

Occupational Therapy Consensus Recommendations for Functional Neurological Disorder

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1 **ABSTRACT**

2 **Background**

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

8 **Methods**

9 The recommendations were developed in 4 stages. Stage 1: An invitation was sent
10 to occupational therapists with expertise in FND in different countries to complete
11 two surveys exploring their opinions regarding best practice for assessment and
12 interventions for FND. Stage 2: A face to face meeting of multidisciplinary clinical
13 experts in FND discussed and debated the data from stage 1, aiming to achieve
14 consensus on each issue. Stage 3: Recommendations based on the meeting were
15 drafted. Stage 4: Successive drafts of recommendations were circulated amongst
16 the multidisciplinary group until consensus was achieved.

17 **Results**

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

24 **Conclusions**

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

28

1 INTRODUCTION

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

7 Functional neurological disorder (FND) is characterised by symptoms of altered
8 voluntary motor or sensory function with clinical findings providing evidence of
9 incompatibility between the symptoms and recognised neurological or medical
10 conditions.[1] Symptoms are diverse and can include weakness, movement
11 disorders (tremor, jerks, dystonia), sensory symptoms, cognitive deficits and seizure-
12 like events (commonly known as dissociative seizures or non-epileptic seizures).
13 Fatigue and persistent pain are also commonly experienced as part of the disorder.
14 Symptoms can present acutely and resolve quickly or can be long lasting.
15 Regardless of duration, those affected frequently experience high levels of distress,
16 disability, unemployment, social care utilisation and reduced quality of life.[2] The
17 stigma associated with FND contributes to the burden of the diagnosis.[3]

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

25 The current evidence base for OT in FND rehabilitation is limited to several studies
26 of multidisciplinary rehabilitation,[6–9] including one with a randomised design.[10]
27 The interventions delivered by OTs in these studies are described only briefly, they
28 include; retraining normal movement within function, graded re-introduction to daily
29 activities, anxiety management and the re-establishment of structure and routine.
30 Outcomes from these studies are promising, reporting improvement in scales of
31 physical function and quality of life, immediately after treatment and at follow up
32 periods of 12 to 25 months.[7–9] High levels of patient acceptability have been

1 shown in at least one study which identified that OT compared favourably to other
2 treatments.[9] Evidence from randomised control trials is needed to demonstrate
3 effectiveness of the specific rehabilitation interventions described in these studies.

4 In summary, OT is recognised as part of MDT intervention for FND, however there is
5 a limited evidence base and the role of OT within the MDT is not well defined. With
6 this paper, we aim to develop a broad set of consensus recommendations to guide OT
7 practice for people with FND across the range of clinical settings (hospital,
8 rehabilitation ward, community) and time following symptom onset (acute to chronic).
9 These recommendations come from our experience working with people with FND
10 aged 16 and over, however recommendations may have transferability to adolescent
11 and paediatric populations. This work aims to complement existing clinical
12 recommendations for FND [11, 12] and to form a starting point from which to develop
13 evidence-based interventions.

14

15 **METHODS**

16 **Consensus Process**

17 Data collection and analysis was based on a Delphi method, with 4 key stages.

18 *Stage 1.* In 2017/18 12 OTs from different countries with extensive experience in
19 FND were invited to complete 2 online surveys exploring assessment and
20 interventions for FND. The surveys were developed, data collated and summarised
21 (by CN). Elaboration and clarification were sought through a series of follow up
22 emails.

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

26 *Stage 3.* Recommendations based on the meeting were drafted.

27 *Stage 4.* A series of drafts were sent to the multi-disciplinary group for feedback.
28 Participants either endorsed each section of the draft or provided comments and
29 suggestions. This process continued until a consensus was reached.

30

1 **Participants**

2 *Occupational Therapists*

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

9 *Multidisciplinary Clinician Group*

10 There were representatives from neuropsychiatry (n=1), neurology (n=2), neuro-
11 physiotherapy (n=2) and neuropsychology (n=1). There was also service user
12 (patient and public) representation (n=2).

