Commissioning for Functional Neurological Disorders

June 2015
(Final)
What is the purpose of this document?

This document aims to provide guidance on commissioning a stepped care model for the management of functional neurological disorders, including examples of good practice, resources to support local organisations and sources of further information.

What are functional neurological disorders?

Functional neurological disorders (FND) are symptoms such as blackouts and paralysis that are genuine but not due to a neurological disease. The term ‘functional symptoms’ includes dissociative (non-epileptic) attacks, functional limb weakness/movement disorder, sensory, visual, speech and cognitive symptoms (Healthcare Improvement Scotland).
What can be done to treat people with these symptoms?

Functional neurological disorders can be effectively treated with psychoeducation, physiotherapy, psychology and medication to treat co-morbidities. However, across the North East and North Cumbria there is limited or no access to treatment for patients with functional neurological disorders. Patients are often severely affected by their condition, faring worse than patients with other neurological disorders across a range of psychosocial domains often resulting in the development of significant levels of psychiatric comorbidity.

The lack of service provision for patients with functional neurological disorders can lead to frequent GP attendances, frequent secondary care referrals, A&E attendances, unnecessary investigations and unnecessary social care support being put in place (e.g. carers).

Prompt diagnosis and treatment can mitigate this to a large extent, so improving access to effective treatment is therefore a priority for these patients.

The [document produced by Health Improvement Scotland](#) explains one approach to treating this common problem, using a stepped care model. This model will be explained in more depth later.
Is it a big problem?

Yes. Scotland is a world leader in functional neurology and, in 2003, conducted comprehensive research to estimate the size, cost and extent of the problem. The Scottish Neurological Symptoms Study found:

- **31% of people attending neurology outpatient clinics had functional symptoms.** As a whole, this is the largest single group accessing neurological services.

- **27% of people attending with functional symptoms were not working for health reasons.** This impacts on the wider economy, including an increase in benefits claims.

- **At least 5,000 people per year are estimated to be diagnosed with a functional neurological disorder.**

- The cost to the health economy in Scotland for people with functional symptoms is estimated at
  - **£1.3 million per year for outpatients**
  - **£6.01 million for inpatients**
  - **£4.01 million for primary care**

Scottish studies suggest a 50% decrease in health service utilisation may be possible if patients receive appropriate treatment.
But what about England?

There are no similar studies for England, but the Department of Health estimates that:

- ‘medically unexplained symptoms’ cost the economy £18 billion every year
- £3.1 billion of this is NHS cost
- a further £5.2 billion in lost productivity, and
- £9.3 billion attributed to a reduced quality of life.

Locally, data collected in the Durham Medically Unexplained Physical Symptoms (MUPS) service indicated that 85% of people with a diagnosis of non-epileptic attack disorder were unemployed.
The solution – a stepped care approach

STEP 4: Highly complex patients requiring inpatient treatment or MDT working. This would be a very small group of patients

STEP 3: Longer term intervention delivered by specialist

STEP 2: Brief intervention delivered by a trained nurse or therapist, based within specialism (group based or 1:1)

STEP 1: Good initial diagnosis and explanation of functional symptoms by neurologist (or Consultant in another specialty as appropriate)
So, how does this ‘stepped care model’ work?

Step 1: Improving initial diagnosis and management within neurology. One in ten patients will be cured of the disorder if this step is done well. Optimal explanation of symptoms by neurologists has been shown to help patients and reduce health care utilisation. Many patients wait years for an accurate diagnosis, and this leads to psychosocial comorbidities that is not only an adverse outcome for the patient, it also makes later treatment more complex and costly.

