

Optimum clinical pathway: Functional Neurological Disorder

September 2019

Executive summary

This optimum clinical pathway for people with Functional Neurological Disorder (FND) was designed by a working group of specialist clinicians, allied health professionals and charity representatives (see Appendix for group membership), as part of an NHS England specialised neurology programme of work. FND is a very frequent disorder in clinical practice (at least as common as Parkinson's Disease and MS) and current long-term outlook for patients is poor with most remaining with long-term disabling symptoms.

The group agreed that people with FND face specific challenges in accessing appropriate care and support. These challenges include: stigma and misunderstanding regarding the diagnosis amongst healthcare professionals and society at large (suspicion of malingering/exaggeration of symptoms), poor quality or absent explanation of the diagnosis by neurologists, frequent discharge after diagnosis without treatment plan or follow-up, referral into treatment services (neurotherapy, mental health) that lack expertise, often resulting in early discharge without treatment, lack of coordination between mental and physical health services in assessment and treatment, lack of a clear pathway to access specialist services, lack of availability of specialist services.

The group emphasised the fundamental importance of people with FND receiving a swift and well-explained diagnosis. This aspect of care requires a change in practice in neurology services (and related services where people with FND commonly present such as neurosurgical services, A&E, hyperacute stroke services) to ensure that 1. diagnosis is made according to positive criteria, 2. the full range of diagnoses present are explored (FND is commonly co-morbid with other neurological and/or mental health diagnoses), 3. diagnosis is explained according to best practice guidelines. In some circumstances, diagnosis can be difficult, and therefore a key role for a specialist FND service is to provide expertise in diagnosis in such cases.

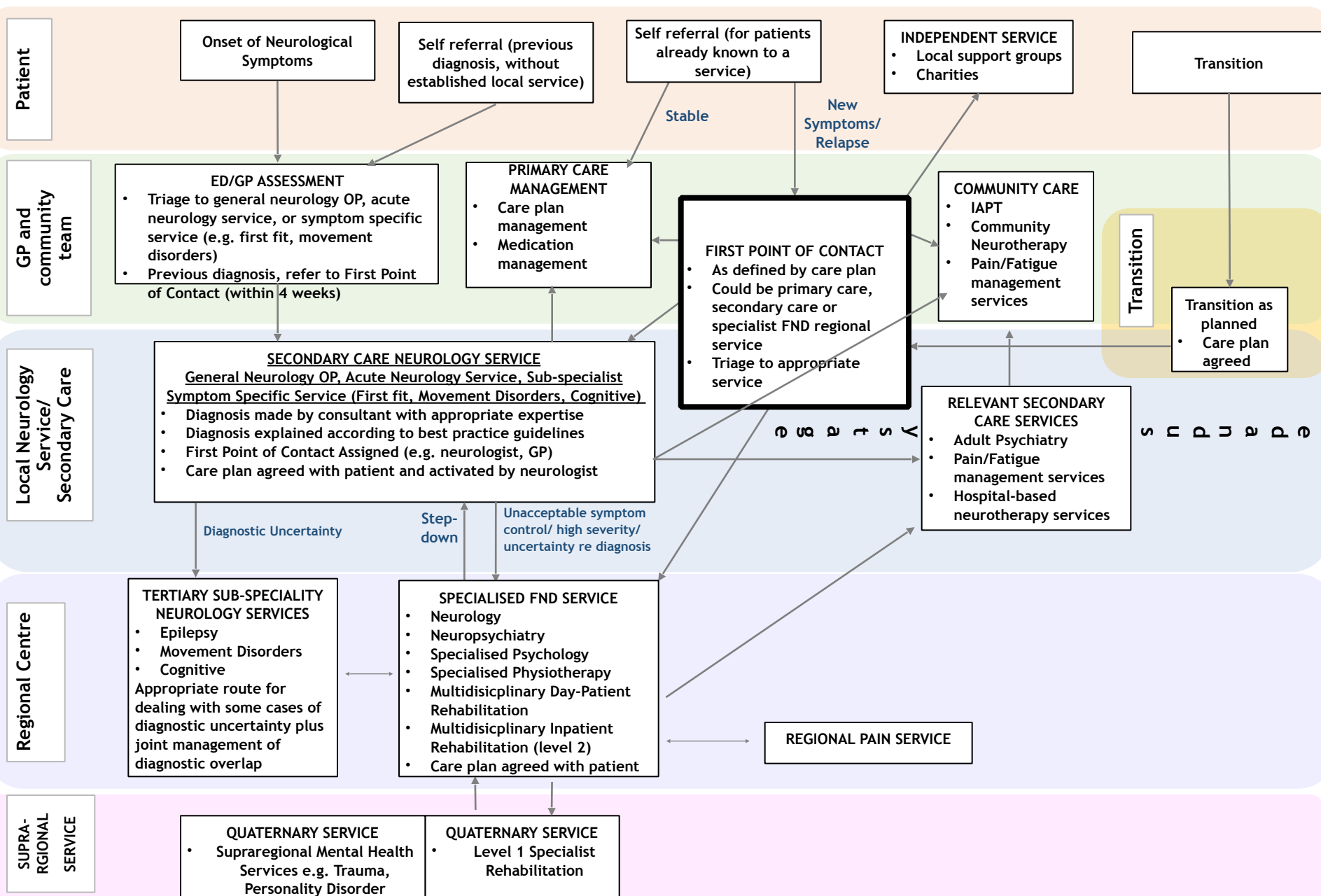
The group acknowledged that the symptoms, disability and co-morbidities of people with FND are highly heterogeneous. A successful pathway for people with FND will therefore need a range of services available into which people can be referred depending on need and complexity. Achieving effective triage is therefore a key outcome of an optimum clinical pathway for FND.

