

Occupational Therapy Consensus Recommendations for Functional Neurological Disorder (Long Version)

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ABSTRACT

Background People with functional neurological disorder (FND) are commonly seen by occupational therapists; however, there are limited descriptions in the literature about the type of interventions that are likely to be helpful. This document aims to address this issue by providing consensus recommendations for occupational therapy assessment and intervention.

Methods The recommendations were developed in 4 stages. Stage 1: an invitation was sent to occupational therapists with expertise in FND in different countries to complete two surveys exploring their opinions regarding best practice for assessment and interventions for FND. Stage 2: a face to face meeting of multidisciplinary clinical experts in FND discussed and debated the data from stage 1, aiming to achieve consensus on each issue. Stage 3: recommendations based on the meeting were drafted. Stage 4: successive drafts of recommendations were circulated among the multidisciplinary group until consensus was achieved.

Results We recommend that occupational therapy treatment for FND is based on a biopsychosocial aetiological framework. Education, rehabilitation within functional activity and the use of taught self-management strategies are central to occupational therapy intervention for FND. Several aspects of occupational therapy for FND are distinct from therapy for other neurological conditions. Examples to illustrate the recommendations are included within this document.

Conclusions Occupational therapists have an integral role in the multidisciplinary management of people with FND. This document forms a starting point for research aiming to develop evidence-based occupational therapy interventions for people with FND.

and seizure-like events (commonly known as dissociative seizures or non-epileptic seizures). Fatigue and persistent pain are also commonly experienced as part of the disorder. Symptoms can present acutely and resolve quickly or can be long lasting. Regardless of duration, those affected frequently experience high levels of distress, disability, unemployment, social care utilisation and reduced quality of life.² The stigma associated with FND contributes to the burden of the diagnosis.³

Occupational therapy (OT) is generally recognised as an integral part of multidisciplinary rehabilitation for people with FND. As a therapy, it has face validity for FND; however, there is little published evidence to support its efficacy, and there are few published descriptions of interventions to guide practice.⁴⁻⁵ Given that FND differs in a number of important ways from other neurological conditions, typical OT neurorehabilitation strategies may not be directly translatable to people with FND and a more specific approach may be required.

The current evidence base for OT in FND rehabilitation is limited to several studies of multidisciplinary rehabilitation,⁶⁻⁹ including one with a randomised design.¹⁰ The interventions delivered by OTs in these studies are described only briefly; they include: retraining normal movement within function, graded reintroduction to daily activities, anxiety management and the re-establishment of structure and routine. Outcomes from these studies are promising, reporting improvement in scales of physical function and quality of life, immediately after treatment and at follow up periods of 12 to 25 months.^{7-9, 11} High levels of patient acceptability have been shown in at least one study that identified that OT compared favourably with other treatments.⁹ Evidence from randomised control trials is needed to demonstrate effectiveness of the specific rehabilitation interventions described in these studies.

In summary, OT is recognised as part of MDT intervention for FND; however, there is a limited evidence base, and the role of OT within the MDT is not well defined. With this paper, we aim to develop a broad set of consensus recommendations to guide OT practice for people with FND across the range of clinical settings (hospital, rehabilitation ward and community) and time following symptom onset (acute to chronic). These recommendations come from our experience working with people with FND aged 16 years and over; however, recommendations may have transferability to adolescent and paediatric populations. This work aims to complement existing

INTRODUCTION

Occupational therapists (OTs) assist people with physical and mental health difficulties across the lifespan to enable participation in daily activities. OTs are dually trained in physical and mental health rehabilitation. This skill set combined with a focus on function rather than impairment makes OTs ideally suited to help people with functional neurological disorder (FND).

FND is characterised by symptoms of altered voluntary motor or sensory function with clinical findings providing evidence of incompatibility between the symptoms and recognised neurological or medical conditions.¹ Symptoms are diverse and can include weakness, movement disorders (tremor, jerks, dystonia), sensory symptoms, cognitive deficits



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clinical recommendations for FND^{12,13} and to form a starting point from which to develop evidence-based interventions.

METHODS

Consensus Process

Data collection and analysis was based on a Delphi method, with 4 key stages. Stage 1: in 2017/18, 12 OTs from different countries with extensive experience in FND were invited to complete two online surveys exploring assessment and interventions for FND. The surveys were developed, data collated and summarised (by CN). Elaboration and clarification were sought through a series of follow-up emails.

Stage 2: the expert OT group, together with experts in FND from other clinical disciplines were invited to take part in a face-to-face meeting in Edinburgh, UK, in September 2018. The collated data from stage 1 was discussed and debated.

Stage 3: recommendations based on the meeting were drafted.

Stage 4: a series of drafts were sent to the multidisciplinary group for feedback. Participants either endorsed each section of the draft or provided comments and suggestions. This process continued until a consensus was reached.

Participants

Occupational therapists

The group represented OTs from three nations: England (n=7), Scotland (n=3), and the USA (n=2) who work with people with FND in a variety of clinical settings: acute neurological in-patients, neurological outpatients, neurological community rehabilitation, neuropsychiatry outpatients, neuropsychiatry inpatients, community mental health and accident and emergency. Participants had between 10 and 23 years (mean=17; SD=14) of postgraduate experience.

Multidisciplinary clinician group

There were representatives from neuropsychiatry (n=1), neurology (n=2), neurophysiotherapy (n=2) and neuropsychology (n=1). There was also service user (patient and public) representation (n=2).

All clinicians attended the meeting, except the OTs from the USA (who participated via Skype) and the neuropsychologist.

Conceptualisation of FND / aetiological model

The group's consensus on the definition and conceptual understanding of the diagnosis of FND was as follows: FND is a diagnosis that exists at the interface between neurology and psychiatry and is a genuine cause of disability due to motor and non-motor symptoms. Within the patient population, there is considerable heterogeneity in terms of symptom presentation, disability and psychiatric comorbidity. The aetiology is best understood within a biopsychosocial framework, considering predisposing, precipitating and perpetuating factors, each of which can include biological, psychological and/or social events (See table 1 below).

The motor symptoms of FND can be considered, at one level, as abnormal patterns of movement, that are 'driven' by involuntary self-focused attention. Thus, when the person's attention is redirected away from their body (distraction), abnormal movement reduces or disappears. Non-motor symptoms, including sensory changes, are also likely to be similarly affected by unconscious, self-focused attention.

People with FND commonly experience other health problems; this can include psychiatric comorbidity, coexisting neurological disease and other functional symptoms. Common

coexisting symptoms such as chronic pain and fatigue are often important determinants of disability and quality of life.^{14,15}

Role and rationale for OT for FND

The term 'occupational' in OT refers to any activity that has meaning and importance to an individual, based on what they need to do, want to do or are expected to do within societal and cultural norms.¹⁷

Common Reasons to refer to occupational therapy:

- ▶ Disability affecting participation in daily activities (eg, personal care, domestic activities, childcare, community or leisure activities).
- ▶ Determining care needs for people with disability.
- ▶ Difficulty accessing home, education, work or community environments.
- ▶ Vocational rehabilitation and support to sustain paid employment, education, voluntary roles.
- ▶ Pain, fatigue, mental health and cognitive difficulties which impede activity engagement.

When and how to refer to OT

OTs can be involved from symptom onset to support in the community. It is preferable that a physician makes and explains the diagnosis to the patient prior to referring for treatment.^{18,19} We suggest sharing clinical consultation letters with the treating therapy team and the patient. A referral letter should include information such as the diagnosis, assessment findings, results from medical investigations, follow up plans, other professionals involved and reason for referral.

Different factors may influence the suitability for treatment. For example, ongoing investigations and litigation can negatively impact a person's ability to engage with rehabilitation. In some cases, it may be appropriate to hold off on treatment until such issues have been resolved. However, given that symptom chronicity can affect functional outcomes we would caution against unnecessarily delaying treatment.

The group suggest that OT intervention is more likely to be successful if the person with FND:

- ▶ Has some degree of understanding and agreement with the diagnosis.
- ▶ Has agreed to the referral.
- ▶ Can identify rehabilitation goals or areas of need and are motivated to make changes.
- ▶ Has an understanding that the initial focus of OT is to improve function and therefore is unlikely to include provision of aids and adaptations.

It is not uncommon for people to lack confidence in the diagnosis of FND. Through providing education about the diagnosis at a level that is accessible to the patient, OT can help to turn around low diagnostic confidence. In instances where there is still doubt, we would suggest that OT can still be of benefit by focusing on the impact of symptoms on function rather than addressing symptoms at a diagnostic or impairment level. However, where there is strong disagreement about the diagnosis, therapy is much less likely to be helpful.

Assessment and outcome measurement

OT assessment for people with FND is usually undertaken over a number of sessions. Taking time to listen to the person and explore the impact of their symptoms is key to developing a positive therapeutic relationship, as well as understanding their rehabilitation needs. The following structure may be useful to guide an initial assessment:

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Table 1 Potential predisposing, precipitating and perpetuating factors for FND (adapted from Stone, 2009¹⁶)

Factors	Biological	Psychological	Social
Predisposing vulnerabilities	Illness and disease. History of previous functional symptoms.	Personality traits. Poor attachment / coping style. Emotional disorder.	Adverse life events or stressors. Childhood neglect. Difficulties in interpersonal relationships. Symptom modelling. Financial difficulties /deprivation.
Precipitating mechanisms	Physical injury or state (eg, drug side effect). Abnormal physiological event (eg, hyperventilation and sleep paralysis).	Panic attack. Perception of life event as traumatic/negative.	Adverse life events or stressors.
Perpetuating factors	Plasticity in sensory and motor pathways leading to abnormal movement patterns. De-conditioning. Fatigue. Chronic pain.	Illness beliefs (person and significant others). Feeling disbelieved. Maladaptive behaviours. Co-morbidities including anxiety and depression.	Diagnostic uncertainty (eg, ongoing medical investigations). Reliance on care and benefits. Compensation claims. Ongoing social stressors (eg, relationship difficulties, financial hardship and loss of roles).

