Stepped care for functional neurological symptoms

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

Report and recommendations

February 2012
The quality of medical care for patients with functional neurological symptoms is variable. Such symptoms make up a common subset of functional disorders in general. The problem is frequent and the patients are disabled by the disorder but medical services are not always well set up to meet the patients’ needs. Doctors find such patients difficult to help, unnecessary medical investigation is common, the cost of managing these patients is high, therapy is often inaccessible, and there is not enough research. Freud’s ideas about this situation stimulated a whole field of thought and therapy, but psychoanalysis has had its day and does not speak to the massive problem we are now facing. In fact, psychoanalysis was so influential that it essentially stopped other lines of investigation. There is now a new interest in the subject in various places around the world, and it is clear that one group of leaders is in Scotland.

The important epidemiological study in Scotland in 2003, the Scottish Neurological Symptoms Study, has carefully identified the nature and extent of the problem. In neurology clinics, one of three new patients has symptoms not explained by identifiable organic disease. An important subgroup of these patients has functional neurological symptoms and comprise 1 in 10 of all neurological patients. Follow-up studies have demonstrated that the diagnosis of a functional disorder can be made with high accuracy. Such patients have similar disability and more distress than patients with organic disease.

Studies in Scotland have also made clear the high cost of functional neurological symptoms. Direct healthcare costs are about £11.3 million, and there is even greater expense due to disability payments and the fact that many of these persons are not at work. In the United States a similar study, dealing with functional symptoms, came to the conclusion that 16% of the US health dollar is spent on patients with these problems.

It makes excellent sense to take a proactive approach to dealing with this. Enter the ‘stepped care programme’ which is proposed in this document. Education is a necessary start. Healthcare workers need to be educated about these symptoms. Physicians have to be able to diagnose these conditions accurately and then convey the diagnosis appropriately to the patients. The next step is treatment. Generally treatment has been unsatisfactory, and the prognosis for these patients has been dismal. Fortunately, a treatment programme for these patients can be designed based on a number of high quality studies performed in Scotland. Explanation of the problem might be enough for some patients. Failing that the next ‘step’ would be an evidence-based, brief, guided, cognitive behavioural self-help programme that has already been proven to have some success. If necessary, a further ‘step’ would be to see an expert for a more intensive programme. Oversight of the whole programme, to maintain organisation and to monitor success, is also sensible.

Accepting the stepped care programme would bring better care to patients, lower costs, and show the rest of the world how to deal with this important problem.

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Rationale for report

In June 2011, a number of healthcare professionals (representing neurologists, psychiatrists, clinical neuropsychologists, clinical psychologists, specialist nurses, AHP’s, service managers, planning and the Neurological Alliance of Scotland) attended a Healthcare Improvement Scotland event in Dundee to discuss how best to help people with functional symptoms referred to neurological services. The event ended with delegates asking for help to identify the size of the problem and for some recommendations for ways to help these patients so that services could respond appropriately. A reference group of neurologists, psychiatrists and clinical neuropsychologists, all with a specialist interest in functional neurological symptoms, was convened to address the issue.

This report provides:
- a description of functional neurological symptoms
- an estimate of the size of the problem in Scotland, and
- some management recommendations that NHS boards may wish to consider in respect of their local position.

The report also highlights that:
- functional symptoms in neurology (sometimes called neurological symptoms unexplained by disease or medically unexplained neurological symptoms) are very common, cause considerable disability and distress, and they are also poorly understood and under-researched, and
- improvements need to be made to the services delivered to people with functional neurological symptoms.

NHS boards, in consultation with the Scottish Government, may wish to consider carrying out a cost benefit analysis on the recommendations included in this report. The Scottish Government is willing to provide advice on how to prepare this and review the findings.

Figure 1: Proposed model of stepped care for functional neurological symptoms as described in this document
Summary of the management recommendations

The following stepped care recommendations are for guidance and are not intended to be prescriptive. There will be many cases where a clinician may wish to take a different approach along an established pathway that is already working well. Also not every patient necessarily has to pass through each step.

We offer suggestions about the principles and resources that should be available locally.

Step 1: Functional neurological symptoms need to be diagnosed and appropriately explained by a neurologist as the first step in successful management

RECOMMENDATION 1

Background: Health professionals’ attitudes and skills relating to patients with functional neurological symptoms vary. Successful communication of the diagnosis and initial management plan is:

- the cornerstone of good clinical practice
- often therapeutically successful in itself, and
- a pre-requisite for successful physical and/or psychological treatment if required.

Recommended: NHS boards to optimise appropriate initial explanation to, and management of, patients by enhancing ongoing education and access to learning resources for neurologists, GPs and allied health professionals likely to be involved in the diagnosis of functional neurological symptoms. 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. An approach could be made to NHS Education for Scotland (NES) to explore this further.

Step 2: Brief and effective treatments can be offered for functional neurological symptoms when explanation alone is unsuccessful

RECOMMENDATION 2

Background: A substantial number of patients will benefit from a brief, low cost intervention from a therapist specifically trained in the treatment of functional neurological symptoms.

