to:

- Functional limb weakness or paralysis, sensory and speech disturbance
- Functional movement disorders like tremor, dystonia, gait disorder and jerks
- Functional seizures– events that look like epileptic seizures or syncope
- Persistent postural perceptual dizziness (PPPD)
- Functional cognitive disorders
- Functional dysphonia, swallowing problems, and hearing problems
- Functional visual problems

What is not FND?

FND should not be used to describe ALL functional symptoms and disorders. It does not, for example include chronic pain/fibromyalgia, persistent fatigue, or functional gastrointestinal problems such as irritable bowel syndrome. Those disorders commonly co-exist in people with FND and may have shared mechanisms.

Who is this pathway for?

This pathway has been created 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.

Key Components of Pathway and Recommendations for Implementation

Recommendations for Pathway

- 1. FND diagnosed and explained using positive criteria by specialists with neurological expertise.** We recommend care is taken to share the rationale for the diagnosis with the person and usually at least one follow up from the diagnosing clinician.
- 2. A multidisciplinary core FND network team, which is responsible for assessing and management.** This team will typically consist of health professionals already working in health services with neurological expertise centred on a clinically active co-ordinator.
- 3. A wider network of other health professionals involved in FND supported and educated by the core FND network.** We recommend other health professionals, for example, in pain services and mental health can be enabled to help manage FND.

Recommendations for Implementation

- 1. Access to FND specialist practitioner** with a clinical patient-facing role, who can also create local pathways and networks for people with FND, educate other health professionals, co-ordinate care and respond to relapses.
- 2. Access to FND Specialist assessment clinics (typically neurology or neuropsychiatry)** which can carry out required detailed assessments and make therapeutic recommendations for people with FND with a recommended duration of at least 1 hour.