1. Ask the person about when and how their symptoms started.
2. Create a list of current symptoms. For each symptom, ask about exacerbating and easing factors, variability, severity and the impact on function.
3. Clarify the person's understanding of their diagnosis and whether they are in agreement with it.
4. Ask about other health problems and past medical history (including psychological health).
5. Take a detailed social history, exploring usual roles, responsibilities and meaningful activities.
6. Gain a picture of their 24-hour routine. This is helpful to uncover symptom perpetuating factors such as poor sleep hygiene, boom and bust activity patterns, lack of occupation and structure.
7. Determine if they have care needs, and if so, are these needs being met and by whom?
8. Ask about access to the home, education or work environment and the use of environmental adaptations and aids.
9. If they are in work or education, ask about the impact of their symptoms. If unemployed or retired, it may be appropriate to ask about receipt of benefits / insurance.
10. Undertake an observation of daily activities (e.g. personal care, meal preparation, functional transfers) to establish the impact of symptoms on activity engagement. During observation, note distractibility and variability of symptoms so that these can be discussed in a supportive way.²⁰

Identify the person's goals for treatment and their expectations of OT. It is important to come to a shared understanding of what treatment can be offered; a verbal agreement at the start of intervention can prevent potential difficulties when concluding treatment. We suggest discussing that OT intervention will be directed by the goals or problems that the person has identified and that independent practise outside of sessions will be required. If, after some discussion, the person is unable to identify goals or areas of need, then it may be appropriate to discuss whether OT intervention is right for them at this time.

Unique to OT is the use of occupation-based conceptual models of practice which guide intervention. The two models of practice most commonly used by the consensus group are The Model of Human Occupation (MOHO) and The Canadian Model of Occupational Performance and Engagement (CMOP-E).^{21,22} Other models may be helpful, but these two were favoured owing to their links with well-established tools which are used by the consensus group to guide assessment and intervention with FND (see Table 2). Although none have been

specifically validated in an FND population, these tools can be also be used to measure the outcomes of intervention.

There is an absence of clinically useful, validated outcome measures specific to FND. Assessing change in FND is challenging due to the heterogeneity of presentations, variability of symptom severity and multiple interacting comorbidities. Outcome measures should therefore address multiple domains including physical function and disability, quality of life, mental health, healthcare utilisation and perception of symptom severity. We direct readers to a recent systematic review of outcome measurement in FND and recommendations by Nicholson *et al* and Pick *et al*.^{30 31}

OT treatment

OT aims to help people overcome the effects of disability through practical support to improve performance and satisfaction in activities of daily living. The consensus group identified that core OT interventions for FND include physical rehabilitation through guided activity practise, practical management of pain and fatigue, support to address mental health problems, and support to reduce dependency and optimise independence.

The group suggest that supporting self-management of symptoms is particularly important in FND and should be considered through all aspects of OT. The person is supported to take ownership of their rehabilitation and develop an internal locus of control, rather than placing control in the hands of clinicians and family members. This is achieved through understanding the diagnosis, understanding the rationale for interventions and graded goal setting. Interactive workbooks or a therapy journal can be a useful tool to support self-management.

Goal Setting

Goal setting is generally considered an important part of OT intervention.³² Goal setting with people with FND can differ from methods used in typical neurorehabilitation settings, for example after stroke, where therapists may be able to relatively accurately predict recovery and help set realistic goals. With FND, it can be helpful to consider that recovery often follows a pattern of symptom remission and exacerbation. For this reason, most of the consensus group reported that they take a more flexible approach to goal setting; goals are set by the person with FND, in their own words and may not necessarily be time dependent.

The group felt that it may also be more appropriate to develop functional (activity-based), rather than impairment-based goals. An example of an impairment-based goal might be: "I want to be

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Table 2 Useful occupational therapy specific assessment tools for FND

The Canadian Occupational Performance Measure (COPM)	Evidence-based outcome measure that captures a person's self-perception of performance and satisfaction with performance in daily activities. Has been widely adopted in occupational therapy research. Used for both paediatric and adult populations. ²³
Occupational Circumstances Assessment Interview and Rating Scale (OCAIRS)	Semistructured interview design based on the model of human occupation (MOHO); captures information regarding occupational engagement from 11 domains including habits, roles, personal causation, values, skills, physical environment, social environment and readiness for change. ²⁴
The Worker Role Interview (WRI)	Semi-structured interview format addressing factors that may impact upon a person's ability to maintain or return to work during or after a period of illness or injury. ²⁵
The Model of Human Occupation Screening Tool (MOHOST)	Assesses the impact of a person's volition, habituation, skills and environment on their occupational functioning. ²⁶
The Occupational Self-Assessment (OSA)	Based on the MOHO. Captures a person's perceptions of their own occupational competence and occupations of importance. Therapist observations are also considered when scoring. ²⁷
Adolescent and Adult Sensory Profile (AASP)	Evaluates behavioural responses to everyday sensory experiences. Used for ages older than 11. ²⁸
The Assessment of Motor and Process Skills (AMPS)	Clinician rated tool. Allows therapists to simultaneously observe and evaluate a person's ability to perform activities of daily living (domestic and personal) and the quality of their motor and process skills. ²⁹

FND, functional neurological disorder; MOHO, Model of Human Occupation

able to hold my hand still without tremor." A similar goal with a functional emphasis is: "I want to be able to brush my teeth using my right hand with less interference from the tremor."

The COPM, OCAIRS and OSA can be useful tools to guide goal setting for people with FND as the identified occupational performance problems can be collaboratively converted to goals.

Education

Education to improve understanding about symptoms is widely considered to be an important part of FND treatment.^{33,34} Helping people with FND to understand the diagnosis can improve their confidence that it is correct and builds the foundations for rehabilitation and self-management. It is important that occupational therapists are aware that there is often stigma attached to the diagnosis of FND. Patients report that interactions with health care professionals have often left them feeling misunderstood and abandoned by the health care system.³ Clinicians should therefore be mindful to impart information with empathy and sensitivity, emphasising the genuine nature of symptoms. Education should include how activities and occupations, combined with taught strategies, form part of symptom management. It is important to pitch education at the right level, recognising the person's attitude, knowledge and skills in order to change, support and enhance occupational performance.³⁵ See box 1 for points that can be included in an explanation of FND and the role of OT.

Vocational rehabilitation

OTs have a key role in supporting people with FND to manage their condition in the context of work and/or study.³⁶ We suggest that vocational rehabilitation principles for neurological rehabilitation can be applied to people with FND. This includes helping employers and educators to understand that they have genuine symptoms which may vary in severity, with possible periods of remission and exacerbation. OTs can work jointly with occupational health departments to identify and advocate for reasonable adjustments to improve work performance and symptom management. This may include role modifications, reduced hours, regular rest breaks and flexible working options. Another important aspect of vocational rehabilitation is to develop a graded return to work/study following a period of sick leave.³⁷

Sustaining paid employment is likely to be important in maintaining good health; however, in some cases it may not be possible for the person to continue despite reasonable adjustments.³⁸ In

Box 1 Ingredients of education about functional neurological disorder (FND)

1. Acknowledge that FND is a real, common and disabling condition that causes neurological symptoms that are outside the person's control.
2. The symptoms of FND are caused by a potentially reversible miscommunication between the brain and the body.
3. Discuss that FND is diagnosed by a neurologist using 'positive clinical signs' (eg, Hoover's sign, distractibility, entrainment of tremor, variability in symptoms during function) and is not a diagnosis of exclusion. It can be diagnosed alongside other neurological conditions.²⁰
4. Help the person understand the relevance of triggering events if they report them.¹²
5. Discuss how self-directed attention can make symptoms worse and conversely redirecting attention (distraction) can temporarily reduce symptoms.
6. Provide education on how the body's stress response can influence functioning of the nervous system and therefore FND.
7. Discuss how symptom focus and chronic health conditions can exacerbate or cause cognitive difficulties, fatigue, anxiety, low mood and pain.
8. Discuss the role of OT in treating FND.
9. Discuss the importance of a 24-hour approach to therapy; that is, implementing rehabilitation strategies throughout the daily routine as part of self-management.
10. Signpost to sources of information including: www.neurosymptoms.org and to patient-led organisations, for example, FND Hope International, FND Hope UK, FND Hope US, FND Hope Canada, FND Action (UK), FND Dimensions (UK), FND Australia Support Services. The book: *Overcoming Functional Neurological Symptoms: Five Areas Approach*³³ can be a useful resource in helping people understand symptoms and management strategies, especially in those that recognise anxiety and/or mood instability to be part of their problem.

these cases, the consensus group suggests that OTs can have a role in supporting people to positively withdraw from their current role and seek alternative roles (paid or unpaid).