Mental Health co-morbidity is common in people with FND, and regardless of whether or not this is present, psychological therapy can be an important aspect of treatment. The group acknowledged that the traditional organisational and budgetary separation of mental and physical health services present a major challenge in effectively providing for the needs of people with FND. Within specialist services for FND, full integration of physical and mental health professionals is likely to be the most effective model of care. In primary care, community services and secondary care, joint working and information sharing between physical and mental health providers should be an effective way of providing "joined up" care for people with FND.

Given the frequency of the diagnosis of FND, it is imperative that secondary care neurology services and primary care/community services provide treatment and long-term care for people with FND. Beyond this, the group agreed that there is a clear need for specialist FND services to provide expertise in diagnosis and specific programs of treatment. These services should ideally be located within or strongly linked to regional neuroscience centres. Patients exiting these services will often need follow up and support from secondary care, primary care and community services. An optimum pathway of care will allow for patient flow between such services, including re-involvement of specialist services if significant new symptoms or relapse of symptoms occur.

This pathway requires a significant investment in consultant and therapist time to provide specialist FND services within each regional neuroscience centre and to bolster community services. However the pathway is expected to create efficiency savings while improving clinical outcomes for people with FND by, for example, providing early diagnosis, reducing unnecessary investigations, reducing unnecessary medical and surgical treatments, and ensuring that patients are referred to the most suitable treatment service depending on need.

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Contents

Context	5
Pathway	6
Pathway: first presentation to diagnosis	6
Pathway: treatment and ongoing management	7
Pathway: defining a specialised FND service	8
Pathway: efficiency savings	9
Barriers and enablers	10
Patient flow	10
Access to research and clinical trials	11
Pathway map	12
Clinical guidance	13
Appendix	14
Appendix 1. Clinical working group membership	14

Context

FND is one of the commonest diagnoses made in neurology outpatient clinics. Presentation is varied and includes seizure-like episodes, motor symptoms (paralysis, movement disorders such as tremor and dystonia), and sensory symptoms (numbness). Cognitive symptoms, pain and fatigue are commonly present. Mental health co-morbidity is common. FND is likely to be commoner than MS and Parkinson's disease and has similar rates of long-term disability and impaired quality of life. Despite this, FND has languished behind other causes of neurological symptoms in recognition and respect, quality of diagnostic explanation, availability of relevant treatment services and clinical pathways to aid organisation of care.

This information pack is the output of the FND Clinical Working Group's efforts to define the optimum pathway for patients with FND. The guidance outlines:

- The “optimum” pathway for patients with FND from first presentation to accessing appropriate treatment and chronic care.
 - The definition of “specialised” FND care.
 - Possible efficiency savings to come out of the optimum pathway.
 - Identifies barriers and provides recommendations around patient flow, information sharing and research and clinical trials.
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Pathway: first presentation to diagnosis

Good practice

Common sites for presentation of FND are to primary care services, A&E and Hyperacute Stroke services. Effective diagnosis of FND requires neurological assessment and frequently investigations such as brain imaging. Existing pathways from primary care to outpatient neurological assessment and A&E to in-hospital neurology assessment or referral to acute neurology "hot clinics" should ensure access for patients with FND to swift neurological assessment.