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

15

16 **Conceptualisation of FND / Aetiological Model**

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

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

1 People with FND commonly experience other health problems; this can include
 2 psychiatric comorbidity, coexisting neurological disease and other functional
 3 symptoms. Common coexisting symptoms such as chronic pain and fatigue are often
 4 important determinants of disability and quality of life. [13, 14]

5

6 **Table 1. Potential pre-disposing, precipitating and perpetuating factors for**
 7 **FND (adapted from Stone, 2009 [15])**

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 (e.g. drug side effect) Abnormal physiological event (e.g. hyperventilation, 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	Illness beliefs (person and significant others) Feeling disbelieved	Diagnostic uncertainty (e.g. ongoing medical investigations) Reliance on care and benefits

	De-conditioning Fatigue Chronic pain	Maladaptive behaviours Co-morbidities including anxiety and depression	Compensation claims Ongoing social stressors (e.g. relationship difficulties, financial hardship, loss of roles)
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1

2 **Role and Rationale for Occupational Therapy for FND**

3 The term 'occupational' in OT refers to any activity that has meaning and importance
4 to an individual, based on what they need to do, want to do or are expected to do
5 within societal and cultural norms.[16]

6 **Common Reasons to Refer to Occupational Therapy:**

- 7 • Disability affecting participation in daily activities (e.g. personal care, domestic
8 activities, childcare, community or leisure activities).
- 9 • Determining care needs for people with disability.
- 10 • Difficulty accessing home, education, work or community environments.
- 11 • Vocational rehabilitation and support to sustain paid employment, education,
12 voluntary roles.
- 13 • Pain, fatigue, mental health and cognitive difficulties which impede activity
14 engagement.

15

16 **When and How to Refer to Occupational Therapy**

17 OTs can be involved from symptom onset to support in the community. It is
18 preferable that a physician makes and explains the diagnosis to the patient prior to
19 referring for treatment.[17, 18] We suggest sharing clinical consultation letters with
20 the treating therapy team and the patient. A referral letter should include information
21 such as the diagnosis, assessment findings, results from medical investigations,
22 follow up plans, other professionals involved and reason for referral.

1 Different factors may influence the suitability for treatment. The group suggest that
2 OT intervention is more likely to be successful if the person with FND;

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

9 It is not uncommon for people to lack confidence in the diagnosis of FND.

10 Through providing education about the diagnosis at a level that is accessible to
11 the patient, OT can help to turn around low diagnostic confidence. In instances
12 where there is still doubt, we would suggest that OT can still be of benefit by
13 focusing on the impact of symptoms on function rather than addressing
14 symptoms at a diagnostic or impairment level. However, where there is strong
15 disagreement about the diagnosis, therapy is much less likely to be helpful.

16

17 **Assessment and Outcome Measurement**

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

- 23 1. Ask the person about when and how their symptoms started.
- 24 2. Create a list of current symptoms. For each symptom, ask about exacerbating and
25 easing factors, variability, severity and the impact on function.
- 26 3. Clarify the person's understanding of their diagnosis and whether they are in
27 agreement with it.
- 28 4. Ask about other health problems and past medical history (including psychological
29 health).

- 1 5. Take a detailed social history, exploring usual roles, responsibilities and
2 meaningful activities.
- 3 6. Gain a picture of their 24-hour routine. This is helpful to uncover symptom
4 perpetuating factors such as poor sleep hygiene, boom and bust activity patterns,
5 lack of occupation and structure.
- 6 7. Determine if they have care needs and if so, are these needs being met and by
7 whom?
- 8 8. Ask about access to the home, education or work environment and the use of
9 environmental adaptations and aids.
- 10 9. If they are in work or education, ask about the impact of their symptoms. If
11 unemployed or retired, it may be appropriate to ask about receipt of benefits /
12 insurance.
- 13 10. Undertake an observation of daily activities (e.g. personal care, meal
14 preparation, functional transfers etc) to establish the impact of symptoms on activity
15 engagement. During observation, note distractibility and variability of symptoms so
16 that these can be discussed in a supportive way.[19]
- 17
- 18 Identify the person's goals for treatment and their expectations of OT. It is important
19 to come to a shared understanding of what treatment can be offered; a verbal
20 agreement at the start of intervention can prevent potential difficulties when
21 concluding treatment. We suggest discussing that OT intervention will be directed by
22 the goals or problems that the person has identified and that independent practise
23 outside of sessions will be required. If, after some discussion the person is unable to
24 identify goals or areas of need, then it may be appropriate to discuss whether OT
25 intervention is right for them at this time.
- 26
- 27 Unique to OT is the use of occupation-based conceptual models of practice which
28 guide intervention. The two models of practice most commonly used by the
29 consensus group are The Model of Human Occupation (MOHO) and The Canadian
30 Model of Occupational Performance and Engagement (CMOP-E).[20, 21] Other