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Aids and adaptations

The use of aids and equipment is generally thought to be unhelpful to the rehabilitation process in FND, potentially preventing future improvement by interrupting normal automatic movement patterns and causing maladaptive ways of functioning. It is important to recognise that aids and equipment can cause new secondary problems such as joint pain (eg, shoulder pain from walking with crutches) and deconditioning of muscles.¹² The group endorsed these concerns but recognised that there are times when providing adaptive equipment is appropriate and/or necessary. Each case should be considered individually. It can be helpful to consider the person's journey, differentiating the acute phase where improvement is more likely, from situations where people have treatment resistant symptoms. In the acute phase, it is advisable to avoid aids and environmental adaptations. If aids are necessary, for example to enable a safe discharge from hospital, equipment should be: (1) considered as a short-term solution; (2) issued with a minimalist approach; and (3) a plan to progress from its use. It is important to assess the person with new equipment and teach them how to use it correctly to minimise maladaptive movement patterns. Follow-up appointments should be available to monitor equipment use and support plans to progress towards independence.

For people who have completed rehabilitation but experience ongoing disability, it is reasonable and appropriate to consider aids and environmental adaptations. Equipment should maximise safety, increase independence, improve community access and have an overall positive impact on quality of life.

Splinting

As with adaptive aids, splinting may prevent restoration of normal movement and function. Potential problems with splinting are: (1) increasing attention and focus to the area, thereby exacerbating symptoms; (2) increasing accessory muscle use, (3) use of compensatory movement strategies, (4) immobilisation leading to muscle deconditioning; (5) learnt non-use, and (6) increased pain. Serial casting for fixed functional dystonia has been associated with worsening symptoms and the onset of complex regional pain syndrome.^{39,40}

We suggest trying strategies that encourage normal movement patterns and resting postures before considering splinting. It is possible that removable splints may have an overall positive effect in some cases, but benefits should be balanced against potential harm. If a splint is issued, the person should be monitored regularly and feel empowered to discontinue use in the event of adverse side effects such as pain and skin break down.

Use of language

The language used by both people with FND and therapists is important as it may indicate a lack of understanding or unhelpful illness beliefs. For example, words and phrases about related spinal issues such as 'crumbling', 'degenerative', 'unstable', 'wear and tear' and 'out of alignment' suggests a belief that movement and pain is harmful, which may lead to activity avoidance. The clinician can address these issues with education, highlighting the inaccuracy of these terms. For example, 'wear and tear' could be re-phrased as 'normal age related change' if appropriate.⁴¹

When speaking to people about FND, clinicians should aim to use language that removes blame and reinforces the message that FND is a genuine problem. This will help build rapport and engagement. Some examples of how to talk about FND are given below in table 3.

Careful use of language may help to evoke movement on a more automatic level. Explicit instructions, such as "take a step" or "pick this up", may encourage the person to focus on the mechanics and steps of a movement. Whereas less explicit instructions, such as, "allow yourself to come forward" may lead to more automatic ways of moving (with less attention driven towards the body).

Use of CBT strategies within OT interventions

Some occupational therapists within the consensus group have specialist training in cognitive behavioural therapy (CBT), where such interventions may form part of a treatment package for people with FND. However, we suggest that clinicians that do not have specialist CBT training may still find CBT principles to be of benefit to their practice. Examples of this include:

- ▶ Discuss how thoughts, feelings, behaviours and physical symptoms interact and influence the development and maintenance of FND.
- ▶ Identify and address unhelpful behaviours related to symptoms and disability. Examples include, boom-bust patterns of activity, sedentary behaviour, fear avoidance.
- ▶ Use thought re-framing to positively impact symptoms and function. See table 4 for examples:

Symptom-specific treatment suggestions**Functional Motor Symptoms**

Functional motor symptoms include tremor, weakness, dystonia, gait disorder and jerks. Movement strategies that redirect attention away from the body can help to reduce motor symptoms and normalise movement (see table 5 for examples). OTs can help people identify and practise normal movement strategies and integrate them into daily activities.

Functional tremor in the upper and lower limbs is a common symptom that can significantly impact upon function. It is usually generated by muscle co-contraction or by alternate activation of agonists and antagonists around a joint.¹²

Functional jerks or myoclonus are brief, usually repetitive muscle contractions or twitches, most commonly affecting trunk and abdominal musculature. The intermittent nature of functional jerks makes them particularly challenging to treat. As a starting point we suggest looking for distractibility and patterns of movement or behaviour that occur prior to a jerk (eg, demonstrable signs of anxiety, frustration or effort, such as breath-holding) which are commonly relieved briefly by the involuntary movement.

Functional dystonia is typically seen in the upper limbs, lower limbs, cervical spine and facial muscles. It is often associated with significant disability, as well as secondary hypersensitivity and pain and can overlap with complex regional pain syndrome.⁴⁰

Functional limb weakness can occur in any pattern in the limbs (eg, monoplegia, hemiplegia, paraplegia). Through task practise, OTs should encourage even weight bearing, appropriate weight transference and appropriate joint/body alignment. Helping the person experience more normal movement and proprioceptive feedback is likely to be helpful.

With all symptom types, employing anxiety management and distraction techniques when undertaking a task can be helpful. Video recording interventions (with consent) can be useful to play back to the person to identify changes in symptoms (eg, in tremor amplitude or extinction). It can demonstrate change-ability, highlight successes (and build confidence) and act as a reference point for replication of strategies outside of therapy.

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Table 3 Useful ways to talk about FND

Instead of:	Rephrase as:
"You are thinking about it too much"	"Let's try and shift your focus".
"I would expect you to be able to..."	"With some practise I think you may be able to learn how to..."
"There is nothing wrong"	"Your nervous system is not working normally but this is potentially reversible with practise and time."
"This is not serious..."	"This is serious but not dangerous".
"Your symptoms are not present all of the time."	It is common for symptoms to stop or reduce when people are distracted. This is why distraction techniques form an important part of treatment."

Functional cognitive impairment

Cognitive symptoms are common in FND either as a primary problem or as part of a combination of symptoms. Several factors can contribute to cognitive problems including pain, fatigue, anxiety, low mood, poor sleep, sensory hypersensitivity, symptom focus and medication side effects.⁴⁴ Before advising practical cognitive strategies, it is helpful to discuss the link between potential contributing factors and cognitive function. The aim is to understand, and where appropriate normalise, these experiences and reframe the symptom as part of FND rather than an additional health problem. Discussions should help the person to understand that their cognitive skills are likely intact (unless there is underlying comorbidity), but multiple factors are competing for their cognitive resources.

Key to managing cognitive symptoms is to address the contributing factors (fatigue, pain, anxiety, poor sleep), either as part of OT or to encourage the person to seek help from their general practitioner (eg, to consider reducing sedating medications). Other helpful strategies include encouraging structure and routine; writing out a daily plan to prevent activity and cognitive overload; taking time out for relaxation (to minimise stress); normal use of (but not dependence on) calendars and alarm functions in mobile phones. OTs can also support the person and significant others to gradually reduce practical assistance (if applicable) and provide opportunity for positive risk taking within function. Finally, like other functional symptoms, overly attending to the problem (ie, trying to remember) is unhelpful; most people can relate to the experience of remembering a forgotten name once they have stopped trying to think about it.

Functional visual impairment

Functional visual loss may be experienced as a persistent absence of vision, intermittent loss of sight or reduced visual acuity.⁴⁵ While the person may experience a lack of vision, it is usually possible to observe actions that demonstrate that they are making use of visual information in an automatic (or subconscious) way. For example, they may avoid obstacles while walking or pick up an object without guidance. Whilst there is little published information regarding treatment, there was experience within the

consensus group of helping people with functional visual loss, including a description of treatment for two patients who had a positive outcome.⁴⁶ This approach included: (1) helping the person understand the diagnosis and (2) sensitively communicating to the person and positively reinforcing events when they are likely to have used visual information (although without awareness). OT intervention should aim to prevent activity avoidance and dependence on others. OTs also have a role in assisting to minimise secondary problems associated with light hypersensitivity, agoraphobia and unhelpful behaviours such as keeping the eyes closed.

Dissociative (non-epileptic) Seizures (DS)

DS are a specific presentation of FND characterised by temporary episodes of impaired awareness. The episodes may resemble epilepsy or syncope, but they are not associated with abnormal electroencephalography changes. DS are a common reason for frequent attendance to accident and emergency.⁴⁷ Acute hospital admissions can be highly distressing and are usually unnecessary for DS. The main evidence-based treatment for DS involves psychological therapy, delivered by specially trained clinicians.⁴² Here we provide ways in which core OT skills can be used to help people with problems associated with DS.

A good place to start treatment is to ask the person how they wish to be supported if they have a DS during a therapy session. They may have devised a plan with other clinicians which you can follow. If not, this could be an initial focus of OT intervention. See box 4 for an example of a DS management plan. A DS plan can help put clinicians at ease and make the person feel safer which may prevent escalation and reduce duration of the episode.⁴⁸ Important elements are to help the person to a safe space where they are unlikely to injure themselves. Let them know they are safe but avoid constant reassurance and physical contact or restraint. Advising others to behave as they would if someone is having a panic attack can be helpful. People can sometimes hear and understand what you say during a DS, even if they are unable to respond.