Example from practice: Using a ‘computer analogy’ for explaining a functional diagnosis in neurology

“This looks like a software sort of problem. The hardware is intact - we know there is nothing degenerating or nasty, but the programme is not responding. With a computer you can just switch it off and back on to rectify the problem, but with people it isn’t quite as simple. Some computer systems seem more prone to crashes, in the same way that some people are more prone to getting these sorts of problems. If there are lots of rogue programs in the background using computer processing power it can cause crashes, and similarly, if there are things in the background using brain processing power, such as stress issues, functional problems are more likely, so addressing these background factors can help. There are helpful techniques to try and get things working again.”
Step 2:
Four-session group or 1:1 CBT based psycho-education delivered by a specialist nurse or physiotherapist, within neurology. This is a cost effective intervention that can be delivered in a timely fashion to most patients immediately after diagnosis. Evidence suggests that early additional psychoeducation from a trained nurse / physiotherapist following diagnosis significantly improves patient long term outcomes. Many patients would not need more than this. There could also be a role for IAPT within this step.

Example of a ‘Step 2’ intervention - nursing

For patients with disorders such as non epileptic attack disorder, 5 sessions of psychoeducation could be delivered in a group setting. This is currently provided in the Medically Unexplained Physical Symptoms Service in Durham and Darlington. Peer support and shared experience is reviewed very positively by patients and it is often the first step to the route to psychosocial recovery. It helps destigmatise the condition and make patients feel they are not alone.

It is also a more cost effective way of delivering treatment. One support worker and one band 6 nurse run the groups, which are 5 sessions and have approximately 5 patients per group, at an estimated cost of £25 per patient for the total intervention.
Glenn Nielsen, a physiotherapist at the National Hospital for Neurology and Neurosurgery, works in a functional neurological disorders service providing treatment for patients with functional motor disorders. In 8 sessions of physiotherapy over a 5-days, approximately two thirds of patients reported themselves to be ‘better’ or ‘much better’ and the effect is sustained at 12-month follow up. Nielsen has developed a consensus document on approaches to treatment for people with functional motor disorders.
Step 3:
For those patients who need it, this would involve 2 options:

• **support worker intervention** to rehabilitate those patients who have lost independence and to help them to engage in meaningful and purposeful activities, designed to improve self esteem, symptoms and upskill patients. This can also be a necessary first step to stabilise the patient so that they can then engage in psychology. If this is not done, then expensive psychology time can be wasted stabilising patients which can be done in a more cost effective manner by support workers.

• 1:1 **psychology** and / or longer term physiotherapy for more complex patients. This step is **time limited**. Following this intervention, the **patient would leave the pathway then be referred back to their GP for continued management**.

Example of support worker-led rehabilitation

Mrs T

Mrs T developed seizures 5 years ago and was diagnosed with non epileptic attack disorder 1 year ago. In the four years before diagnosis she had lost all independence, receiving 24 hour care from family members.

Following treatment from the psycho-education group and work with her support worker, Mrs T and her family understand the condition better and Mrs T is now able to go out by herself and use public transport, has joined a craft group, can take her children out alone and is aiming to get back to work in the next 2 months. Mrs T can be seen talking about her progress on the functional conditions video.
Examples of psychological interventions (including and excluding physiotherapy)

Ms P, 35 year old single mother, presented with a stroke like episode. This was diagnosed as functional. She was left with severe gait disturbance. She worked with psychology, who identified previous trauma which contributed to the condition. She was subsequently treated using eye movement desensitisation therapy and between this and physiotherapy involvement her walking returned to normal over a series of 12 sessions.

Mr H had a 10 year history of health anxiety which had resulted in severe functional abdominal pain and multiple A and E admissions. He was treated using antidepressants and 18 sessions of CBT which resulted in Mr H going back to work.
Why should we commission this model?

Commissioners may like to consider the stepped care model for the following reasons:

• A stepped care approach such as this will aim to treat according to levels of need, thus ensuring that the **right treatment** gets to the **right patient**.

• The **greatest number** of patients can be treated in the most **timely** and **cost effective** way.

• It can be **based within neurology**, with links to liaison psychiatry and IAPT as required for patients with psychiatric co-morbidity, or for those who require CBT as a psychological intervention.

• It is a model that can be **transferred to other conditions**, outwith neurology, as demonstrated in the ‘MUS Commissioning Guide for London’.
What are the components that make this model work?