Recommended: Provision of brief, guided cognitive behavioural self-help programme delivered by therapists under supervision. Should NHS boards decide to adopt this approach, it should be rigorously evaluated for effectiveness and cost-effectiveness. Innovative approaches using telemedicine may be appropriate, particularly for remote and rural areas. This level of management will be appropriate for patients with moderate disability and mild to moderate anxiety or depression. Some more severely affected patients will have to move directly from Step 1 to Step 3.
Step 3: Services for patients with severe and intractable functional neurological symptoms

RECOMMENDATION 3

**Background:** A considerable number of patients require more complex assessment and treatment from consultant level clinicians. The full range of clinicians with specialist expertise in this area is currently uneven across Scotland.

**Recommended:** NHS boards to maintain and develop existing high quality centres and pathways, while other NHS boards should develop similar services where there are gaps, including consideration of strategies for knowledge transfer.

This level of management will be appropriate for patients who have severe disability and complex co-morbid psychiatric disorder.

A co-ordinated national network to deliver training, care and research

RECOMMENDATION 4

**Background:** Recent developments in disease management have consistently demonstrated that small investments in organisation of care can provide substantial cost savings by helping efficient, timely and appropriate navigation of patients through a network of services.

**Recommended:** NHS boards could develop a national network of locally integrated teams dealing with functional neurological symptoms, led by a senior clinician experienced in both diagnosis and treatment. This network could assist with the supervision of brief therapies and co-ordinate training and education. This network should also be linked to existing research teams and exploit the possibility of routine data collection on all patients, while providing a system for the development and testing of novel therapeutic interventions. Should NHS boards decide to adopt this approach it could be developed into a formal application to the National Services Division (NSD) of NHS National Services Scotland.

We believe our proposals will provide an excellent opportunity for Scotland to build on its world leading reputation in the area of functional neurological symptoms research to create the best possible model of service delivery.
Introduction

The Neurological Health Services Implementation and Improvement Support Programme was established in January 2010 to assist NHS boards to implement the Clinical Standards for Neurological Health Services1.

Criteria 4.4a and 4.4b in the standards relate to providing services to patients with symptoms at the interface between neurology and psychiatry, especially patients presenting with neurological symptoms unexplained by disease, such as paralysis, blackouts and abnormal movements often called functional neurological symptoms. These criteria were considered by NHS boards to be a priority area for improvement support.

Criteria 4.4a The neurology service has access to an integrated neuropsychology and neuropsychiatry service providing a diagnostic and treatment service for patients with neurological symptoms unexplained by disease, and patients with defined neurological disease that have co-morbid psychiatric disorders.

Criteria 4.4b At least 80% of patients referred to this service requiring urgent assessment will have initial contact within 24 hours if referred from inpatient consultation, or within 20 working days if referred from outpatient consultation.

These criteria explicitly refer both to patients with functional neurological symptoms as well as patients with defined neurological disease who have co-morbid psychiatric disorders.

All NHS boards completed a self-evaluation of the standards and many had difficulty meeting these criteria. Indeed only four of 14 NHS boards said that they met the standard for 4.4a and only two for 4.4b. In particular, the ongoing care and management of patients with functional neurological symptoms was identified as one of the priority areas for improvement support by many of the NHS boards.

In June 2011, Healthcare Improvement Scotland hosted a meeting in Dundee specifically to discuss how best to help patients with functional neurological symptoms. The meeting heard that this is a large group of patients with considerable disability and distress, who have potentially treatable symptoms, and yet are not well served by existing neurology, psychiatry, clinical neuropsychology and rehabilitation services. And they are virtually unrepresented by patient organisations. It was clear that NHS boards needed some help with where to start and what to do in order to meet criteria 4.4a and 4.4b and make services more person-centred, safe and effective as reflected within the three quality ambitions of The Healthcare Quality Strategy for NHSScotland. Representatives indicated that it would help to have some guidance about how to improve the quality of services and meet the needs of this patient group.

In this report we summarise what is known of the burden and causes of functional neurological symptoms in adults, highlight problems with current provision, and we make some recommendations – evidence based where possible – for improved services.

Patients with organic neurological disease and co-morbid psychological problems clearly also have significant needs and require a separate strategy, not discussed here. Also we are not considering patients with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS).
What are functional neurological symptoms?

Functional neurological symptoms include amongst others, blackouts, paralysis and abnormal movements which suggest the presence of a neurological disease such as epilepsy, multiple sclerosis or stroke – but are not explained by any neurological disease. They are due to, and can be maintained by, a complex combination of physical, psychological and social influences on brain function (Figure 2).

Figure 2: Functional paralysis (left) and functional movement disorder (right)

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Functional neurological symptoms are sometimes known as ‘psychogenic’, ‘non-organic’ and ‘dissociative’ symptoms. They have also been referred to as ‘neurological symptoms unexplained by disease’. They are classified psychiatrically as ‘conversion’ symptoms. Patients are not imagining or feigning their symptoms which are as real as the symptoms of multiple sclerosis, stroke and epilepsy. Functional imaging studies, which provide a greater understanding of physiological processes within the brain, have helped create an understanding of these symptoms at the interface between neurology and psychiatry (Figure 3).

The stigma attached to the diagnosis has resulted in the virtual absence of patient support groups and, as a result, poorer quality of care. Furthermore, health services are currently not well orientated to deliver effective treatments for these patients even though in the last few years some evidence-based treatments have finally emerged3,4.