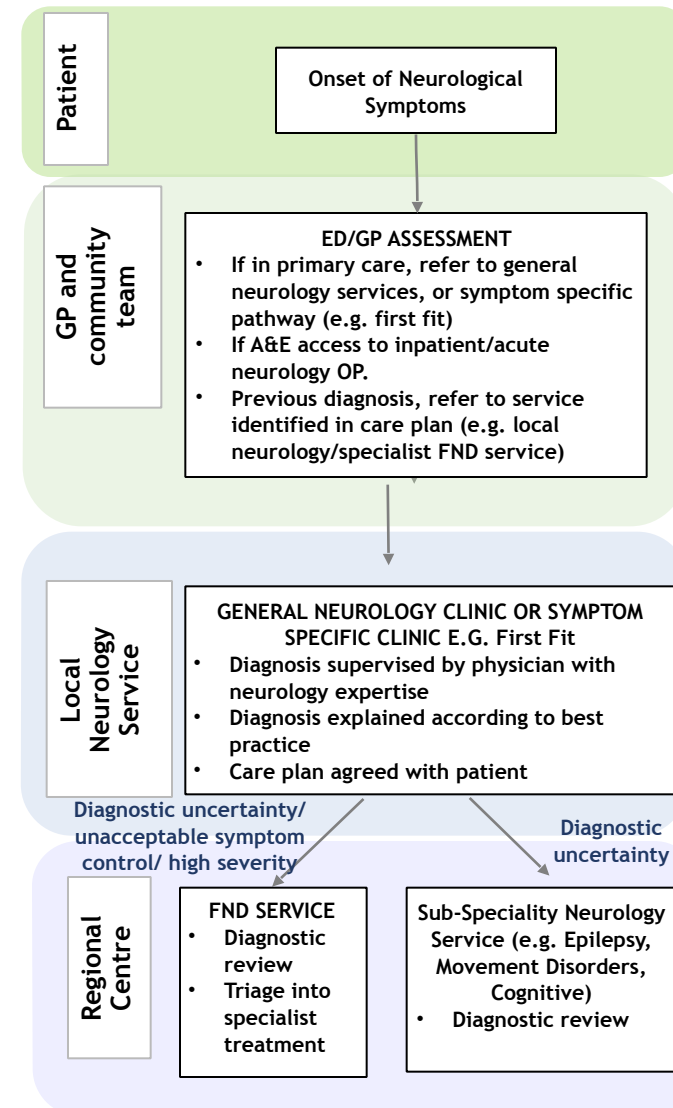
Existing symptom specific pathways are suitable for specific people with suspected FND in order to achieve a correct diagnosis. People with seizure presentations should be referred through "first fit" services for assessment. Those meeting criteria for acute stroke/TIA should be referred through hyperacute stroke/TIA pathways. This implies that such services need to have expertise in the diagnosis of FND and in the diagnostic explanation, and to be aware of pathways for treatment.

Principles of FND Diagnosis

The diagnosis of FND should not be a diagnosis of exclusion, but should instead be a diagnosis made on positive criteria from history and examination. While mental health co-morbidity can be present in FND and rates of previous adverse life events are higher in FND than many other causes of neurological symptoms, these are neither necessary nor sufficient to make the diagnosis. "Overlay" of FND on top of other diagnoses, both physical and mental health, is common. Therefore, thorough assessment of patients is important. Diagnostic uncertainty is unavoidable in some patients, and in such cases explanation of the uncertainty and referral to specialist services (FND or sub-speciality e.g. epilepsy, movement disorders, cognitive) is appropriate.

Principles of Diagnostic Explanation:

- ❖ Should follow a similar pattern as for other diagnoses;
- ❖ Is the responsibility of the neurologist;
- ❖ Name the disorder (FND, functional weakness, functional seizures);
- ❖ Explain how the diagnosis was made;
- ❖ Explain the relevance in some people of comorbidities and triggers, physical, psychological and social;
- ❖ Recommendations and signposting for independent support services; and
- ❖ Practical self-management actions agreed with patient, with treatment plan developed depending on need.