Figure 1. Summary of FND pathway content and key implementation recommendations

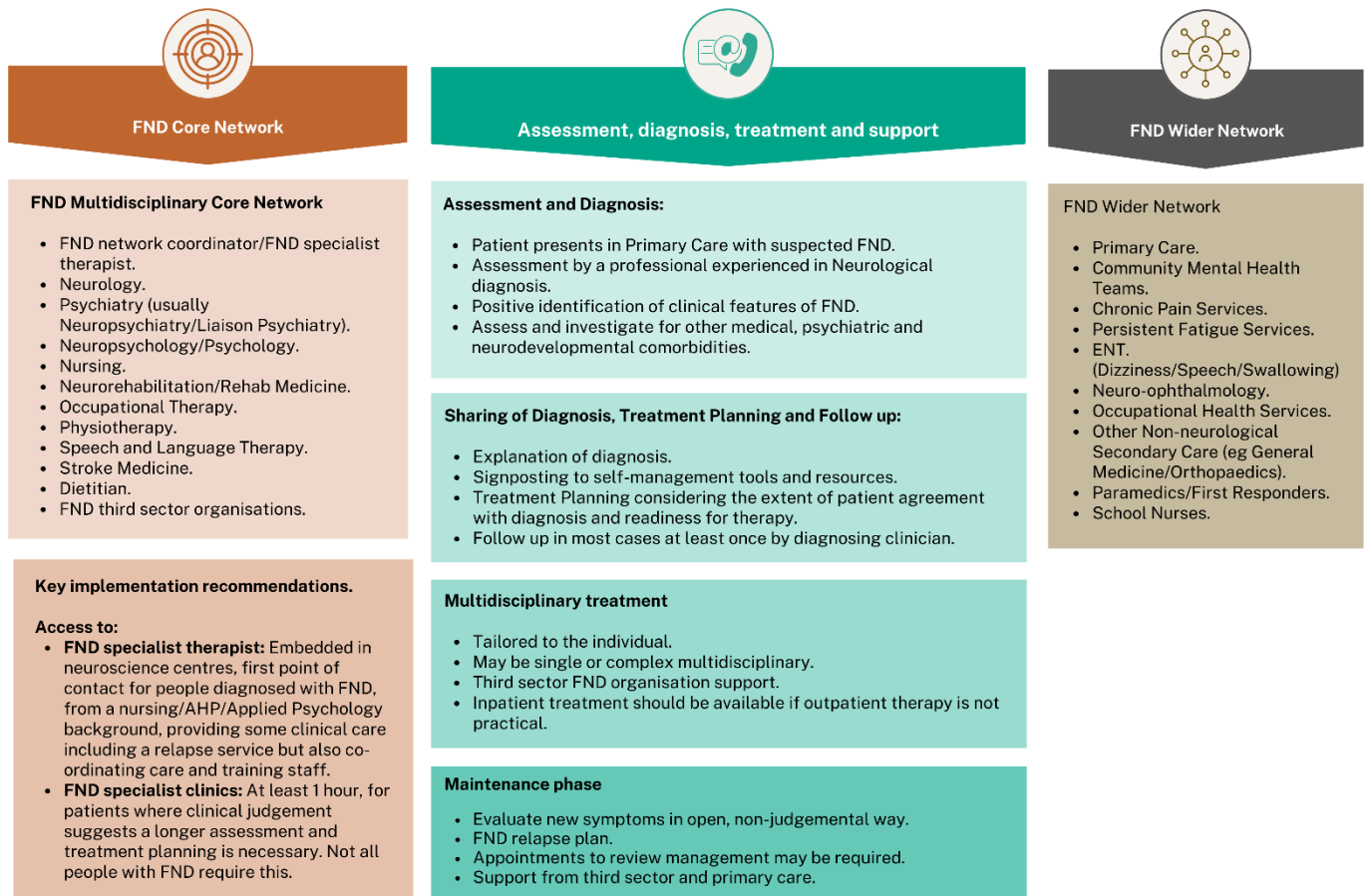
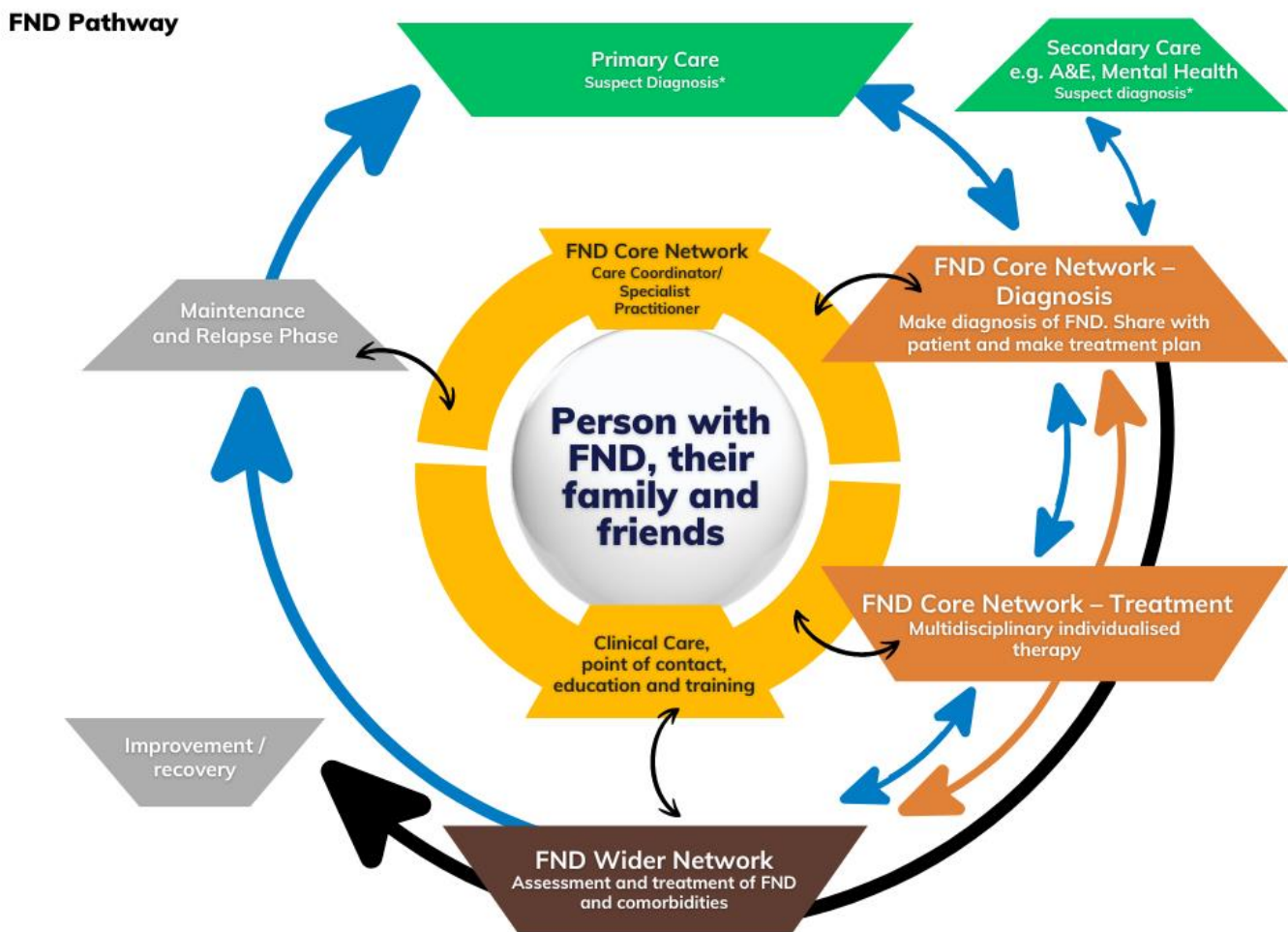