Figure 3: Brain scans have helped provide evidence of functional changes in the brains of patients with functional neurological symptoms (functional paralysis right) which are distinct from feigning (feigned paralysis left)5,6

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Olivia’s story
I have been suffering with both localised and general seizures for over 2 years now. I have received no treatment and no support from neurologists. I have been referred to a psychiatric service but will have to wait at least 12 months to be seen. I feel that this problem needs to be more thoroughly publicised. People such as myself have to put vital parts of their lives on hold for years at a time. Due to the severity of my seizures I am unable to drive and my education has suffered. People such as us deserve so much better than we get from the NHS. I have been left feeling alienated and alone. One medical student even told me that I must have epilepsy as dissociative seizures were only found in people with mental disabilities and learning difficulties. At the beginning of my illness I was admitted to hospital and was told that I was dying. I was 18 years old and terrified. A week later I was discharged with no explanation of what was happening. I hope that nobody else is ever subjected to the abysmal treatment that I have received. I am still waiting for a definitive diagnosis of my illness. I would like to thank the author for explaining these problems in an easy to understand format, and for assuring people in this situation that we are not mad and should not feel ashamed of our illnesses.
(Abridged from www.neurosymptoms.org)

The current situation in Scotland appears to be one of patchy service provision, although formal process mapping would help provide a more accurate picture. Effective management requires collaboration between neurology, psychiatry, clinical neuropsychology and rehabilitation services. But too many patients fall between these services, because one service does not necessarily take responsibility for the problem. Not only does this let down patients, but paradoxically it also leads to increased healthcare costs as patients often seek multiple second opinions, and ever more investigations, in an attempt to find an answer to their problems.

By contrast, timely intervention – ranging from simple but transformative advice from a neurologist, who makes the diagnosis, to complex treatments delivered by a multidisciplinary team – could lead to decreased disability and distress for patients. Timely intervention could also lead to an earlier return to work and decreased consumption of health service resources.
The size of the problem

Most people working outside neurological services are astonished when they learn how common functional neurological symptoms are.

Scotland leads the world in the study of these symptoms so we already have accurate and contemporary data. In 2003, a nationwide study of 3,781 patients, the Scottish Neurological Symptoms Study (SNSS), defined the size, extent and cost of the problem7-10. Around one third of new outpatients attending neurology clinics had symptoms rated as ‘not at all’ or only ‘somewhat’ explained by disease (Figure 4). These included patients with functional neurological symptoms (around 1 in 10 of all new outpatients), patients with fatigue or chronic pain (for which other services exist), and primary psychological diagnoses such as anxiety and depression10. As a rough estimate, based on Scottish Neurological Symptoms Study data linked to SMR data, neurologists in Scotland are diagnosing functional neurological symptoms in at least 5,000 people per year10.

Patients with symptoms ‘not at all explained by disease’ reported the same disability, but more distress than patients whose symptoms were ‘completely explained by disease’ (Figure 5). This study has been complemented by a programme of epidemiological research on non-epileptic (dissociative) attacks (Glasgow)11,12 and functional paralysis (Edinburgh)13,14.

Figure 4: One third of new patients attending neurology outpatients have symptoms unexplained by disease

![Pie chart showing one third of patients have symptoms unexplained by disease](data:image/png;base64,)<br>Number of patients with neurological symptoms explained by disease: n=2637<br>Number of patients with neurological symptoms unexplained by disease (functional symptoms): n=1144<br>Data source: Scottish Neurological Symptoms Study

Figure 5: Patients with symptoms unexplained by disease have similar self-rated physical disability but more anxiety and depression than patients with neurological disease

![Bar chart showing disability and anxiety/depression](data:image/png;base64,)<br>Increasing disability<br>Decreasing disability
Data source: Scottish Neurological Symptoms Study
The commonest functional neurological symptoms are:

- **non-epileptic attacks** are where the person suddenly collapses and is unresponsive, often with shaking limb movements that look like an epileptic seizure.

**Helen’s story**

I suffered attacks for 2 years before getting a diagnosis. At the worst of it I was having attacks 5-6 times a month. I would be going about my everyday business and then just suddenly black out, sometimes losing consciousness completely and other times being half conscious being able to hear those around me but unable to respond or move. When I came round I would feel weak, exhausted, dizzy and confused for hours and often I wouldn’t feel well for a few days after the attack.

I became quite withdrawn… I was always nervous that I would black out and felt constantly on edge. I was embarrassed by my attacks and felt guilty when they happened. I was angry with doctors who just continued to tell me we can’t do anything for you, I knew I couldn’t continue to black out like this because it was not simply a problem for me but those around me and my family.

Once I was referred and got the right diagnosis, a huge amount of stress and worry was lifted from me. I no longer had to worry about anything really sinister being responsible for my attacks, I knew that they could at least be managed. I now haven’t had an attack for 4 or 5 months and hardly even think of them very often.

(Abridged from www.neurosymptoms.org)

- **functional weakness/movement disorder** is where one or more limbs are weak or heavy, or conversely move uncontrollably. The patient may limp or drop things; they may look as if they have multiple sclerosis, a stroke or Parkinson’s disease. Pain and fatigue are common accompanying symptoms.