Education

Education of key professions involved in this stepped care model is a necessary starting point for implementation. To help with this, Health Education North East and the Northern England Clinical Networks have developed an educational awareness video (link to video).

CCGs should support ongoing education and access to learning resources for all health professionals. Functional conditions manifest in all areas of medicine and well meaning but inappropriate management (diagnostic labels, repeated tests, unnecessary prescriptions and equipment provision) is both costly and can cause harm.

This should be supplemented with high quality patient information material in a variety of formats. This level of management will be appropriate for all patients with functional neurological symptoms and may be all that is necessary for patients with mild to moderate disability, and no accompanying major psychiatric disorder.

NHS England “High quality care for all, now and for future generations.”
Good education leads to good diagnosis

By making a positive diagnosis, clinicians can avoid harm and cost from multiple referrals and investigations, and also offer a therapeutic route to improvement. **It will free up neurology outpatient clinic slots** as currently, (in the case of non epileptic attack disorder), these patients take up to 8 years to diagnose.

CCGs need to consider investing in tools to reduce time to diagnosis, such as video EEG (current wait for this in Newcastle 18 months). For example, in Glasgow, suspected non epileptic attack disorder patients get a 30 minute video EEG the day after being seen in clinic by neurology.
Physiotherapy

For patients with functional motor disorders, physiotherapy is a vital part of treatment, both in providing diagnostic support, brief intervention and complex treatment in conjunction with psychology. Currently, there is no dedicated physiotherapy service for patients in this area, and CCGs need to consider how physiotherapists working with both inpatients and in the community can be upskilled to treat patients with functional neurological disorders as part of this pathway.
Psychology and psychiatry provision

Psychology provision is needed for the complex end of the patient spectrum, with provision required for about a third of patients, although psychologists also need to provide supervision to other team members. Ideally this would be provided by psychology within neurology, but in areas where there are no dedicated neurological services, liaison psychiatry or IAPT could be commissioned to provide it, in the context of having access to allied health professionals such as physiotherapy as required.

Liaison psychiatry can link into neurology services to help diagnose and manage co-morbid mental health conditions and patients with more challenging and complex needs (Step 4), such as those who are frequent A&E attenders, those with complex psychiatric comorbidity and levels of risk to self or others.
Multi-disciplinary team working

Key to this model is multidisciplinary team working. Other professionals such as occupational therapy, speech and language therapy, and the pain team may need to also be linked to the model to ensure a consistent and holistic approach. This would also support the increase of skills and knowledge to work with these patients within these professional groups.

Ms L

Ms L presented with a functional tremor. Following 1:1 psycho-education with a psychiatrist, and the addition of antidepressants, her mood started to improve and she started to work out ways to reduce her tremor. She worked with a physiotherapist to learn progressive muscular relaxation, which further improved the situation, and finally an OT worked with her to put in aids to promote a relaxed grip and adapt tasks so she had a more relaxed posture, which again reduced her tremor. Her tremor is significantly improved.
Recovery

Recovery with support worker intervention. Many patients have lost independence and confidence through having a functional neurological disorder. They do not necessarily need complex psychology but need support for psychosocial rehabilitation to learn to do tasks such as getting on a bus again. This can link to vocational rehabilitation programmes such as volunteering and the Shaw Trust, which helps patients with disabilities back to work. It is a key step that can really improve patient's quality of life, improve functioning, and prevent relapse. It is also a step which can be necessary in order to stabilise the patient before accessing psychological therapy.

Severe and complex inpatient provision

For the few patients who have the most severe and complex needs, specialist inpatient services may need to be developed, like the Yorkshire Centre of Psychological Medicine in Leeds. Walkergate Park neuropsychiatric service may be the most appropriate place to develop this, with training and closer joint working with mainstream neurosciences.
Are there any local services that treat these conditions?