Pathway: treatment and ongoing management

Good practice

1. **Patients with FND are highly heterogenous in symptoms, severity and co-morbidity. Therefore the care pathway should prioritise effective triage.**

There is no “one size fits all” treatment for FND. Many different services may be of help to individual patients with FND, and clinicians have a responsibility to ensure that patients are referred to the most appropriate service(s) depending on need.

2. **As much care as possible should be kept local.**

Given that FND is a very common condition and that a significant proportion of people remain with persistent disabling symptoms, local care is essential to maintain the viability of specialist assessment and treatment services and to provide efficient local support for patients with long-term symptoms.

3. **A First Point of Contact (FPOC) for people with FND will facilitate management of new symptoms/relapse.**

Many patients with FND experience fluctuations in symptom severity and may develop new symptoms over time. Development of new symptoms may indicate the emergence of an additional disorder alongside the FND. Many people with FND with chronic symptoms need assistance in navigating the social care system. A FPOC can ensure appropriate assessment and support. Depending on the patient, this could be a GP, practice nurse, CPN, secondary care neurologist, FND specialist nurse or a tertiary FND neurologist/neuropsychiatrist.

4. **Intensive specialist treatments for FND are necessary for a proportion of patients**

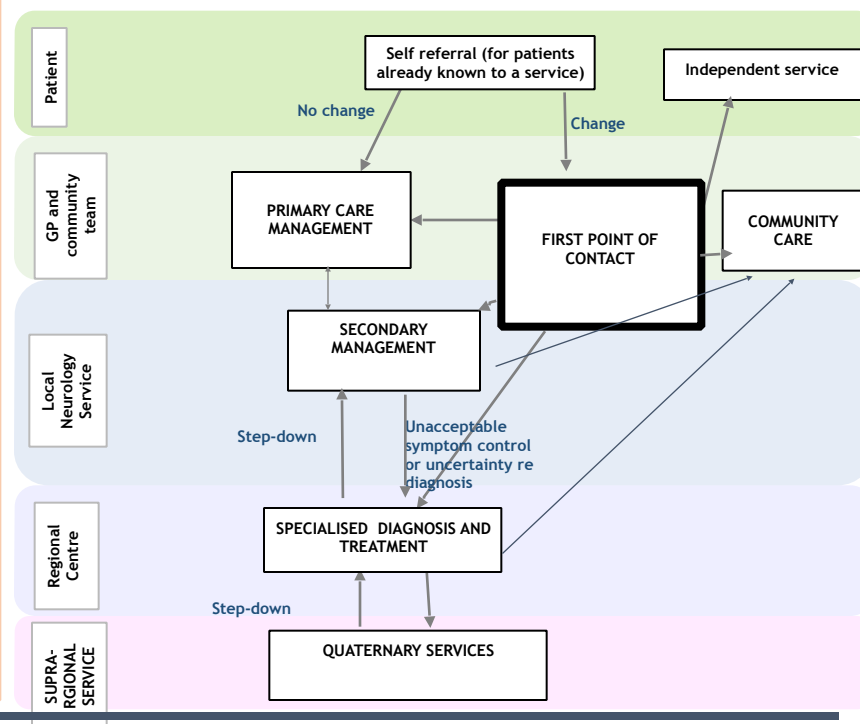
Specialist assessment to resolve diagnostic uncertainty and specialist treatments are necessary for a proportion of patients and should be accessible with minimal delay to ensure best outcomes.

5. **Integration of mental health services at a primary, secondary and tertiary care level is essential**

Many people with FND would benefit from mental health involvement in care, however this needs to be at the appropriate level of expertise and intensity, and to address specific problems that are important to the person with FND.

Secondary care functions include the following:

- Organising appropriate investigations, diagnosis and diagnostic explanation, managing medications.
- Providing self-management advice and signposting to sources of information and support (e.g. charity).
- Follow up in selected patients, including assessment of new symptoms
- Acting as a FPOC and patient advocate.
- Triaging the patients directly into appropriate secondary care and primary care treatment services (e.g. community neurotherapy, IAPT).
- Recognising when diagnostic uncertainty, high symptom severity or unacceptable symptom control indicate referral to specialist services.
- Accepting patients stepping down from specialist services.