**Hannah’s story**

I have just been diagnosed with a functional movement disorder. At its worst it pulled my head down to my waist. I also had a shaking right hand. The spasms were set off by contact (especially to hands and feet) and loud noises. I also had two episodes where I had flailing arms, like I was playing the drums. I’ve been lucky in that I haven’t had any pain, but it has been very debilitating and I’ve had three and half months off work, and for a month of that I didn’t really leave my flat. My GP and Professor of Neurology could not tell me what was wrong, which was very scary. In the end it was a neuropsychiatrist who gave me the diagnosis. I’ve discovered that I hold tension in my muscles and skeleton which has played a factor in my problems. So, a combination of physical and emotional treatments has really worked.

(Abridged from www.neurosymptoms.org)
Data collected in Scotland have also shown the following.

- Non-epileptic attacks account for 1 in 7 referrals to a first fit clinic, and up to 50% of patients brought to hospital with suspected ‘status epilepticus’. Patients often mistakenly end up with treatment for epilepsy including ITU admission for ‘status epilepticus’\textsuperscript{15}.

- Functional weakness is at least as common as multiple sclerosis\textsuperscript{13}. Moreover, a follow-up study showed that 12 years after diagnosis, one third of patients were medically retired and levels of disability were comparable to a group of patients with multiple sclerosis of similar duration\textsuperscript{16}.

- Patients with functional neurological symptoms have high rates of other physical and psychological symptoms especially pain, fatigue, poor memory and concentration, gastrointestinal symptoms, anxiety, panic and depression\textsuperscript{13}. Indeed, functional symptoms are not confined to neurology but are a significant problem in many other specialties (for example, irritable bowel syndrome and chest pain with normal coronary arteries). Not surprisingly, many of these patients are referred to multiple specialties\textsuperscript{17}. Patients may have chronic fluctuating symptoms or be unable to improve with optimal management. But even then, greater understanding can improve health related quality of life (See Sarah’s story on page 16).
The economic impact of functional neurological symptoms

People typically develop functional neurological symptoms in their twenties and thirties, i.e., working age. The Scottish Neurological Symptoms Study found that 27% of patients with symptoms unexplained by disease were not working for health reasons, incurring high social costs as well as a high consumption of healthcare estimated as approximately:

- £1.3 million per year for outpatients,
- £6.01 million for inpatients (including 13,887 bed days), and
- £4.01 million for primary care.

They were also very likely to be receiving disability benefits; indeed, a higher proportion were not working and receiving benefits. In comparison, over half of patients whose symptoms were explained by disease were working (Figure 6). There is clearly a spectrum of severity, as there is for other neurological conditions.

Figure 6: Patients with functional neurological symptoms are often not working and many receive disability benefits because of ill health

However, with appropriate explanation and treatment, substantial cost savings may be made. For example, a study of 260 patients with non-epileptic attacks in Glasgow demonstrated that 50% of patients were using emergency services on a regular basis before diagnosis. After diagnosis, that figure dropped to 18%.

Another study of patients with non-epileptic attacks found that in the 6 months after diagnosis, total seizure-related medical costs dropped by 84%.

Many patients with functional neurological symptoms have other physical symptoms that lead to investigation as well as treatment that may be unnecessary. Therefore, it is likely that more effective treatment will have benefits over and above those to do with their functional neurological symptoms.
Stepped Care for Functional Neurological Symptoms: A new approach to improving outcomes for a common neurological problem in Scotland

Management recommendations

The following stepped care recommendations are for guidance and are not intended to be prescriptive. There will be many cases where a clinician may wish to take a different approach along an established pathway that is already working well. Also not every patient necessarily has to pass through each step.

We make suggestions about the principles and resources that should be available locally.

Step 1: Functional neurological symptoms need to be diagnosed and appropriately explained by a neurologist as the first step in successful management

A commonly asked question is ‘If patients have no neurological disease, why do they need to see a neurologist at all?’ The answer is because making the diagnosis of functional neurological symptoms is far from easy and requires knowledge and skills typically possessed by a neurologist. GPs in Scotland have understandable uncertainty in this field and rarely make this diagnosis with confidence unassisted.

The diagnosis is based primarily on the demonstration of physical features typical of a functional disorder, and secondly on the absence of any evidence of recognisable neurological disease on assessment or investigation. Unless the investigations demonstrate an incidental finding which often requires considerable experience to interpret in the light of the patient’s symptoms, they are usually normal - but the patient is not.

For example, non-epileptic attacks are best diagnosed by inducing a typical attack while undergoing EEG (electroencephalogram) monitoring. Functional weakness and movement disorder are diagnosed using positive signs of inconsistency of limb weakness such as Hoover’s sign or the tremor entrainment test (Figure 7). This combination of clinical knowledge and specific positive signs leads to an accurate and stable diagnosis of functional neurological symptoms. In the Scottish Neurological Symptoms Study, out of 1,144 patients with ‘symptoms unexplained by disease’, a diagnostic error emerged in only four patients after 18 months of follow-up. This is lower than for many other neurological conditions.

Figure 7: Functional neurological symptoms are diagnosed on the basis of positive clinical signs, typically by a neurologist, for example Hoover’s sign.

Test hip extension - hip extension is weak

Test contralateral hip flexion against resistance - hip extension has become strong

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Neurologists can help many patients improve without the need for further treatment

Because they can make the diagnosis with confidence, neurologists are in a key position to provide a therapeutic explanation for patients with functional neurological symptoms and signpost sources of self-help. For example, a study of 260 patients given a diagnosis of non-epileptic attacks in Glasgow showed that at 12 months follow-up, 38% of patients had stopped having attacks following a single consultation in which the neurologist carefully explained the diagnosis to them\textsuperscript{11}. Simple communication strategies during a neurological consultation can result in a marked increase in patient satisfaction and outcome. These include the following.