Figure 2. FND pathway flow showing importance of a central clinical co-ordinator and variability of treatment plans and outcomes.



Detailed Pathway Recommendations

First FND presentation, assessment, and diagnosis in Secondary care

1. **Diagnostic confirmation by someone with expertise in neurological diagnosis in secondary care.** FND is often suspected in primary care and can be raised as a possibility by any health professional including those in emergency care, secondary medical and surgical and mental health care settings. However, the diagnosis requires expertise in neurological diagnosis – typically a neurologist but may be another health professional including: TIA, Stroke or Memory services. There is only limited scope to reduce referral using active triage in people with suspected FND for this reason. Some milder neurological symptoms which do not need a ‘disorder’ diagnosis may be diagnosed and managed in primary care.
2. **Assessment for a range of comorbidities.** This need not be done by one health professional but at all stages we recommend the high frequency of additional physical health, mental health and neurodevelopmental conditions be considered by assessing and treating teams.
3. **Keeping a low threshold for investigations.** Comorbidity with additional neurological and other medical conditions is common. Diagnosing clinicians are encouraged to have a low threshold for investigations where this comorbidity is possible, but presentations are too varied to recommend mandatory investigations. This is why neurological expertise is required.

4. **Making a diagnosis using positive diagnostic criteria.** FND is not a diagnosis of exclusion. FND is diagnosed made on the basis of typical clinical features of the condition⁵ – for example: typical features of a functional seizure, positive diagnostic features such as a positive Hoover’s Sign or tremor entrainment test. There will be some situations where positive diagnosis is harder, for example, sensory symptoms but this principal should rarely be violated.
5. **Access to Specialist FND assessment clinics.** In situations where there is diagnostic uncertainty, high complexity, or symptom severity then access to a specialist clinic, typically run by a neurology or neuro/liaison psychiatrist with additional expertise in FND assessment and management may be appropriate. We recommend at least one hour for an FND specialist clinic initial diagnostic assessment. In some cases, this may need to be longer. Only some people with FND require to be seen at a specialist clinic. All neurologists running general neurology clinics, for example, should already have expertise in FND. The decision to refer on to a specialist FND clinic relies on clinical judgement.