Pathway: defining a specialised FND service

With appropriate development and support, many people with FND could be effectively cared for at primary and secondary care levels. However, a proportion of people with FND will need the input of a specialist service for FND. Specialist FND services are most likely to be located within Regional Neuroscience Centres.

Referral Criteria for Access to a Specialised FND Service:

- ❖ Diagnostic Uncertainty (note that in some patients where there is diagnostic uncertainty, referral to sub-speciality neurology clinics would be appropriate e.g. Epilepsy, Movement Disorders, Cognitive).
- ❖ Symptom severity and/or complexity is high.
- ❖ Patient has failed to improve with primary/secondary management.
- ❖ Symptom type is associated with a poor prognosis or specific treatment e.g. fixed dystonia, functional seizures

Elements of specialised care: tertiary

Tertiary services are provided by all specialised centres and are not available at district general hospitals.

- ***Specialist diagnostic services (Video EEG, pre-movement EEG potentials)***
- ***Neuropsychiatry service***
- ***Specialist Psychology Treatment Service***
- ***Specialist Intensive Physiotherapy Treatment***
- ***Specialist Multidisciplinary Day-Patient Treatment***
- ***Specialist Multidisciplinary Inpatient Treatment (level 2)***

Elements of specialised care: quaternary

Quaternary services are considered 'super specialised' and are only provided at some specialised centres, linked closely to tertiary FND Specialist Services.

- ***Highly Specialised Inpatient Multidisciplinary Rehabilitation (Level 1).***
- ***Quaternary Specialised Psychiatric Services (PTSD, Personality Disorder).***
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Pathway: efficiency savings

Early diagnosis

Early diagnosis of FND has the potential to deliver cost savings to the NHS as well as improving clinical outcomes for patients. For example, in patients with non-epileptic attacks, diagnostic explanation resulted in an 84% average reduction in total seizure-related medical charges in the 6 months following diagnosis. Average diagnostic testing charges declined 76%, average medication charges decreased 69%, outpatient clinic visits declined 80%, and emergency room visits reduced by 97% (1)

Access to appropriate treatment improves outcomes and reduces long-term costs

Access to appropriate treatment can be associated with significant improvement in disability in a proportion of people with FND. For example, in a randomised feasibility study of specialist vs. standard neurophysiotherapy for people with functional motor symptoms, patients randomised to the 5 day treatment had significantly better outcomes than those randomised to standard neurophysiotherapy with over 75% of those in the specialist treatment group improved at 6 months, compared to 18% of the standard physiotherapy group. This was despite these patients being on average 5 years after diagnosis, having received physiotherapy previously and most being out of work. Healthcare costs in the intervention group in the period 3-6 months after treatment were half those of the standard care group (2).

Long-term care

For those with chronic symptoms despite treatment, organised care for FND is likely to result in cost savings by rationalising the processes of reassessment if symptoms relapse or if new symptoms occur, and by ensuring that patients are supported as far as possible by good quality community services rather than in specialist/secondary care services.

Patient flow

With current models of care, there is a very large gap in provision of services for people with FND. Some services do exist, but these are largely fragmented, offering a specific intervention (e.g. inpatient multidisciplinary rehabilitation) without being part of a specific care pathway. Community and secondary care services that could help some people with FND often report lack of expertise or support as barriers to them providing care for people with FND. Access to specialist assessment and treatment is patchy across England.

Barrier	Potential solution(s)
<i>General neurology services to which patients most commonly present may fail to provide a well explained diagnosis, and often discharge patients rather than offering follow up or referral into treatment</i>	<ul style="list-style-type: none"> ❖ <i>Clear guidelines regarding expectations of general neurology services with regard to people with FND.</i> ❖ <i>Education programmes on making and explaining the diagnosis of FND.</i> ❖ <i>Clear pathway for accessing treatment or specialist assessment depending on symptoms and co-morbidities.</i>
<i>Community and Secondary care generic rehabilitation services often report lack of expertise and support for managing patients with FND</i>	<ul style="list-style-type: none"> ❖ <i>Education program for IAPT, community neurotherapy and secondary care neurotherapy teams in FND.</i> ❖ <i>Establishing direct links between specialist FND diagnostic and treatment services and community services for support and to facilitate patient flow</i>
<i>Lack of specialist diagnostic and treatment services</i>	<ul style="list-style-type: none"> ❖ <i>Support development of Specialist FND diagnostic and treatment services within each regional neuroscience centre underpinned by rigorous data collection on outcomes</i>
<i>Unclear which patients should be referred to which treatment service</i>	<ul style="list-style-type: none"> ❖ <i>Clear referral guidelines agreed within each region</i>

Cross-cutting recommendation: support for self management

Access to self management programmes and support groups will help patients navigate the service.