- The doctor making it clear that they believe the patient’s symptoms.
- Emphasising that the patients have something recognisable, common and reversible.
- Explaining the reasoning behind the diagnosis.
- Copying the clinic letter to the patient in many if not most cases.
- Providing sources of self-help information such as leaflets and website addresses.
- Explaining sensitively the rationale for referral to psychology or physiotherapy if appropriate.
- Using additional time to carry out the above, typically 45 minutes compared to the standard 30 minute new patient consultation. As with other complex consultations, neurologists hope that varying case mix in their clinics allow other consultations to be quicker, but this is not always the case.
- Seeing the patient for at least one follow-up visit to answer further questions.

In recent years, free online self-help information has been developed for these patients. The website www.neurosymptoms.org developed in Edinburgh in 2009 provides information on the whole range of functional neurological symptoms and now receives 10,000 visits a month. And www.nonepilepticattacks.info developed in Sheffield was created in 2011 (Figure 8).

Figure 8: Free online self-help material for patients with functional neurological symptoms has become available on the web in the last 3 years

www.neurosymptoms.org    www.nonepilepticattacks.info

There is good evidence that many patients with functional neurological symptoms commonly feel ‘disbelieved’ by neurologists\textsuperscript{21} and are understandably angry if they think their symptoms are not being taken seriously. If the diagnostic explanation is handled badly, many patients will look elsewhere for a diagnosis consuming further resources in second opinions and unnecessary additional investigations. Not surprisingly, this series of events is associated with a worse overall outcome\textsuperscript{22} as it is rarely possible for patients to engage with any treatment while they remain preoccupied with the lack of a diagnosis. It is simply no good being told ‘you don’t have any serious disease’ without further explanation. Patients want to know what they have got, not what they have not got.
Neurologists and related services must shoulder some of the responsibility for this state of affairs. However, other clinicians must also play their role. A clear diagnostic message can be ruined if another clinician dismisses the diagnosis and suggests further tests because of their lack of understanding of the problem. Or, concludes there is no role for psychological treatments. It is imperative that training is broad enough to include all services involved in a patient’s journey so that the advice they get is both authoritative and consistent.

Considerable improvements in this area have already taken place in the last 10 years. This is especially the case in Scotland, in part probably because all neurologists in the four regional centres took part in the Scottish Neurological Symptoms Study. In addition, the maintenance of world class centres of research excellence in non-epileptic attacks (Glasgow) and functional motor symptoms (Edinburgh) has driven up standards among general neurologists. However, more improvements are possible by continuing education and training, and crucially by continuing Scotland-wide research into the problem. Education also needs to be taken to GPs, medical students, allied health professionals and nursing staff. Much of this education is already taking place, but the proposed network would formalise it and ensure it reaches all parts of Scotland.

**RECOMMENDATION 1**

**Background:** Health professionals' attitudes and skills relating to patients with functional neurological symptoms vary. Successful communication of the diagnosis and initial management plan is:

- the cornerstone of good clinical practice
- often therapeutically successful in itself, and
- a pre-requisite for successful physical and/or psychological treatment if required.

**Recommended:** NHS boards to optimise appropriate initial explanation to, and management of, patients by enhancing ongoing education and access to learning resources for neurologists, GPs and allied health professionals likely to be involved in the diagnosis of functional neurological symptoms. 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. An approach could be made to NHS Education for Scotland (NES) to explore this further.

**Step 2: Brief and effective treatments can be offered for functional neurological symptoms when explanation alone is unsuccessful**

Appropriate treatments depend on the nature and severity of the symptom. For mild symptoms, a careful explanation combined with information on self-help is often sufficient. But some patients with physical disability will also need physiotherapy or occupational therapy which is likely to be more effective if the therapist is familiar with functional symptoms. Some patients require psychological assessment to understand problems associated with their physical symptoms, to identify what factors maintain the symptoms and what factors need to be addressed by therapy to allow recovery.

**Generic services are ill equipped to deal with patients with functional neurological symptoms**

Service providers may well wonder why these treatments cannot simply be provided by the rehabilitation, psychology and psychiatry services currently in place. The problem is that so many of these services are unsure how to proceed with patients who have functional neurological symptoms, and they may even unwittingly make the situation worse because of lack of familiarity and appropriate training. For example, a physiotherapist seeing a patient with functional weakness of one leg who is not familiar with how the diagnosis is made may shake the patients confidence by suggesting that some kind of nerve damage may be present after all. Or some psychiatrists, sent a patient with non-epileptic attacks who has no evidence of anxiety and depression, may sometimes wonder what they are supposed to do because this situation was not well covered in their training. Other professional groups have similar problems.
Cognitive behavioural therapy (CBT) is an evidence-based treatment for a range of physical symptom syndromes and psychological disorders. It aims to collaboratively achieve changes in thought and action that result in relief of the symptoms. It is traditionally conducted as multiple one hour sessions in which the patient and therapist discuss the patient's symptoms, thoughts, emotions and behaviour. The patient is also required to keep written records of these and to carry out ‘homework’ during which they observe the effects of changing their behaviour. However, there are real practical difficulties in providing the typical 15–20 one hour sessions for every patient. Therefore, whilst effective, the impracticality of delivery usually results in either recruitment of unskilled practitioners (and loss of effectiveness) or lengthy waiting lists (and no access to treatment).