Initial explanation and treatment planning of FND in Secondary care

1. **Sharing the diagnosis of FND is an important first step in treatment.** Sharing and providing explanation of the diagnosis of FND is the responsibility of the clinician who has made the diagnosis and is a key first step in treatment. Important principles include: Communicating FND in the same way as other similar conditions, naming the condition, explaining how the diagnosis has been made using positive diagnostic criteria and formulation with comorbidities. Not all FND symptoms require an FND diagnosis. It may be appropriate to explain how a particular functional neurological symptom such as limb weakness or tremor, overlaps with another primary diagnosis – for example fibromyalgia/chronic pain.
2. **Signposting to self-management tools.** We recommend diagnosing clinicians signpost someone with a new diagnosis of FND to resources. However, there should not be an expectation that this alone constitutes satisfactory treatment in most cases.
3. **Further treatment decision making.** We recommend that the diagnosing clinician along with the person with FND, make an initial assessment of whether to refer to another member of the multidisciplinary team or whether onward referral is required at all using principles of realistic medicine. There are many potential factors influencing triage.

Multidisciplinary FND treatment

4. **Follow up by the diagnosing clinician, or clinician competent in diagnosis at least once.** We recommend that people diagnosed with FND are usually seen again by the diagnosing clinician, or by another clinician competent to answer relevant questions about diagnosis. At least one follow up visit for the majority of people with FND can enable someone gain the confidence in the diagnosis required to benefit from subsequent treatment.
5. **Multidisciplinary FND-specific management from knowledgeable health professionals.** We recommend that people with FND have access to evidence-based rehabilitation therapies tailored to their symptoms from health professionals who are knowledgeable about FND. This varies considerably depending on the nature of the symptoms. People with FND often have comorbidities which mean they need to be co-managed within mental health, chronic pain, persistent fatigue, and rehabilitation services such as mental health, chronic pain, persistent fatigue, and rehabilitation services. There is good evidence and strong consensus that therapies need to be FND specific, e.g., e.g., physiotherapy, occupational therapy, speech and language therapy and psychological therapy, ^{6,8-10}. For example: FND focused physiotherapy might actively use distraction during treatment and FND focused psychological therapy can use techniques to gain better control of seizures or dizziness, and not just help someone cope with symptoms better. Some people need only one therapy. Others require multiple therapies with liaison between health professionals.
6. **Local ‘core’ networks of health professionals skilled in FND for each Health Board created, usually from existing clinical staff.** FND is a common condition, which is already seen by local neuroscience, mental health services and allied health professional teams attached to neurological services. These core staff are usually familiar with FND but may benefit from additional training which could be greatly enhanced by an FND specialist practitioner role (see Recommendations for Implementation) in combination with other training resources such as those provided by the FND Society. A list of core professionals is listed in Figure 1.
7. **A wider network of health professionals who do not work primarily in neurological services also have a vital role to play.** People with FND are also commonly seen by other services for example, Community Mental Health teams, Chronic Pain and Fatigue services. At present people with FND often experience barriers to treatment in these settings due to lack of education of health professionals which is relatively easily rectified. Many treatment approaches overlap with existing ones in rehabilitation and mental health services. We recommend an approach that enables ***all professionals who interact with people with FND to gain some expertise in the condition to enable them to help more.*** Lower intensity training and liaison between professionals in an FND network and these practitioners has the potential greatly improve skills and treatment.
8. **Measurement of outcomes underpin any new investment in FND.** We recommend that any change in configuration of services is underpinned by the collection of outcome data. The challenge of collecting data in such a heterogeneous group is recognised, especially if there is no additional funding³. Some potential solutions to this include:
 - a. Use of patient diaries via apps and other digital platforms
 - b. Collection of attendance data before and after treatment through a patient register, which could be embedded in electronic records.
 - c. Measurement of contacts with the service.
 - d. Measurement of knowledge and benefits of pathway in health professionals.

- 9. Inpatient treatment for people with FND who cannot have outpatient treatment.** There are a small number of people with FND who cannot have outpatient treatment because of severe disability or present acutely with FND symptoms which cannot be managed as an outpatient. We recommend that everyone with FND in Scotland is able to access inpatient treatment if the core FND network team decide that inpatient treatment is suitable. Here we are referring to multidisciplinary inpatient treatment in an acute setting such as a neurology ward, as well as a chronic setting such as those run by rehabilitation/neurorehabilitation services.
- 10. Children and adolescent care overlaps with adult care.** This pathway is for adults. However, we recognise that FND is a condition that disproportionately affects children and especially teenagers between the ages of 16 to 18 who may fall between adult and paediatric services. We recommend that adult services work to improve liaison with paediatric services and share expertise.