Ask about triggers and warning signs of an imminent episode. It is common for people to report having no memory of events prior to and during a DS, however after some discussion many start to recognise patterns. If a warning sign is experienced prior to a DS, taught strategies can be used to try and avert an

Table 4 Use of thought re-framing strategies to aid function

Symptom	Negative thought	Negative behaviour	Re-framed thought (after intervention)	Positive behaviour
Dissociative Seizures	I might have a dissociative seizure on the bus and hurt and embarrass myself.	Stops using public transport and avoids going out.	I can use my strategies to control my dissociative seizures. I can manage this.	Goes on the bus and uses grounding strategies and diaphragmatic breathing to manage dissociative seizures and anxiety. ⁴²
Upper Limb Tremor	I might shake and burn myself.	Stops cooking and making hot drinks.	I can use my strategies to control my tremor and need to take some risks to improve.	Re-engages with meal and hot drink preparation using learnt relaxation, thought re-framing and tremor management strategies.

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Table 5 Examples of intervention strategies for functional movement symptoms

Symptom	Intervention Strategy
Functional Tremor	<ul style="list-style-type: none"> - Superimpose alternative, voluntary, 'rhythms' on top of the existing tremor and gradually slowing all movement to a complete rest. - Unilateral tremor: use the unaffected limb to dictate a new rhythm (eg, tapping/opening and closing the hand), that is entrain the tremor to stillness.¹² Music can be introduced to dictate a rhythm to follow. - Assist the person to relax the muscles in the limb to prevent co-contraction. - Try to control a tremor with the person at rest, before moving on to activity. - Use of gross rather than fine movements (which take more concentration) eg, handwriting retraining; using a marker and large piece of paper or white board with big lettering or patterns / shapes rather than trying to focus on 'normal' handwriting. - Discourage co-contraction or tensing of muscles as a method to suppress a tremor, as this is unlikely to be a helpful long-term strategy.
Functional Jerks	<ul style="list-style-type: none"> - Addressing unhelpful prejerck cognitions and movement (eg, signs of anxiety, frustration or effort, such as breath-holding). - General relaxation techniques; diaphragmatic breathing or progressive muscular relaxation. - Sensory grounding; a strategy which can be used to bring oneself into the present moment⁴³ (eg, noticing details in the environment (sounds, sights and smells), feeling a textured item, cognitive distractors such as counting backwards and singing). - Encourage learning of "slow" movement activities such as yoga or tai chi as a way of regaining movement control and redirecting attention away from the symptom.
Dystonia	<ul style="list-style-type: none"> - Encouraging optimal postural alignment at rest and within function, considering a 24-hr management approach. - Encourage even distribution of weight in sitting, transfers, standing and walking to normalise movement patterns and muscle activity. - Grade activity to increase the time that the affected limb is used (using normal movement techniques) within functional activities. - Avoid postures that promote prolonged positioning of joints at the end of range (eg, full hip, knee or ankle flexion while sitting). - Discourage nursing of the affected limb but demonstrate and promote therapeutic resting postures and limb use. - Strategies that reduce muscle overactivity, pain and fatigue, for example, muscle relaxation strategies, supporting the affected limb when at rest, using pillows or furniture to take the weight of a limb when sitting or lying down. - Address associated problems of pain and hypersensitivity.
Functional limb weakness	<ul style="list-style-type: none"> - Engage the person in tasks that promote normal movement, good alignment and even weight-bearing. Task examples may include: transfers, sit to stand, standing, perch sitting in personal care or kitchen tasks, using the hand to stabilise objects (so as to avoid learnt non-use) and placing the hand on the kitchen bench whilst standing to prepare food (rather than letting it hang by the side). - Bilateral functional lower limb weakness; joint sessions with PT colleagues to complete tasks using the upper limbs while standing with the aid of a standing frame.

event at this point.⁴⁹ A group of strategies that can be helpful are Sensory Grounding Techniques, which aim to keep people present in the moment and focus attention to prevent dissociation.⁴³ Some examples include noticing the detail in the environment (eg, colours, textures, noises); cognitive distractions (eg, word games, counting backwards); sensory-based distractors (eg, flicking a rubber band on the wrist, feeling a textured item).

Functional speech disorders

Functional communication disorders typically present as dysphonia, verbal dysfluency or prosodic abnormalities.⁵⁰⁻⁵¹ Where available, a referral to or collaborative working with a speech and language therapist with experience of FND is recommended, however, communication difficulties can also be addressed within OT sessions in the following ways:

- ▶ Recognition and discussion of distractibility of voice within functional tasks. This demonstrates changeability of symptoms.
- ▶ Identify unhelpful breath-holding and encourage normal breathing within communication.
- ▶ Encourage and assist the person to assume postures within tasks that optimise breath control.
- ▶ Positive re-enforcement of the production of voice change (eg, when the person is able to use taught strategies to manage a functional stutter).
- ▶ Identification of triggers to communication difficulties (eg, talking to strangers elicits verbal dysfluency).
- ▶ Develop and practise strategies to manage anxiety (eg, slow, diaphragmatic breathing, positive thought reframing).
- ▶ Graded task practise. For example, if talking to strangers is difficult or brings on symptoms, a progression of task practise might include: practicing telephone skills or ordering a coffee in a café.
- ▶ Graded reduction of communication aids and / or compensatory strategies (eg, writing instead of speaking).

Common problems associated with FND

Hypersensitivity

Many people with FND report hypersensitivity to touch, light, sound and movement. Specific terms have been used to describe these problems, including sensory modulation difficulties, sensory defensiveness and sensory over-responsiveness.²⁸⁻⁵² These symptoms are not unique to FND; in fact, they are also common in people with other diagnoses, such as migraine, chronic pain and fatigue. It is important to address hypersensitivity as it can become a maintaining factor, resulting in avoidant behaviours, limiting participation in functional activities and exacerbating other symptoms and disability.

The experience of hypersensitivity can influence the pace and intensity at which treatment can be delivered and should therefore be carefully assessed and considered as part of triage and treatment planning. UK group members outlined that sensory hypersensitivity (for people with FND) tends to be addressed within function by encouraging graded exposure to various sensations experienced within the persons day-to-day routine. The UK group also endorsed gradual minimisation of compensatory techniques such as use of sunglasses when indoors for photophobia or the use of headphones or ear plugs for auditory sensitivity or the more content-specific misophonia, as these are thought to perpetuate and exacerbate hypersensitivity. In some settings in the USA, treatment and assessment of sensory modulation difficulties are based on the Jane Ayers Theory of Sensory Integration.⁵³ The Adolescent/Adult Sensory Profile (AASP) assessment tool can be used to direct the development of a personalised sensory exposure regimen. This regimen may combine compensatory strategies to inhibit and grade exposure to sensory sensitivities alongside sensory-based activities to better regulate emotional responses, improve cognitive functioning and increase functional participation.

Hypersensitivity of the skin or allodynia is a common secondary consequence of "fixed" functional dystonia (as are other trophic changes associated with complex regional pain

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Box 2 In practice: functional limb weakness

SJ was admitted to an acute neurology ward via accident and emergency (ER) with left sided lower limb weakness after a fall down his stairs at home. He had a past medical history of mild spinal canal stenosis. An MRI showed 'wear and tear' but no changes that could account for his new symptoms. He was reviewed by neurology; was found to have a positive Hoover's sign, was diagnosed with functional weakness and he was given an explanation of the diagnosis. Despite this explanation SJ held the belief that he had caused damage to his spinal cord during the fall.

In the first OT treatment session, education about the diagnosis was provided, which explained how functional symptoms were commonly triggered by physical events and maintained by excessive amounts of the brain's attention being directed towards the body.¹² It was discussed that both physical and psychological stressors can impact on physical functioning.

A functional mobility assessment was undertaken, focusing on sit to stand and transfers. SJ required some assistance; it was noted that he had excessive weight bearing through the right side with over-reliance on his upper limbs. In addition, he was noted to breath hold and have significant muscle over activity when transferring. The OT explained to SJ what they were seeing. A video of his transfers was taken to provide feedback but also to act as a reference point to demonstrate progress in future sessions. SJ was instructed on how to use diaphragmatic breathing and muscle relaxation strategies when at rest and during function to minimise tension and stress response in the body. The OT worked with SJ to normalise his transfers by encouraging even weight bearing through the left and right sides and the use of forward momentum. The transfer techniques and even weight bearing strategies were then integrated into graded periods of perch sitting and standing when undertaking personal care and meal preparation. The benefits of even weight bearing to increase proprioceptive feedback on the affected side, to promote normal function of the nervous system and to minimise unhelpful compensatory techniques (prevent secondary pain issues) were explained. Initially SJ benefited from the use of toilet rails to aid his transfers, however, as he built confidence, he was able to grade to push up with his hands on his knees and then to standing without the use of his arms. Pacing education to manage the effects of deconditioning was also incorporated into function. SJ was encouraged to view every transfer, every stand, every functional activity as part of his rehabilitation as it provides opportunity for strategy consolidation, helps to normalise automatic functioning of the nervous system and acts to build functional endurance and confidence.

SJ progressed to the point where he was mobilising indoors over short distances without an aid and with supervision on the stairs (with the use of a rail). As his standing tolerance was reduced, he was provided with a shower chair for showering and a perching stool for kitchen tasks but was encouraged to alternate between sitting and standing to complete these tasks in order to build his tolerance over time. Community access had not been attempted in the acute hospital environment. He was discharged home with:

- ▶ *A relapse management plan with step by step instructions for improving sit to stand and mobility if he had a relapse of functional weakness.*
- ▶ *A referral for follow up community neurological OT and physiotherapy (PT) to work on goals including; independent use of stairs, review of relaxation and pacing techniques within function, improve activity tolerance, independent community access (including using public transport) and vocational rehabilitation to assist with return to work.*

syndrome).³⁹ Unchecked, hypersensitivity can lead to problems associated with learnt non-use (eg, further pain and hypersensitivity, muscle atrophy and discomfort associated with overuse of the unaffected side). OTs can facilitate graded use of the affected

limb while gradually reducing protective postures. For instance, encouraging arm swing when walking, weight-bearing in sitting or standing, bilateral upper limb use in activity. Graded exposure to different sensory experiences may help to normalise

Box 3 In practice: functional visual loss

MF had a long history of chronic daily migraine and developed functional visual loss after a period of particularly bad headache. She had previously been told that her vision loss was due to stress, which she interpreted as meaning that her problem was not real.