In an attempt to overcome this problem, the Symptom Management Research Trial (SMART) in Neurology aimed to distil CBT into a more time efficient form of therapy using a therapy manual and 4 x 30 minutes of therapy time to guide patients through it. This model was tested in a randomised controlled trial in new neurology patients in Glasgow and Edinburgh. The two therapists had nursing or psychology backgrounds. The therapy manual was designed to help patients gain a better understanding of their functional neurological symptoms and how these symptoms were arising in their body. There were exercises and ‘homework’ for the patients to complete between sessions. During the sessions the therapists could go over the material, dealing with questions arising and making further suggestions for changes in behaviour at home.

The patients recruited into the trial were more disabled than the typical patient with functional neurological symptoms in SNSS. One third had experienced their symptoms for more than 5 years and 45% were not working. However, there were clear benefits after treatment. Their presenting symptoms were significantly better at 3 and 6 months and their overall physical function was better at 6 months. Overall there was a 13% absolute difference in the numbers of patients who were ‘better’ or ‘much better’. This is an impressive result given the severity and duration of the symptoms and the brevity (and low cost) of the treatment.

This evidence suggests that a substantial number of patients would benefit from a brief and low cost, low intensity – but individually tailored – therapeutic intervention from a therapist specifically trained in the treatment of functional neurological symptoms. This creates an opportunity to provide a service to patients who currently do not have access to beneficial treatment, but have substantial disability and who are consuming unnecessary NHS resources in a largely fruitless search for help. However, it is well recognised that the routine implementation of research proven brief therapies often fails owing to a lack of a similar level of high quality supervision compared with the original trials. Therefore, the therapists should be under the supervision of a senior clinician within a national supporting framework to standardise delivery, and evaluate the outcomes, both in terms of effectiveness and cost-effectiveness.

**RECOMMENDATION 2**

**Background:** A substantial number of patients will benefit from a brief, low cost intervention from a therapist specifically trained in the treatment of functional neurological symptoms.

**Recommended:** Provision of brief, guided cognitive behavioural self-help programme delivered by therapists under supervision. Should NHS boards decide to adopt this approach, it should be rigorously evaluated for effectiveness and cost-effectiveness. Innovative approaches using telemedicine may be appropriate, particularly for remote and rural areas. This level of management will be appropriate for patients with moderate disability and mild to moderate anxiety or depression. Some more severely affected patients will have to move directly from Step 1 to Step 3.
Step 3: Services for patients with severe and intractable functional neurological symptoms

Like all common illnesses, functional neurological symptoms occur in a range of severities. The brief interventions above will offer timely treatment for many patients with less severe presentations, but may not be adequate to help those patients who are more severely affected. Therefore, a range of approaches is commonly needed and will involve more intensive psychological interventions and often medication as well. Therapies are not just targeted at the functional symptoms, but additional co-morbid mood disorders, and, in some of the very severe cases, at the effects of multiple psychological traumas, abuse and neglect experiences. Additionally, patients commonly develop secondary physical problems from disuse of limbs, so specialised physiotherapy and occupational therapy may become essential. Furthermore we emphasise that it is the expertise of the individual health professional in functional neurological symptoms that is most important for management (rather than their exact discipline).

Some common psychological therapies used to facilitate change are:

- further education and explanation of the physiological and psychological nature of the diagnosis when appropriate
- narrative approaches to help people acknowledge and consider how any upset or trauma might relate to their symptoms
- assessment and treatment of any accompanying anxiety, depression and an explanation how neurological symptoms like weakness or blackouts relate to other chronic symptoms such as fatigue and pain
- cognitive behaviour approaches aimed at changing reactions to symptoms by modifying beliefs and behaviour about symptoms
- mindfulness and relaxation training, acceptance and commitment therapy, positive psychology approaches aimed at personal empowerment and self-development during multidisciplinary rehabilitation, and
- specific treatments – for example cognitive distraction techniques for non-epileptic attacks.

A particular challenge is that a small number of the most severely affected patients persistently seek help for their symptoms, but are paradoxically unable to engage with treatments and develop a relationship with healthcare providers. This can be time consuming yet unproductive for NHS services. Other patients do engage with the best possible treatments available, but despite everyone’s best efforts do not improve.

Sarah’s story

in my late teens I was diagnosed with irritable bowel syndrome, more recently, four years ago, age 28 I was finally diagnosed with functional weakness. Over the next six months I was sleeping better, my pain was more manageable and I tried to do some extra walking. When I returned to see my neurologist I managed to walk in on my two elbow crutches. I had a major set back one day I woke up and every joint in my body was screaming in pain, it felt like someone was rubbing them together with sand. Then I developed more gastrointestinal symptoms and the doctors ended up taking my appendix out. Last year I was made medically retired. I still feel like I am back at square one, I am having extra pain in my lower back. I have now been given a walker with a seat for use indoors but I still need my wheelchair for outside. In the past six years I have visited a number of doctors who don’t understand this condition. I have learnt now to hold my tongue and to let it wash over me, I hasten to add this would not be possible for me had I not been introduced to my neurologist, who was able to put this all into perspective for me. No one can really foresee the future. I just hope I have the strength to confront it.