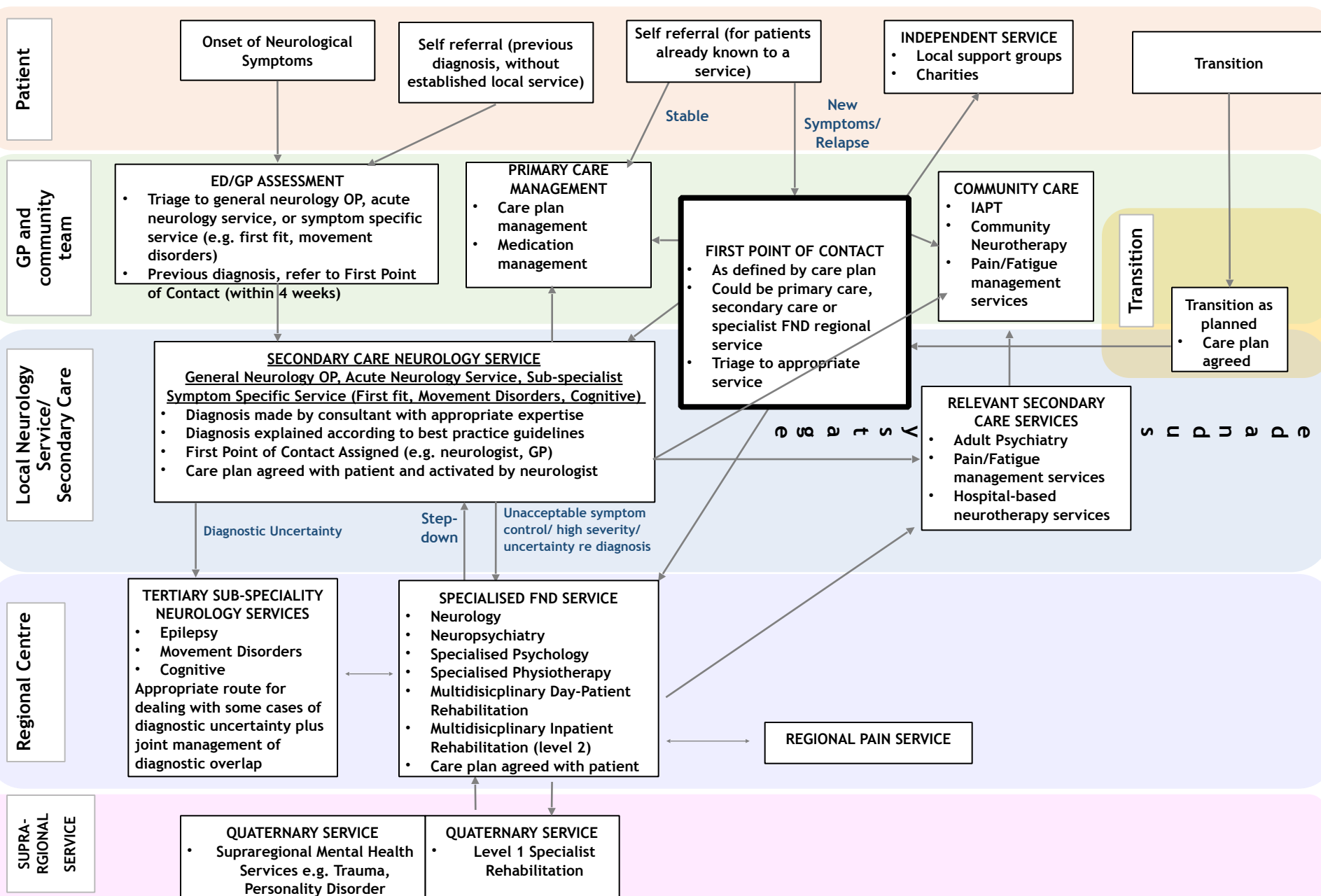
- ❖ Apps to help patients navigate the service.
- ❖ Advice to help patients self-manage condition (e.g. charity websites, peer-to-peer support groups, neurosymptoms.org).