1 models may be helpful, but these two were favoured owing to their links with well-
 2 established tools which are used by the consensus group to guide assessment and
 3 intervention with FND (see Table 2). Although none have been specifically validated
 4 in an FND population, these tools can be also be used to measure the outcomes of
 5 intervention.

6

7 **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. [22]
Occupational Circumstances Assessment Interview and Rating Scale (OCAIRS)	Semi-structured 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. [23]
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.[24]
The Model of Human Occupation Screening Tool (MOHOST)	Assesses the impact of a person’s volition, habituation, skills and environment on their occupational functioning.[25]

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.[26]
Adolescent and Adult Sensory Profile	Evaluates behavioural responses to everyday sensory experiences. Used for ages older than 11.[27]
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.[28]

1

2 There is an absence of clinically useful, validated outcome measures specific to
3 FND. Assessing change in FND is challenging due to the heterogeneity of
4 presentations, variability of symptom severity and multiple interacting comorbidities.
5 Outcome measures should therefore address multiple domains including physical
6 function and disability, quality of life, mental health, health care utilisation and
7 perception of symptom severity. We direct readers to a recent systematic review of
8 outcome measurement in FND and recommendations by Nicholson et al (2019) and
9 Pick et al (2020).[29][30]

10

11 **Occupational Therapy Treatment**

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

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

8

9 *Goal Setting*

10 Goal setting is generally considered an important part of OT intervention.[31] Goal
11 setting with people with FND can differ from methods used in typical
12 neurorehabilitation settings, for example after stroke, where therapists may be able
13 to relatively accurately predict recovery and help set realistic goals. With FND, it can
14 be helpful to consider that recovery often follows a pattern of symptom remission and
15 exacerbation. For this reason, most of the consensus group reported that they take
16 a more flexible approach to goal setting; goals are set by the person with FND, in
17 their own words and may not necessarily be time dependent.

18

19 *Education*

20 Education to improve understanding about symptoms is widely considered to be an
21 important part of FND treatment.[32, 33] Helping people with FND to understand the
22 diagnosis can improve their confidence that it is correct and builds the foundations
23 for rehabilitation and self-management. It is important that occupational therapists
24 are aware that there is often stigma attached to the diagnosis of FND. Patients report
25 that interactions with health care professionals have often left them feeling
26 misunderstood and abandoned by the health care system. [3] Clinicians should
27 therefore be mindful to impart information with empathy and sensitivity, emphasising
28 the genuine nature of symptoms. Education should include how activities and
29 occupations, combined with taught strategies, form part of symptom management. It
30 is important to pitch education at the right level, recognising the person's attitude,
31 knowledge and skills in order to change, support and enhance occupational

1 performance. [34] See Box 1 for points that can be included in an explanation of
2 FND and the role of OT.

3

4 **Box 1. Ingredients of education about FND**

5 1. Acknowledge that FND is a real, common and disabling condition that causes
6 neurological symptoms that are outside the person's control.

7 2. The symptoms of FND are caused by a potentially reversible miscommunication
8 between the brain and the body.

9 3. Discuss that FND is diagnosed by a neurologist using 'positive clinical signs' (e.g.
10 Hoover's sign, distractibility, entrainment of tremor, variability in symptoms during
11 function) and is not a diagnosis of exclusion. It can be diagnosed alongside other
12 neurological conditions.[19]

13 4. Help the person understand the relevance of triggering events if they report them.
14 [11]

15 5. Discuss how self-directed attention can make symptoms worse and conversely
16 redirecting attention (distraction) can temporarily reduce symptoms.

17 6. Provide education on how the body's stress response can influence functioning of
18 the nervous system and therefore FND.

19 7. Discuss how symptom focus and chronic health conditions can exacerbate or
20 cause cognitive difficulties, fatigue, anxiety, low mood and pain.