In the first OT treatment session, education about the diagnosis was provided. It was explained that although she may not always perceive visual information, there may be instances where her brain is accessing and using visual information even though she is not aware of it. For example, her family reported that at times she could reach towards an object or sometimes avoid obstacles unaided while walking.

Two functional assessments were undertaken; wash and dress and meal preparation. While MF required orientation to the kitchen with some hand over hand guidance, there were occasions where she was able to locate items without support. Within her personal care she was able to navigate the bathroom and collect toiletries independently. On completion of the assessments the occasions suggesting that visual information was being processed were discussed with MF. They were described as very typical for this type of problem and a positive sign that the neural pathways were intact and visual information was being processed by the brain, despite her not consciously experiencing sight. Follow up occupational therapy sessions were planned around practising other meaningful daily activities and developing strategies to maximise independence. MF was encouraged to continue to complete her daily activities as normally as possible ensuring that she remained safe. A graded approach to supervision and positive risk taking was handed over to her care givers (eg, initially close supervision progressing to distant supervision and independence as MF's confidence grew). It was discussed that this graded task practise should help to trigger automatic visual pathways; while striving to see was probably unhelpful as this may interfere with normal automatic functioning of the nervous system. The OT explained that return of vision may occur slowly and that it would be helpful for MF and her family to recognise positive events where vision was used, for example when choosing clothes to wear.

A discussion was had about the pros and cons of using visual impairment aids such as a white cane. The OT reported that there was a belief amongst experts that this may delay return of sight because the brain would prioritise the other senses above vision. It was agreed to hold off from using aids for now and reconsider the issue in following appointments.

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Box 4 Example of a Dissociative Seizure management plan

Dissociative Seizure Management Plan for John Smith

I have dissociative seizures. I do not have epilepsy. My seizures are not harmful but I can take some time to come around. The events are genuine and not deliberately produced.

This plan is designed for the following type of events: (description to be inserted; eg, my body starts to shake, my limbs go rigid or jerk).

Warning Signs: (description to be inserted; eg, looking 'zoned out', slurring words).

- ▶ People can help by prompting me to use my grounding strategies.
- ▶ My grounding strategies are; (description to be inserted; eg, counting back from 100 by 7, focusing on details in my environment).

If I start to have a DS you can help me by (this list should be individualised to the person) eg;

1. Support me to the floor and keep me safe by clearing the space around me.
2. Not holding me down or touching me.
3. I can sometimes hear people speaking during my DS but may not be able to respond.
4. Do not put anything in my mouth.
5. Allow my DS to run its course.
6. When I come around allow me to recover in a quiet space.

There is no need to call an ambulance, unless

1. I have hurt myself.
2. You think that the presentation of my symptoms is different to what is described above.
3. The DS continues for an abnormally long time, for me this is longer than 30 minutes.

If an ambulance is called, please show them this management plan.

My Medications Are:

Other Health Conditions:

Please contact:

NOK details

sensation, for example, wearing clothing on the affected limb, applying moisturiser, washing up in warm water.

Anxiety

Although not universal, anxiety is common in FND and may act as a symptom precipitating or perpetuating factor. Some people may experience the physiological and somatic consequences of anxiety (eg, racing heart rate and tight chest) without recognising the experience emotionally. This has been described as panic without panic or alexithymia.⁵⁴ OTs can help to address anxiety through education by describing the physiological process of anxiety and its physical impact on the body. The concept of a fight or flight response may be useful for patients who do not identify as feeling anxious. OTs can help people identify how anxiety interacts with FND symptoms to impede involvement in daily activities and implement anxiety management strategies. This can include breathing techniques, progressive muscle relaxation, grounding strategies, visualisation, distraction, thought reframing, mindfulness, integrating activities of enjoyment, regular cardiovascular exercise and supporting the person to undertake an anxiety provoking task in graded steps.

Fatigue and pain management

People with FND often experience pain and/or fatigue. These can be disabling symptoms and should therefore be considered as part of any intervention. Evidence for the management of pain and fatigue in other long-term conditions currently exist and can be adapted for use in FND.^{55 56}

In the first instance, OTs can assist people to develop an understanding of the mechanisms behind pain and fatigue, how the person experiences these symptoms and how these symptoms impact on behaviour and occupational engagement. The use of activity logs completed over the course of several days can be helpful to identify how pain and fatigue may influence activity participation. Factors that contribute to and exacerbate

Box 5 In practice: graded task practise to improve confidence

If a person with DS reports disengaging from all beverage and meal preparation tasks after having burned themselves, then practising bilateral upper limb tasks in a safe and graded environment can be helpful. Prior to starting, discuss potentially useful strategies that may help (eg, grounding techniques, diaphragmatic breathing, positive thought reframing). The task practise could start by pouring cold water from a kettle into cups using two hands and then as the step is mastered gradually increasing the temperature of the water and the difficulty of the physical requirements of the task (pouring with one hand, carrying a cup of tea across the room). If 'warning signs' of a DS are noted then the person should be encouraged to step away from the task, use learnt grounding / anxiety management strategies and then resume as able. Support offered is gradually downgraded with the eventual aim of complete independence. (Refer to the end of this document for a further example of graded task practise).

fatigue and pain (eg, boom/bust behaviour, poor sleep hygiene, poor nutrition/hydration) should be explored and management strategies developed. OTs can assist people to re-establish a balanced daily structure and routine, incorporating graded activity to build functional endurance. Reduction of maladaptive postures to improve comfort and efficiency within function and the integration of the work/rest principle is key during such interventions. Learnt strategies should then be incorporated into the person's self-management plan.

Psychological trauma

A systematic review found that serious adverse life events are more common in people with FND compared to the general population.⁵⁷ Of note, childhood neglect was found to be a greater risk

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factor than physical or sexual abuse. Importantly, adverse life events were not universal, and even if present, may be relevant to some but not all as also evidenced by a recent case controlled study exploring predisposing risk factors for functional limb weakness.⁵⁸ For some people, addressing the impact of adverse events (eg, in post-traumatic stress disorder) may be a necessary part of treatment. For others, a more symptom focused intervention may be appropriate. The group felt that addressing the sequelae of psychological trauma is not a generic OT role. Some OTs have sufficient experience and qualifications to manage difficulties that arise from serious mental health problems, but this usually is the result of additional training and accreditation. However, people sometimes disclose information about traumatic events during OT intervention. It is therefore important that therapists have the skills to listen and contain the person's distress. Using reflexivity to acknowledge one's own limitations within the context of your professional role is imperative. There are some OTs who may feel more capable in managing trauma due to their skill set and practice setting (eg, mental health or neuropsychiatry settings). Less experienced clinicians should be encouraged to seek supervision and support. Knowing who to refer on to if a person discloses trauma (and consents to onward referral) is important and clear lines of how to do this should be established.

Risk management

People with FND often disengage from usual activities due to a perceived risk to their personal safety (eg, fear of having a DS upon leaving the house). It is an OTs' role to help manage risk and increase independence by enabling people to engage in activities through a process of supported positive risk taking. This concept is explored in a recently published guidance document for OTs in the UK, 'Embracing risk; enabling choice'.⁵⁹ The identified principles can be applied to working with people with FND and the group endorses its guidance. Here we provide an example of how the framework can be applied to a person with DS:

1. What are the benefits of working towards the set goal?
 - Will participation in the activity improve fitness and endurance, confidence, mood, functional independence?
 - Will participation in the activity give the person opportunity to manage their symptoms within function?
2. What are the risks involved in working towards the set goal?
 - Will the person be at risk of hurting themselves or others? There is a risk of injury with DS but it appears the same indoors and outside, and serious or life-threatening injury, and injury to others are not features of the condition.
 - Will their confidence and mood be compromised if the goal is not achieved?
 - What are the risks to the person if they do not attempt the activity (eg, will they remain dependent on care givers?)
3. Risk assessment for the person and others:
 - Consider the wide array of possibilities that could occur from participating in the chosen activity; what are the pros and cons, do the benefits outweigh the risks?
4. Develop a plan to minimise risk to the person. What skills does the person bring to the intervention in order to mitigate risk?
 - Does the person demonstrate a good awareness of their symptoms (eg, can they recognise when a DS is coming on? Do they know when they should take a rest?)
 - Is the person able to independently use taught symptom management strategies to good effect?
 - Is the person able to employ active problem solving skills and communicate their needs effectively?

5. Record and share the enablement plan:
 - Develop and record a plan for graded task practise with the person and significant others. Highlight strategies that should be employed to maximise safety and independence.
6. Establish plans for regular review

A review of the enablement plan should be undertaken throughout step 5. A record is kept as each step of the task is mastered and onward goals set (using a graded goal setting approach).

Disability management

Care

OTs can provide advice on the need for carers to assist with activities of daily living and the extent of care required. If carers are needed, care that provides opportunity for the person to be actively involved in tasks (facilitatory), rather than having a task completed for them (passive care) should be encouraged.