Service provision is patchy and inequitable. None of these have physiotherapy input:

<table>
<thead>
<tr>
<th>Service</th>
<th>Description</th>
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<tbody>
<tr>
<td>Durham and Darlington</td>
<td>The Medically Unexplained Physical Symptoms (MUPS) service. This service is commissioned to treat all patients with MUPS from secondary care which includes functional neurology.</td>
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<tr>
<td>North Durham</td>
<td>Dissociative Seizures Services. This provides psychological treatment to patients with dissociative (non-epileptic) seizures.</td>
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<tr>
<td>Middlesbrough</td>
<td>Neuropsychology service within neurology. There is one neuropsychologist working into this service with a three-year waiting list.</td>
</tr>
<tr>
<td>Sunderland</td>
<td>No dedicated service although IAPT provide a Persistent Physical Symptoms service, and see people with non-epileptic attack disorder.</td>
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NHS England “High quality care for all, now and for future generations.”
Is this model only for neurological conditions?

No! Functional conditions are very common in most specialities, for example, gastroenterology, respiratory and rheumatology. The underlying principles can be applied to all patients with functional symptoms, with group based therapy provided in a specialty-specific context. Local examples of this are the pilot service within gynaecology for women with chronic pelvic pain in Durham and Darlington, and the Chronic Pain Service run by Northumbria Healthcare NHS Foundation Trust:

**Gynaecology Service (Durham and Darlington)**

‘Step 1’ is two sessions of psycho-education delivered jointly by gynaecology and psychiatry / psychology. Patients are then offered an 8-session group intervention with a nurse and support worker (Step 2). At the end of this, they are reassessed and either discharged or offered further, more complex treatment (Step 3) such as IAPT, liaison psychology / psychiatry, support worker.

**Chronic Pain Service (Northumbria)**

‘Step 1’ is a half-hour face to face or telephone assessment with a Consultant or Extended Scope Practitioner. This includes a discussion about the biopsychosocial nature of persistent pain. ‘Step 2’ is ‘education and assessment’, delivered as a 90-minute group session, run twice a month, for up to 8 patients. It is facilitated by a physiotherapist and a clinical psychologist. Following this, patients are invited to attend a range of group-based interventions, or less intensive drop-in sessions. Individual psychology and physiotherapy sessions are available if necessary.

Longer term support is offered through a monthly self-management group. Any patients who require more complex interventions are referred back to their GP.
What next?

There is currently a dearth of economic data relating to functional disorders services. A **health needs analysis** needs to be completed to establish the level of need and service provision that would be required. Scottish Data suggests that patients with neurological symptoms alone cost the Scottish healthcare system £11.3 million a year, and in England, patients with medically unexplained symptoms in general cost the health service an estimated **£3bn a year**, with costs to the wider economy amounting to **£18bn a year**.

Commissioners would need to identify the **best geographical location** for this type of service, and decide whether these services be aligned solely with existing neurology services (in Sunderland, Middlesbrough and Newcastle) or whether there needs to be service provision in district general hospital settings, either as stand alone services or based within liaison psychiatry.

Commissioning for **early diagnosis, treatment and management** for patients with functional neurological disorders in the North East should aim to provide **cost effective, patient focused services** where none exist currently. The ideal is that every patient with these disorders in the North East can have access to **timely treatment** and experience minimal disruption to their lives, with a **reduction in cost** to the health service and wider economy as well as an **increase in patient quality of life**.
Resources and Contacts

Symptoms and patient support websites
www.neurosymptoms.org
www.fndhope.org
http://www.nonepilepticattacks.info

Resources for professionals and useful documents
http://www.fnforum.org/

www.myhealthskills.com (Northern Association for Persistent Physical Symptoms group)

British Medical Journal learning module (requires login)

Healthcare Improvement Scotland neurological symptoms report

Scottish Neurological Symptoms report

London Commissioning Model for MUS

Investing in emotional and psychological wellbeing for patients with long term conditions, (section on ‘medically unexplained symptoms’)

Publications from Sheffield Neurology Psychotherapy Service

Northern England Strategic Clinical Networks:
www.nescn.nhs.uk

For more information contact the Northern England Clinical Networks team at:
england.nescn@nhs.net