(Abridged from www.neurosymptoms.org)
Many different health professionals should be involved with an ‘integrated neuropsychiatry and clinical neuropsychology service’ described and aspired to in the standards.

**Neurologists** work in all NHS boards except the island NHS boards. Although capacity means that additional patients are still seen on waiting list initiatives in some areas, patients can usually access a neurologist within 12 weeks of referral from primary care. There are centres of research excellence in Glasgow for non-epileptic attacks (where there has been a comprehensive treatment service for over 10 years) and in Edinburgh for functional weakness.

**Neuroscience nurses** working in neuroscience units play an important positive role in the treatment of neuroscience inpatients. Around 5–10% of all neuroscience inpatients at any one time have a functional neurological symptom which accounts for their admission. It might be a patient admitted for investigation of leg paralysis or a patient having videotelemetry because of non-epileptic attacks.

**Liaison psychiatrists and neuropsychiatrists** have skills in carrying out the complex assessments that some patients with functional neurological symptoms require. They supervise medication and psychological therapies and have particular skills in the management of patients through and between healthcare systems. It is widely acknowledged that general adult psychiatrists generally do not possess these skills. However, provision of liaison psychiatry is patchy, with some areas adequately provided for and others having no liaison psychiatry service at all. At the same time, liaison psychiatry is under pressure to deliver a service to the whole hospital, including timely assessment of deliberate self-harm, which can lead to patients with functional neurological symptoms receiving a low priority.

**Clinical neuropsychologists** have skills in carrying out the complex psychological assessments that some patients with functional symptoms require in order to make headway with treatment. They are skilled in carrying out psychological therapies for a range of problems. Clinical neuropsychologists first qualify as clinical psychologists, then specialise in working with neurological symptoms and disease. However, some health or clinical psychologists may be experienced or working within a team specialising in the assessment and treatment of neurological symptoms. This experience and supervision would enable them to effectively work with neurological medically unexplained symptoms. However, demand for the opinion of a clinical neuropsychologist is high and yet the resource is very scarce. Some NHS boards have no clinical neuropsychology service; others have designated neuroscience services which do not have the capacity to provide treatment for patients with functional neurological symptoms.

**Rehabilitation services** include rehabilitation physicians, occupational therapists, physiotherapists and speech and language therapists. Although many rehabilitation services are willing to engage with patients with functional neurological symptoms, some are not because, for example, their services are for patients with physical disease. And they may be concerned that they could ‘reinforce’ the patient’s disability and make matters worse. There is no evidence that this happens any more often in patients with functional disorders than patients with organic disease. Anecdotally, patients may do very well with community rehabilitation or inpatient rehabilitation.

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**RECOMMENDATION 3**

**Background:** A considerable number of patients require more complex assessment and treatment from consultant level clinicians. The full range of clinicians with specialist expertise in this area is currently uneven across Scotland.

**Recommended:** NHS boards to maintain and develop existing high quality centres and pathways, while other NHS boards should develop similar services where there are gaps, including consideration of strategies for knowledge transfer. This level of management will be appropriate for patients who have severe disability and complex co-morbid psychiatric disorder.
A co-ordinated national network to deliver training, care and research

What we have described for the management of functional neurological symptoms is a model of ‘stepped care’ where a patient’s pathway through the system is monitored and progressed on the basis of their level of need and routine outcome monitoring. However, a stepped care model should not be set in stone. It should be an iterative process responding to its own outcome data, and novel developments both within its system and externally.

Critically it is important to recognise that well-established local services are central to the delivery of care. However, there are distinct advantages to all local services working together to optimise efficiency, standardise approaches and prevent duplication of effort. To achieve this, we propose a clinical network of identified existing specialists described in Recommendation 3.

The network should be led by a senior clinician with adequate protected time and with experience in both the diagnostic evaluation of patients and the delivery of therapy.

The lead clinician would take the responsibility for the following.

- Co-ordinating training and producing training materials on medical diagnosis, psychotherapeutic assessment and treatment.
- Overseeing the training and contributing to supervision of the therapists in collaboration with local clinicians involved in Recommendation 2. Importantly we are not suggesting a centralised service here, but instead that local supervision is supplemented by a national programme which will be of benefit to the therapists themselves in sharing and learning about these patients.
- Knowledge dissemination to NHS boards, including more direct supervision of Step 2 in NHS boards where expertise is lacking.
- Co-ordinating and developing pathways for patients through the system as experience develops.
- Co-ordinating the collection, monitoring and reporting of routine outcome data.

Additional roles for the network would be to look at the use of developing technologies both for care delivery, for example telemedicine and web-based therapy, and also for the potential for collection of routine outcome data using available electronic technology such as short message service (SMS) and other forms of e-data transfer.

Finally, the network would link to University groups for scientific exploitation of routine data and the testing of novel interventions, both psychological and pharmacological.

In all this, the need for local and regional services would not in anyway be diminished, rather they would be linked together and enhanced through the proposed network.

The National Services Division (NSD) should be approached about the governance of the network.

RECOMMENDATION 4

**Background:** Recent developments in disease management have consistently demonstrated that small investments in organisation of care can provide substantial cost savings by helping efficient, timely and appropriate navigation of patients through a network of services.