21 8. Discuss the role of OT in treating FND.

22 9. Discuss the importance of a 24-hour approach to therapy; that is implementing
23 rehabilitation strategies throughout the daily routine as part of self-management.

24 10. Signpost to sources of information including: www.neurosymptoms.org and to
25 patient-led organisations, for example FND Hope International, FND Hope UK, FND
26 Hope US, FND Hope Canada, FND Action (UK), FND Dimensions (UK), FND
27 Australia Support Services. The book: Overcoming Functional Neurological
28 Symptoms: Five Areas Approach [32] can be a useful resource in helping people

1 understand symptoms and management strategies, especially in those that
2 recognise anxiety and/or mood instability to be part of their problem.

4 *Vocational Rehabilitation*

5 OTs have a key role in supporting people with FND to manage their condition in the
6 context of work and/or study.[35] We suggest that vocational rehabilitation principles
7 for neurological rehabilitation can be applied to people with FND.[36] This includes
8 helping employers and educators to understand that they have genuine symptoms
9 which may vary in severity, with possible periods of remission and exacerbation. OTs
10 can work jointly with occupational health departments to identify and advocate for
11 reasonable adjustments to improve work performance and symptom management.
12 This may include role modifications, reduced hours, regular rest breaks and flexible
13 working options. Another important aspect of vocational rehabilitation is to develop a
14 graded return to work/study following a period of sick leave.[37]

15
16 Sustaining paid employment is likely to be important in maintaining good health,
17 however, in some cases it may not be possible for the person to continue despite
18 reasonable adjustments.[38] In these cases, the consensus group suggest that OTs
19 can have a role in supporting people with FND to positively withdraw from their
20 current role and seek alternative roles (paid or unpaid).

23 *Aids and Adaptations*

24 The use of aids and equipment is generally thought to be unhelpful to the
25 rehabilitation process in FND, potentially preventing future improvement by
26 interrupting normal automatic movement patterns and causing maladaptive ways of
27 functioning. It is important to recognise that aids and equipment can cause new
28 secondary problems such as joint pain (e.g. shoulder pain from walking with
29 crutches) and deconditioning of muscles.[11] The group endorsed these concerns,
30 but recognised that there are times when providing adaptive equipment is
31 appropriate and/or necessary. Each case should be considered individually. It can be
32 helpful to consider the person's journey, differentiating the acute phase where

1 improvement is more likely, from situations where people have treatment resistant
2 symptoms. In the acute phase, it is advisable to avoid aids and environmental
3 adaptations. If aids are necessary, for example to enable a safe discharge from
4 hospital, equipment should be; (i) considered as a short-term solution; (ii) issued with
5 a minimalist approach and (iii) a plan to progress from its use. It is important to
6 assess the person with new equipment and teach them how to use it correctly to
7 minimise maladaptive movement patterns. Follow up appointments should be
8 available to monitor equipment use and support plans to progress towards
9 independence.

10 For people who have completed rehabilitation but experience ongoing disability it is
11 reasonable and appropriate to consider aids and environmental adaptations.
12 Equipment should maximise safety, increase independence, improve community
13 access and have an overall positive impact on quality of life. See the online extended
14 version of this document for further details.

15

16 *Splinting*

17 As with adaptive aids, splinting may prevent restoration of normal movement and
18 function. Potential problems with splinting are (i) increasing attention and focus to the
19 area, thereby exacerbating symptoms; (ii) increasing accessory muscle use, (iii) use
20 of compensatory movement strategies, (iv) immobilisation leading to muscle
21 deconditioning; (v) learnt non-use, and (vi) increased pain. Serial casting for fixed
22 functional dystonia has been associated with worsening symptoms and the onset of
23 complex regional pain syndrome.[39, 40]

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

30

31 **Symptom Specific Treatment Suggestions**

1 *Functional Motor Symptoms*

2 Functional motor symptoms include tremor, weakness, dystonia, gait disorder and
3 jerks. Movement strategies that redirect attention away from the body can help to
4 reduce motor symptoms and normalise movement (see Table 3 for examples). OTs
5 can help people identify and practise normal movement strategies and integrate
6 them into daily activities.