Access to research and clinical trials

FND has, in line with lack of development in clinical services, suffered from a lack of research activity at the level of pathophysiological understanding, therapy development and clinical trials, and implementation research. Such work is essential to improve the care of people with FND and to provide a firm evidence base for treatment. Two recent large scale randomised trials have been funded by the HTA (CODES trial for functional seizures, Physio4FMD trial for functional motor symptoms), and national and international networks of clinicians, therapists and researchers are developing. The specification of an optimum clinical pathway for FND is an opportunity to embed research at every stage of the patient pathway in order to monitor and improve practice and outcomes.

Barrier	Potential solution(s)
<i>Lack of capacity and incentives for Trusts to enable clinicians to participate in research. The main barrier is lack of time given heavy clinical workload in job plans.</i>	<ul style="list-style-type: none"> ❖ <i>Identify and free up capacity.</i> ❖ <i>FND registry/database that is linked to routine clinical care.</i> ❖ <i>Clinician and patient partnerships with FND organisations to improve access to funding and PPI support for projects.</i> ❖ <i>Utilising the FNDHope registry for research: https://fndhoneora.presencehost.net/research/</i>
<i>Inadequate networks.</i>	<ul style="list-style-type: none"> ❖ <i>Establish networks to build and deliver research programmes.</i> ❖ <i>Maximise access to identify research.</i>
<i>Lack of consensus on research priorities.</i>	<ul style="list-style-type: none"> ❖ <i>Develop a formal process for all stakeholders to establish clinical research priorities in FND, for example using the James Lind Alliance.</i>

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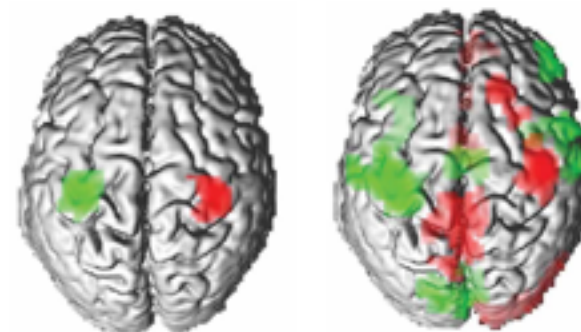
Clinical guidance to be considered alongside the pathway

Stepped Care for Functional Neurological Symptoms

This document from Healthcare Improvement Scotland was published in 2012 and was the result of a consultation exercise amongst clinicians and therapists with an interest in FND in Scotland.

The report makes a number of recommendations, mirroring many within this optimum pathway proposal for FND. They include a recognition of the common and disabling nature of FND, its current major health and socio-economic impact and the need for a co-ordinated pathway of care and need for investment in services and education in order to deliver improved services and to improve outcomes for people with FND.

<http://www.muns.scot.nhs.uk/wp-content/uploads/2013/05/Stepped-Care-for-Functional-Neurological-Symptoms.pdf>



Stepped care for functional neurological symptoms

A new approach to improving outcomes for a common neurological problem in Scotland

Report and recommendations

February 2012

Appendix 1. Clinical working group membership

Name	Profession	Organisation
Mark Edwards	Workstream clinical lead, Consultant neurologist	St George's University Hospital NHS FT
Michael Dilley	Workstream clinical lead, Consultant Neuropsychiatrist	St George's University Hospital NHS FT
Dawn Golder	Executive Director	FND Hope UK

References

1. Martin RC, Gilliam FG, Kilgore M, Faught E, Kuzniecky R. Improved health care resource utilization following video-EEG-confirmed diagnosis of nonepileptic psychogenic seizures. *Seizure*. 1998 Oct;7(5):385-90.
 2. Nielsen G, Buszewicz M, Stevenson F, Hunter R, Holt K, Dudzic M, Ricciardi L, Marsden J, Joyce E, Edwards MJ. Randomised feasibility study of physiotherapy for patients with functional motor symptoms. *J Neurol Neurosurg Psychiatry*. 2017 Jun;88(6):484-490.
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