**Recommended:** NHS boards could develop a national network of locally integrated teams dealing with functional neurological symptoms, led by a senior clinician experienced in both diagnosis and treatment. This network could assist with the supervision of brief therapies and co-ordinate training and education. This network should also be linked to existing research teams and exploit the possibility of routine data collection on all patients, while providing a system for the development and testing of novel therapeutic interventions. Should NHS boards decide to adopt this approach it could be developed into a formal application to the National Services Division (NSD) of NHS National Services Scotland.
Implications for training

Existing consultant neurologists will need some training and explanation about the proposed model. For example, the best way to explain the diagnosis to fit the model and so avoid making matters worse, furthermore who and when to refer. Some may need to be reassured about their diagnostic competence in this area, and encouraged to limit investigations and physical interventions (as do consultants in other specialties who see functional patients).

Trainee neurologists should already have some training in this area, particularly in Scotland where it is a specific part of their curriculum. In addition, they could take on two or three cases for brief CBT under close supervision. Although potentially a little alien they would find it invaluable in their general neurology practice (ie dealing with psychiatric co-morbidities in other patients such as those with multiple sclerosis) and not just in this area.

For medical students, functional problems in general, not just in neurology, should appear on their curriculum. They already should have training in the management of depression and anxiety.

Liaison psychiatrists and their trainees will also need training sessions. Although they should be well versed in treatment strategies, some may need higher level training in the latest developments. Many may also wish to develop basic levels skills in neurological diagnosis in this field.

Clinical neuropsychologists now get some formal training at both undergraduate and postgraduate level but this may need to be reviewed.

Other clinicians likely to be involved in the management of these patients should also have some training in the area, for example physiotherapists, occupational therapists, neurology nurses.

This training could be delivered by the clinical network described above, perhaps in co-operation with NHS Education for Scotland.

Figure 1: Proposed model of stepped care for functional neurological symptoms as described in this document
Additional considerations

Provision for remote areas

Treatment for patients living in remote and rural areas could be facilitated by telephone or telemedicine. For example, currently patients with non-epileptic attacks in the Western Isles are managed by neurologists and clinical neuropsychologists from Glasgow using telemedicine.

Involvement of patient support groups

A small charity for patients with non-epileptic attack disorder, the NEAD Trust, was established in Sheffield in 2009. There are no current support groups for patients with other functional neurological symptoms. There needs to be a patient support group in Scotland.

Managers

Managers need to be made aware, if they are not already, that this is a shared problem between psychiatry, clinical neuropsychology and neurology. It should not be ignored or denied, but incorporated into the job plans of neurologists, clinical neuropsychologists and liaison psychiatrists. Working with functional patients is not the same as managing patients with ‘conventional’ psychiatric diagnoses such as depression and anxiety. Although the skill sets overlap, there are fundamental differences.

Guidance for GPs

There must be up-to-date guidance for GPs outlining good practice, explaining the therapeutic model, with the aim of patients being offered consistent diagnosis, explanation and management across primary and secondary care.

Cost

We have not attempted an economic analysis of the effects of our proposals because there are no available economic data on outcomes with and without treatment. Clearly the cost of Recommendation 1 would be very low, whereas the cost of Recommendation 3 would be higher. To what extent these costs would be offset by improved patient outcomes, reduction in hospital consultations and bed days, as well as investigations, is unknown and should be the subject of further study.

NHS boards, in consultation with the Scottish Government, may wish to consider carrying out a cost benefit analysis on the recommendations included in this report. The Scottish Government is willing to provide advice on how to prepare this and review the findings.
References

1 Neurological Health Services: Clinical Standards. Edinburgh: NHS Quality Improvement Scotland; 2009.
The functional neurological symptoms reference group

Remit of the group
1. To more clearly identify the size of the problem in relation to patients with functional patients referred to neurology.
2. Provide recommendations to NHS boards, based on evidence of best practice, for a strategic way forward, on how to improve the management of patients referred to neurological services with functional symptoms.

Objectives
1. Agree three to five recommendations related to how NHS boards should improve the management of patients referred to neurological services with functional symptoms.
2. Prepare a report justifying the need for improvements for patients referred to neurology with functional symptoms, and recommendations for actions required to be published early 2012. This report to be sent to Scottish Government and all NHS boards.

Accountability
The reference group was accountable to the Healthcare Improvement Scotland Neurological Services Advisory Group. It had no executive powers other than those specifically delegated in these terms of reference.

Membership
- The reference group was chaired by Professor Charles Warlow, Healthcare Improvement Scotland Clinical Advisor for Neurology.
- The core membership was drawn from the neuropsychiatry and clinical neuropsychology services project group, many of whom were part of the clinical standards for neurological health services project group which developed the standards.
- Membership has also sought to ensure representation from the four regional neurology centres in NHSScotland.

Members of the group

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The following organisations were not directly represented on the group, but were consulted with during the development of the report:

- AHP Leads
- Association of British Neurologists
- Division of Clinical Neuropsychology, Scotland
- Heads of Psychological Services, Scotland
- Neurology Advisor to Scottish Government
- Neurological Alliance of Scotland
- Royal College of General Practitioners
- Royal College of Psychiatrists
- Royal College of Physicians, Edinburgh
- Scottish Government.
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The Healthcare Environment Inspectorate, the Scottish Health Council, the Scottish Health Technologies Group, and the Scottish Intercollegiate Guidelines Network (SIGN) are key components of our organisation.

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