Benefits

People with FND are entitled to health and social care benefits / insurance but many find the systems involved difficult to navigate. It may therefore be necessary and appropriate for OTs to support applications for benefits and insurance claims. This may involve liaising with agencies, supporting the completion of paperwork and advocating on the person's behalf regarding the potential benefit of undergoing specialist rehabilitation (eg, a letter outlining treatment options and the evidence base). A simple 'to whom it may concern' letter, describing a person's diagnosis, articulating the finer details of the condition (eg, variability of symptoms), impact on function and their support needs can be a valuable tool to help people negotiate with relevant agencies. When patients are on the cusp of eligibility for benefits and undergoing treatment, an open discussion about whether they wish to defer application until they see the outcome of treatment may be appropriate.

Housing

Rehousing to an adapted property should be avoided when symptoms are presenting acutely and/or access to rehabilitation is available and wanted. Support with rehousing may be appropriate if a patient has chronic symptoms that have not responded to a rehabilitation approach. A person's housing situation may also be a trigger or maintaining factor to their symptoms or lack of occupational independence and therefore if no immediate changes can be affected, then rehousing may be considered. In such instances, OTs may have a role in advocating for rehousing on behalf of the person.

Relapse prevention/staying well plan

During rehabilitation and the journey to recovery, it is common for people with FND to experience periods of symptom exacerbation. OTs should help people to prepare to manage these episodes with a relapse prevention, management, or staying well plan. This essential part of treatment is a written summary that can be completed collaboratively at the conclusion of treatment. A plan should consider the following questions:

1. What have you learnt about your condition?
2. What makes your symptoms worse?/What might trigger setbacks?
3. What are the most helpful management strategies that you have learnt?
4. What were the unhelpful coping strategies that were making it difficult for you to improve?
5. What can you do if you notice that your symptoms and function are getting worse?

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6. What are your goals for the next 3, 6, 9, 12 months? (using a graded goal setting approach).

Concluding treatment

It can be difficult to bring an intervention period to an end if the person continues to experience debilitating symptoms. Commencing the intervention with a treatment agreement (as described above) may help with this process. It is important to maintain the therapeutic relationship, promote confidence and self-efficacy by fostering the person's ability to continue with their self-management plan. In this way, discharge should be framed not as concluding treatment but rather the point in which the person should independently continue to implement their self-management strategies.

There will be some people who do not gain benefit from rehabilitation and who remain symptomatic. If the person has had adequate access to specialist intervention for FND then a focus on disability management may be appropriate. However, given the fluctuating nature of FND it is important to consider that gains may still be possible in the future. Re-engaging in rehabilitation at a later date may be advantageous for some. Booking in a follow-up appointment to review progress, trouble shoot issues and reset goals as the system allows is advised. Peer support organisations can be an important adjunct to treatment, especially for people who continue to experience symptoms.

See box 6 below for a summary of the intervention principles for OT and FND suggested in this document.

LIMITATIONS

Due to a lack of evidence for specific OT interventions, the recommendations provided in this paper are based on expert opinion. Where possible, we have drawn on evidence from multidisciplinary interventional trials and other therapies. These recommendations are aimed at adult patients. Interventions for children and adolescents with FND are likely to be similar to those described here, but may differ in some areas. Treatment advice for younger people is an important direction for future publications. Our international authorship increases the generalisability of the recommendations; however, the information may be less transferable in nations not represented.

CONCLUSIONS/SUMMARY

FND is a complex condition that has far reaching consequences on physical and psychological health, occupational participation and quality of life. Current best practice is for multidisciplinary rehabilitation, of which OT is a part. However, there are few resources available to help guide OT assessment and intervention. Here we provide recommendations for OT assessment and intervention for people with FND, considering their journey from acute presentation to support in the community. The information within this document highlights the important role of OT in helping people with FND and may have relevance for other professional groups. Future research should seek to test the individual components of these recommendations and explore the potential for cost benefit.

FREQUENTLY ASKED QUESTIONS

What do I do if I suspect that someone has FND but has not received a diagnosis?

In the first instance, we would suggest discussing the person's case with the person's physician or ask a colleague for a second opinion. Your findings could then be discussed either verbally or by letter directly with the person's physician or GP. You might suggest onward referral to a neurologist for further assessment.

Box 6 Summary of intervention principles for occupational therapy and functional neurological disorder (FND)

- ▶ Be empathic and recognise that FND is a real and disabling condition.
- ▶ Take the time to listen to the person's story and build therapeutic rapport.
- ▶ Agree treatment parameters at the start of your intervention.
- ▶ Introduce the concept of self-management at initial assessment.
- ▶ Provide education about the diagnosis and the person's symptoms.
- ▶ Involve significant others in education and treatment.
- ▶ Use variability of symptoms on examination and in day-to-day life positively in treatment.
- ▶ Recognise and sensitively challenge unhelpful thoughts, beliefs and behaviours.
- ▶ Integrate specific treatment techniques into function and show the person how to carry these over independently.
- ▶ Focus on activity-based (functional) rather than impairment-based goals and interventions.
- ▶ Be open and consistent in your verbal and written communications with the patient and other healthcare professionals.
- ▶ Where possible avoid use of compensatory aids and techniques in the acute phase or when undergoing active rehabilitation.
- ▶ Avoid use of splints or devices that immobilise joints.
- ▶ Complete a relapse prevention and ongoing self-management plan as part of treatment.

If the person does not have a diagnosis of FND then therapy that focuses on functional goals (rather than at an impairment level) to build on functional independence can still be beneficial.

What if the person does not recognise the role of psychological factors in their health problem but they appear to be relevant?

Not all people with FND have active psychological problems. However, some people may have psychological problems such as anxiety or depression and may be reluctant to acknowledge them. This can be due to numerous factors including societal stigma attached to mental ill-health. Also, some people may have anxiety and depression but not recognise them. This situation is sometimes described as alexithymia, a theoretical concept where people have difficulties recognising and labelling their own emotions. Alexithymia may be a risk factor for developing FND, although consistent data to support the existence and relevance of the concept is lacking.⁶⁰

In this situation, it can help to shift the focus of intervention to the impact of the (presumed) somatic/physical symptoms of anxiety (such as tremor or shaking) on function whilst using a graded goal setting approach. Involving significant others in the assessment and intervention can at times be helpful in that they may recognise signs of anxiety that the person does not. This can then be further discussed if the person is willing.

Talking about the biology of anxiety can be helpful, for instance, referring to the fight or flight response; release of adrenaline and cortisol and the effect that this has on the body. Or you may choose to have a conversation about the importance of identifying and working on triggers and maintaining factors to their FND and integrate anxiety management education (using

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a biological explanation). Taking a video of the person during activity (with permission) can also be helpful to demonstrate signs of anxiety for instance breath holding, tense postures.

Should my assessment and treatment approach be different for people with FND compared to people with functional symptoms that coexist with other problems such as neurological disease (functional overlay)?

Managing expectations about what can be reasonably achieved in the intervention is important, for instance, in a person with both Multiple Sclerosis and FND you have to acknowledge that due to the comorbid pathology some symptoms or function may have limited potential for change. Techniques used to help people with FND are likely to be useful in treating people with neurological disease and FND comorbidity (eg, normal movement principles, relaxation, distraction strategies and focus on functional activities rather than impairment-based intervention). If anxiety is relevant, this should be addressed. For example, discuss the impact of anxiety on exacerbating symptoms and normalise the experience of anxiety, especially in the context of their disability. Whether or not it is useful to label the symptoms as functional and explain this to the person should be considered on a case by case basis, considering the severity of the functional symptoms and any benefits afforded by an additional comorbid FND diagnosis.

Are there rehabilitation approaches that do not seem to work with people with FND?

Intervention strategies that lead the person to focus on their body or symptoms are likely to exacerbate functional symptoms and should therefore be avoided. Delivering therapy within the context of engagement in an activity will help to prevent this symptom focus. You will need to continuously assess the person to determine if they are over-attending to their body or symptoms. When you notice worsening of symptoms you can make a change, for example; give a prompt or cue designed to redirect attention (eg, if the person is looking at their feet while transferring you could ask them to look up, or redirect their attention to their posture); change the activity, or ask the person to stop and rest for a count of 5 seconds ('reset').

How do I manage the discharge of a person with FND who does not feel ready to go home or be discharged from the service?

This is a common difficult situation in acute care settings. The pressure to discharge should not be placed all on one person or profession. Instead, it should be a decision owned by the MDT. In such cases we would recommend that the treating team meets with the person to discuss:

- ▶ Current progress (or lack of progress) according to the rehabilitation goals set by the patient
- ▶ Current barriers to progression and how these barriers may be overcome
- ▶ Future treatment and discharge options, including support in the community and plans for specialist review.

Timing for rehabilitation is important. It may be advantageous for some people with FND to re-engage in rehabilitation at a later date once some of the identified barriers to progression have been addressed. For this reason, we would recommend arranging a follow up appointment to review progress, trouble shoot issues and reset goals.

Are mental health specialist occupational therapists or neurological specialist occupational therapists most suited to help people with FND?

We would suggest that both mental health and neurology OTs can help people with FND. Ideally the treating OT should draw on skills from both areas and address both physical and psychological components of the condition as appropriate. The focus of treatment should always be guided by the person's goals. If the goals are mainly associated with management of psychological problems such as anxiety, low mood, low confidence, post-traumatic stress, then mental health skills are important, and it may be most appropriate for the person to have treatment with a mental health specialist team where available. If the person's preference or needs for treatment are directed towards physical disability, then neurological rehabilitation may be more appropriate.