Maintenance phase of FND management and support

Many people with FND improve with treatment to the point where they no longer require support or treatment from health professionals with expertise in FND. However, others have persistent and disabling symptoms which typically relapse and may present with new symptoms over time.

- 11. Evaluation of new symptoms in an open, non-judgemental way.** People with FND commonly suffer from 'diagnostic overshadowing,' whereby new symptoms may be attributed to FND without adequate evaluation. People with FND have a higher frequency of other neurological and medical conditions. We recommend that new neurological and other symptoms are assessed in an open way by any clinicians involved, e.g., primary care, acute care or neurology, acknowledging that new symptoms are often related to FND but may also be caused by other conditions.
- 12. FND relapse planning and Patient Initiated Review (PIR).** FND commonly relapses, for example with a period of worse mobility, seizures, or speech problems. We recommend discussing the possibility of relapse and putting in place a relapse plan where appropriate. An FND specialist practitioner if present could facilitate more efficient rapid response to relapses as well as make Patient Initiated Review (PIR) without primary care involvement feasible. They can assess which service is most appropriate for a given situation, which may include diagnostic re-evaluation, advice to go to primary care or further contact with a therapy team.
- 13. Support from primary care and third sector organisations.** Some people with FND have a chronic condition which does not respond to treatment and needs to be supported and managed in the community and in primary care. We recommend FND is included in lists of conditions by organisations planning support for people with chronic disabling conditions. Third sector organisations including specific FND voluntary organisations may have an important role to play in supporting individuals with persistent FND symptoms.

Recommendations for Implementation

- 1. FND Specialist practitioners are likely to be a cost-effective way of improving multidisciplinary care.** In other similar chronic conditions, with similar prevalence, such as multiple sclerosis and epilepsy, a specialist practitioner role has been widely agreed to be beneficial for patient care and team working. We recommend that larger neuroscience centres invest in specialist FND practitioner roles. Smaller centres may have a Neurology Nurse or Specialist Practitioner role which could explicitly include FND within a clinical neuroscience remit. If a board has no neurology nurse practitioners, then a service level agreement with another board could help provide some of the training elements described below,

Specialist FND practitioner recommendations:

- Embedded within the neuroscience centre but act as an interface between the community, primary and secondary care.
 - Have primary roles in **co-ordinating treatment, training other staff and delivering some clinical care** including patient education and rehabilitation. However, they are not a substitute for multidisciplinary therapy needed for many people with FND.
 - Have a primary role in creating coherent multidisciplinary teams relating to each person with FND
 - Act as a first “point of contact” for people with existing diagnoses of FND who have been placed on Patient Initiated Review (PIR), have concerns about relapses or who cannot access health services.
 - Co-ordinate a relapse service.
 - Could come from a nursing, allied health professional or applied psychology background.
 - For a larger neuroscience centre could be two or three half time individuals working together and would not necessarily have to be a single individual for consistency of care and peer support.
 - Can help collect data to provide evidence of cost-effectiveness of the network.
 - Would be available to any person with FND and not just those requiring a specialist FND clinic assessment.
- 2. Access to FND Specialist clinics.** Many boards already have FND specialist clinics. For those that don't, we recommend that there is a specific pathway for how to access one if required, although only a proportion of people with FND require this.

References and further resources



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- 12 National Institute for Clinical Excellence. Suspected neurological conditions: recognition and referral Contents Contents. updated 2.10.23 <https://www.nice.org.uk/guidance/ng127>

Resources

FND at NHS Inform - <https://www.nhsinform.scot/illnesses-and-conditions/brain-nerves-and-spinal-cord/functional-neurological-disorder>

FND Guide at neurosymptoms.org – neurosymptoms.org

FND Hope UK - <https://fndhope.org/>

FND Action - www.fndaction.org.uk

FND Society - www.fndsociety.org

MyFND App <https://myfnd.co.uk>



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