I work in a service that does not have access to psychology, what should I do when people with FND are referred to me?

If you are concerned, then we would suggest that you try to speak to the referrer to gain some more information before starting your initial assessment. You may choose to assess the person with a colleague so that you can share ideas and problem solve together, to determine if there are clear goals that can be managed within the remit of your skill set.

If you do not feel comfortable with the referral or with treating the person, then discuss this with a senior member of the team. If the decision is to decline a referral, we recommend that this is done with a letter explaining your concerns and help the referrer to identify alternative treatment options. People with FND benefit from input from health professionals with some confidence in treating the condition. However, in many areas, there are no alternative treatment options, and a common sense approach based on documents like this may be more useful than no treatment at all.

FURTHER CASE STUDY EXAMPLES: CLINICAL REASONING FOR AIDS AND ADAPTATIONS

Case scenario 1: Acute presentation (hospital to home)

Presentation:

AT was admitted electively for embolisation of a left sided Arteriovenous Malformation (AVM). During his post-operative recovery AT experienced the onset of left sided upper limb and lower limb weakness and an exacerbation of his chronic low back pain. Further scanning indicated that the embolisation had been successful and there was no bleed. On assessment it was noted that AT had a positive Hoover's sign and a pattern of weakness that was consistent with functional limb weakness. He was distressed and fearful of falling and AT was frustrated by his lack of independence.

A request for neurology review was made and AT was diagnosed with functional weakness. The diagnosis was discussed at length with AT and his family, by both the neurologist and his acute therapy team and he was in agreement with it. The neurosurgeons were keen to get AT home as soon as possible.

Social history:

AT lived with his supportive extended family in a two storey, privately owned home with the bedrooms and bathroom upstairs, and a toilet downstairs. There were no aids and adaptations in place. AT was unmarried and had no children. He was previously independent with all daily activities, although he had suffered from depression for a number of years and had chronic

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lower back pain. He worked full time as an accountant and described his employer as 'supportive'.

Goals identified to prepare for discharge home:

- ▶ To be able to complete a step round transfer by myself
- ▶ To be able to get on and off the toilet and in and out of the shower by myself
- ▶ To be able to go to the toilet and wash and dress myself without help
- ▶ To be able to walk indoors independently
- ▶ To be able to go up and down a flight of stairs with supervision only

Occupational therapy intervention:

1. Working with physiotherapy colleagues, the treatment plan was to improve mobility, without using a walking aid. However, AT was unable to mobilise independently which he found to be very limiting and frustrating. He did not want to be dependent on others. This was taken into consideration when weighing up the pros and cons of providing equipment. AT was therefore provided with a walking frame so that he could start to mobilise independently on the ward. AT's family were shown how to assist him to walk using graded normal movement strategies (without the use of the frame). This technique was filmed on AT's phone so that he could show other family members and community therapists. Graded goals were set around reducing his dependence on the use of the frame and others when walking.
2. AT was provided with an over toilet frame as without this he required assistance to get on and off the toilet. Provision of this meant that he was independent. AT and his family were shown how to practise sit to stand transfers using momentum and normal weight bearing strategies. This was again filmed for future reference. Graded goals were set around reducing dependence on the use of the over toilet frame.
3. AT was provided with a bath-board and transfers were practised prior to discharge. AT was independent with washing and dressing using this aid. A request was made for the community therapy team to continue to build on safety and independence with bath transfers (without the use of equipment) in the community.
4. By discharge AT was mobilising up and down the stairs with the use of a rail and close supervision. Goals to increase independence with stair mobility were handed over to the community therapy team.
5. A referral was made to AT's local community neurological rehabilitation team for further OT and PT with the aim of reducing his reliance on aids, his family and return to independent participation in daily activities. The community team were provided with a copy of the graded goals as outlined above and advised to review the videos that had been taken on AT's phone.
6. A referral for specialist vocational rehabilitation was made to assist AT with a graded return to work when ready.

Clinical reasoning questions:

Q/ Will equipment provision lead to unhelpful movement patterns / cause secondary pain issues / deconditioning/ increase dependency?

A/ Unhelpful movement patterns: This was a risk; provision of the frame may have led to unhelpful postures and over-reliance on his arms for weight bearing when walking. The use of an

over-toilet frame is unlikely to result in maladaptive movement patterns.

Cause secondary pain: The use of a frame may have exacerbated his back pain and caused upper limb pain.

Cause de-conditioning: No, without the frame AT would likely become more de-conditioned as he would have to wait for assistance to get up and move. Additionally, in this case, provision of a frame encouraged more regular activity and on balance was considered helpful for rehabilitation.

Increase dependency: AT voiced strongly that he did not want to be dependent on his family. With the provision of aids, he was independent with his mobility and personal care.

Q/ Will equipment provision increase safety, confidence and independence with ADL and reduce reliance on others?

A/ In AT's case, yes.

Q/ Will provision reduce pain, fatigue and anxiety when undertaking ADL? Will they increase quality of life?

A/ In AT's case, provision of aids helped reduce anxiety related to falling, which in turn encouraged more independent mobility.

Q/ What are the potential benefits of equipment provision?

A/ Improved independence, safety and confidence.

Q/ What are the risks?

A/ Use of compensatory movement patterns and therefore secondary pain issues when using equipment. Risk of developing long term reliance on equipment.

Commentary:

Ideally AT would have received intensive rehabilitation and progressed towards independence with transfers and mobility without aids prior to being discharged home. However, this was not possible. AT was very motivated to be independent and he was clear that he wanted to move away from using equipment. He demonstrated good carry over of taught strategies and his family were very invested in helping with his rehabilitation. All of these factors were considered when weighing up the pros and cons of equipment provision to facilitate discharge.

Case scenario 2: The person with long term disability

Presentation:

CG had a 15-year history of bilateral functional lower limb weakness, dissociative seizures (DS), fatigue, chronic pain, anxiety, depression and stress incontinence. She was diagnosed with FND by a neurologist one year after symptom onset. CG was clear that the diagnosis of FND was correct. On admission she had been non-ambulant and non-weight bearing for the past 10 years. CG transferred using a lateral transfer with heavy reliance on her upper limbs. She mobilised using a manual wheelchair indoors and could self-propel only short distances outdoors.

Social history and current function:

CG lived alone without care provision. She had limited social contacts. She lived in a council owned two-storey property. The bedrooms, bathroom and toilet were upstairs. She had a shower over the bath with a bath-board in place and one rail beside the toilet. She had a commode with swing away arms downstairs. CG managed the stairs on her bottom, completely relying on her upper limbs. She found this to be extremely difficult and it exacerbated her fatigue, pain and DS. Consequently, she often slept in a lounge chair and strip washed downstairs.

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CG had a shower independently twice weekly but the effort associated with this often meant that she was unable to participate in any other activities for the rest of the day. She reported that the likelihood of having a DS after a shower was very high, with pain, fatigue and frustration identified as triggers. She reported feeling scared of having a shower using the bath-board, as she did not feel secure.

CG reported that all daily activities were extremely effortful. She was essentially housebound as the effort associated with caring for herself meant that she had little energy for any other activities. She also had limited ability to self-propel her manual wheelchair outdoors.

Goals identified for rehabilitation:

- ▶ To increase my cardio-vascular fitness and upper body strength
- ▶ To be able to transfer with less effort
- ▶ To be able to get washed and dressed without feeling so fatigued
- ▶ To explore alternate ways of getting in and out of the bath so that I feel safer
- ▶ To have more energy to participate in leisure activities
- ▶ To be able to go out on my own

Occupational therapy intervention:

CG had had numerous attempts at rehabilitation over the past 15 years. None of these attempts led to a change in her symptoms or function. Therefore, towards the end of a recent in-patient rehabilitation admission, OT intervention included exploration of care, aids and adaptations, to increase her safety with transfers, and her ability to engage in wider meaningful occupations.

Care, aids and adaptations recommended:

- ▶ Slide board to increase safety and decrease fatigue associated with transfers
- ▶ Replace bath-board with bath lift to increase confidence bathing
- ▶ Explored accessing care to support with showering and domestic tasks to aid fatigue management and increase energy for other meaningful activities.
- ▶ Onward referral to explore provision of powered wheelchair to increase community access.
- ▶ Onward referral for assessment for major adaptations / CG to consider moving to single level wheelchair accessible accommodation.

Clinical reasoning questions:

Q/ Will provision of equipment and mobility aids lead to unhelpful movement patterns / cause secondary pain issues / deconditioning / increase dependency?

A/ Unhelpful movement patterns: in this case adaptive movement strategies were more helpful than her current way of moving and transferring.

Cause secondary pain: Depending on the aid, yes, it could cause secondary pain, and this should be considered. However, in this case there were more pertinent issues related to current function and safety, and the provision of aids, adaptations and alternative compensatory strategies meant that the quality of transfers improved.

Cause de-conditioning: Yes, if she stopped doing the stairs, albeit on her bottom, she was likely to be less active overall and lose confidence. Alternate ways that she could exercise were explored in her physiotherapy sessions.

Increase dependency: No, aids could increase her independence.

Q/ Will provision increase safety, confidence and independence with daily activities and reduce reliance on others?

A/ Given the use of an adapted wet room and toilet CG would likely find that she is able to wash, dress and toilet herself with much less effort, frustration and therefore less exacerbation of her symptoms. This was tested and proven in the adapted hospital environment.

Q/ Will provision reduce pain, fatigue and anxiety when undertaking daily activities? Will they increase quality of life?

A/ Possibly. Given the provision of aids and adaptations CG would likely have more energy for other daily activities, including leisure activities. She would possibly feel more secure when showering using a bath lift (as opposed to a bath board). This may have a positive effect on mood and overall symptoms.

Q/ What are the potential benefits of equipment provision?

Improved safety, confidence, reduced disability, increased independence, improved access to the community and increased quality of life.

Q/ What are the risks?

Reduced physical activity which may lead to additional weight gain and de-conditioning.

Commentary:

CG had appropriate rehabilitation on a number of occasions but remained symptomatic. The pros and cons of the provision of aids and adaptations were considered and in this case the benefits outweighed the negative factors.

Dissociative Seizures (DS) case study (demonstrating the occupational therapy process; assessment to discharge)

Presenting history:

FB had an 18-month history of DS, presenting as episodes of vigorous whole body shaking with impaired awareness. Her first DS came on a week after she was assaulted by her then boyfriend. FB was diagnosed with DS by a neurologist after being admitted to hospital where her seizures were observed and she had a series of tests completed, including video telemetry. FB was confident that the diagnosis was correct and that it fit her pattern of symptoms. FB reported that her dissociative seizures had worsened over time, with increased frequency and duration. Her symptoms had progressed to include fatigue, generalised pain, low mood, anxiety and most recently verbal dysfluency. FB had recently moved back in with her mother for supervision and support.

FB was referred to OT by her neurologist as she was experiencing difficulties with daily activities. She had recently been signed off sick from her job as a legal secretary and she reported being fearful of losing her job.

FB's mother lacked confidence in her ability to support FB during a DS and as such she often called an ambulance when they occurred. FB had attended her local A&E frequently since the onset of her symptoms. FB reported that attending A&E often made her symptoms worse as she felt that her condition was misunderstood and medication with a sedative effect was often administered. This resulted in FB feeling exhausted for days after an event.

Occupational Therapy assessment:

- ▶ A detailed initial assessment was undertaken, including: a full list of symptoms, known triggers, easing factors, 24-hour routine; sleep patterns, dietary and hydration intake, inconsistency of function and possible reasons for this inconsistency were identified.

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The following problems were noted on assessment:

- ▶ Continuous whole body pain and headaches with associated adaptive postural sets within function.
- ▶ Continuous fatigue
- ▶ Poor structure and routine (since being signed off sick from work)
- ▶ Difficulties sleeping at night but long periods of daytime sleeping
- ▶ Inconsistency in function: Large discrepancy in activity levels on 'good days' versus 'bad days'. On 'bad days' FB relied more on help from her mother with daily activities.
- ▶ She was fearful of going out on her own due to the frequency of her DS. She was unable to use public transport and had disengaged from social activities, unless her friends visited her at home.

A referral for speech and language therapy (SALT) and psychological therapies was made after the initial assessment to:

- ▶ Offer advice regarding the management of her verbal dysfluency.
- ▶ Address trauma related to the assault, general anxiety and low mood.

Occupational Therapy intervention:

The OT set the parameters for intervention; how many sessions over what time frame could be offered, a supported self-management approach to rehabilitation from day one, and helped to develop person directed goals for intervention.

The COPM was used to assist with goal setting as the five identified occupational performance issues were collaboratively converted to goals. The following goals for OT intervention were identified:

1. To improve the management of my fatigue so that I can do more for myself every day.
2. To have more control over my DS so that I can go out on my own and don't have to go to hospital.
3. To be able to use public transport on my own.
4. To be able to return to work.
5. To be able to meet my friends in town (without support) for a night out.

Education: Diagnosis

The OT explored FB's knowledge and beliefs about her diagnosis. Education was provided on DS in the context of her own story, emphasising that the attacks themselves were typical of the condition and it was not a 'rule out diagnosis' but also exploring the possibility of her assault being an initial symptom trigger. This education was linked to information regarding the stress response cycle, and how this, trauma and anxiety can be a precipitant, exacerbator and maintaining factor in FND, leading to avoidance of daily activities.

Education: Anxiety management

The occupational therapist reviewed how FB experienced stress and anxiety in her body – what did she notice? (eg, sweaty, heart racing, 'jelly legs' etc). Advice was given regarding relaxation strategies: diaphragmatic breathing, progressive muscle relaxation, visualisation, relaxation apps, podcasts, and enjoyable activities. A plan was set to integrate these into FB's daily routine.

Education: Pacing (for fatigue and pain management)

A detailed pacing plan was discussed and implemented using activity diaries to identify unhelpful patterns of behaviour and triggers to pain and fatigue; followed by a timetable of graded activities to improve structure and routine. The importance of using a work/rest approach to activities and gaining a balance of

different types of activities (physical, cognitive, social, 'have to' and 'want to' activities) was discussed. Progress with this plan was reviewed over the course of the intervention.

Sleep hygiene was also addressed with a plan to gradually move away from day-time sleeping and strategies trialled to help improve night-time sleep.

Dissociative Seizure Management Plan:

A management plan for FB's mother was developed to help increase her confidence in supporting FB when she had a dissociative episode, avoiding calling an ambulance where possible. A separate management plan and wallet card was developed for Accident and Emergency (A&E) / Emergency Room (ER) staff with advice from FB's neurologist.

FB and her mother were assisted to recognise her 'warning signs' preceding a DS eg, feeling 'spaced out', tingling in hands. Education regarding the use of grounding techniques and how to implement them with the aim of reducing her DS was then undertaken:

- ▶ Noticing the detail in items around her / the environment
- ▶ Counting backwards by seven
- ▶ Playing cognitive games eg, animal names starting with...
- ▶ Finger tapping
- ▶ Singing
- ▶ Verbal distraction through conversation
- ▶ Thought re-framing
- ▶ Mindfulness

Graded Task Practise:

The OT reviewed FB in function (for example making a meal); re-enforcing practical use of pacing strategies, encouraging good postural sets, applying grounding and anxiety management strategies and reducing the use of compensatory strategies.

Once FB had increased her independence in the home, with increased confidence that she could apply grounding techniques, the OT reviewed how to progress her community access goals with a gradual reduction of her mother's support (using a graded goal setting approach).

Vocational Rehabilitation:

The OT worked with FB, her employer and occupational health department to help support management of her condition at work. This included increasing her employer's understanding of the diagnosis (initially through the completion of a report and then through a face to face meeting). A review of her work roles and responsibilities was undertaken and advice given regarding reasonable adjustments to manage her symptoms in the context of her work roles (eg, regular rest breaks and work from home options). A graded return to work plan was established, monitored and adjustments made as necessary. The SALT and CBT were involved in helping FB to manage her verbal dysfluency and anxiety when she was under pressure or stress at work (eg, when having to speak at meetings, managing competing demands).

Relapse prevention plan:

At the end of the OT intervention period a 'staying well plan' and self-management plan was completed.

Positive risk taking using a graded goal setting approach:

Risk management: (Model taken from: the RCOT guidelines: Embracing risk; enabling choice (2017)⁵⁹).

Identified Goal: FB set a goal of being able to take the bus to and from town and work independently. Prior to being signed

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off sick from work, FB had had a DS on the bus during her commute, and she was admitted to A&E. FB was therefore fearful of doing this on her own.

1. *What are the benefits for FB in working towards her set goal?*
Traveling on the bus independently would be of benefit in the following ways for FB:

- Build upon functional endurance and fitness (incidental exercise to and from work).
- Build upon confidence in her abilities to manage her dissociative seizures through the use of learnt grounding / anxiety management strategies.
- Build upon her functional independence and demonstrate to FB the transferability of this goal e.g. being able to use public transport to meet friends in town.
- Gaining independence with this task would assist with management of her mood.

2. *What are the risks involved in working towards the set goal?*
The risk associated with this goal is that FB may have a DS on the bus. This would present a risk to FB but unlikely a serious or life threatening one.

3. *Risk assessment for FB and others:*

Having a DS on the bus was a possibility. FB could hurt herself; she could be vulnerable during an event in public and she may end up being admitted to A&E (ER).

The risk of not undertaking the task would be that FB would remain dependent on her mother for support to access the community or become housebound and she may lose her job. If this was the case then her mood was likely to suffer and her DS may potentially worsen.

4. *Develop a plan to minimise risk to FB. What skills does she bring to the intervention in order to mitigate risk?*

FB was able to recognise when a DS was coming on, eg, she noticed that her hands started to tingle and that she would get sweaty. With practise she was able to make good use of learnt grounding strategies to prevent some episodes of DS from developing.

5. *Record and share the enablement plan:*

Together with FB and her mother a plan for graded task practise was developed, written out and undertaken:

- The OT initially walked with FB to the bus stop and travelled one stop together before returning. FB was supported to use grounding, anxiety management and pacing strategies as required. FB practised this with her mother outside of sessions and was encouraged to progress the number of stops as able. This progressed to FB travelling on the bus to and from her workplace with the OT and then with her mother, outside of sessions.
- When confident FB then followed the above plan with the OT and her mother travelling ahead and meeting her at particular stops and at the work place. This progressed to FB completing this on her own and phoning her mother when she reached the agreed designation and then without phoning.
- FB travelled by herself to her workplace and met her OT there to meet with her employer to discuss a graded return to work plan.

6. *Establish plans for regular review:*

A review of the enablement plan was undertaken with FB throughout step 5 and updates of the progressed goals were completed (using a graded goal setting approach).

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