7

8 **Table 3. Examples of intervention strategies for functional movement**
9 **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 (e.g. tapping/opening and closing the hand), that is entrain the tremor to stillness. 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) e.g. handwriting re-training; 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 pre-jerk cognitions and movement (e.g. signs of anxiety, frustration or effort, such as breath-holding).- General relaxation techniques; diaphragmatic breathing or progressive muscular relaxation.

	<ul style="list-style-type: none"> - Sensory grounding; a strategy which can be used to bring oneself into the present moment [41](e.g. noticing details in the environment (sounds, sights, smells), feeling a textured item, cognitive distractors such as counting backwards, 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 (e.g. 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 over-activity, pain and fatigue e.g. 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), 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 whilst standing with the aid of a standing frame.
<p>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 (e.g. in tremor amplitude or extinction). It can demonstrate changeability, highlight successes (and build confidence) and act as a reference point for replication of strategies outside of therapy.</p>	

1

2 *Functional Visual Impairment*

3 Functional visual loss may be experienced as a persistent absence of vision,
4 intermittent loss of sight or reduced visual acuity.[42] While the person may
5 experience a lack of vision, it is usually possible to observe actions that demonstrate
6 that they are making use of visual information in an automatic (or subconscious)
7 way. For example, they may avoid obstacles while walking or pick up an object
8 without guidance. Whilst there is little published information regarding treatment,
9 there was experience within the consensus group of helping people with functional
10 visual loss, including a description of treatment for two patients who had a positive
11 outcome.[43] This approach included (i) helping the person understand the diagnosis
12 and (ii) sensitively communicating to the person and positively reinforcing events
13 when they are likely to have used visual information (albeit without awareness). OT
14 intervention should aim to prevent activity avoidance and dependence on others.
15 OTs also have a role in assisting to minimise secondary problems associated with
16 light hypersensitivity, agoraphobia and unhelpful behaviours such as keeping the
17 eyes closed.

18

19 *Functional Cognitive Impairment*

20 Cognitive symptoms are common in FND either as a primary problem or as part of a
21 combination of symptoms. Several factors can contribute to cognitive problems
22 including pain, fatigue, anxiety, low mood, poor sleep, sensory hypersensitivity,
23 symptom focus and medication side effects.[44] Before advising practical cognitive
24 strategies, it is helpful to discuss the link between potential contributing factors and

1 cognitive function. The aim is to understand, and where appropriate normalise, these
2 experiences and reframe the symptom as part of FND rather than an additional
3 health problem. Discussions should help the person to understand that their
4 cognitive skills are likely intact (unless there is underlying co-morbidity), but multiple
5 factors are competing for their cognitive resources.

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

18

19 *Dissociative (non-epileptic) Seizures (DS)*

20 Dissociative seizures (DS) are a specific presentation of FND characterised by
21 temporary episodes of impaired awareness. The episodes may resemble epilepsy or
22 syncope but they are not associated with abnormal electroencephalography
23 changes. DS are a common reason for frequent attendance to accident and
24 emergency.[45] Acute hospital admissions can be highly distressing and are usually
25 unnecessary for DS. The main evidence-based treatment for DS involves
26 psychological therapy, delivered by specially trained clinicians.[46] Here we provide
27 ways in which core OT skills can be used to help people with problems associated
28 with DS. See the online extended version of this document for further information.

29 A good place to start treatment is to ask the person how they wish to be supported if
30 they have a DS during a therapy session. They may have devised a plan with other
31 clinicians which you can follow. If not, this could be an initial focus of OT intervention.
32 A DS plan can help put clinicians at ease and make the person feel safer which may

1 prevent escalation and reduce duration of the episode.[47] Important elements are to
2 help the person to a safe space where they are unlikely to injure themselves. Let
3 them know they are safe but avoid constant reassurance and physical contact or
4 restraint. Advising others to behave as they would if someone is having a panic
5 attack can be helpful. People can sometimes hear and understand what you say
6 during a DS, even if they are unable to respond.

7 Ask about triggers and warning signs of an imminent episode. It is common for
8 people to report having no memory of events prior to and during a DS, however after
9 some discussion many start to recognise patterns. Taught strategies to avert an
10 event can then be integrated at the point of a warning sign occurring.[48] A group of
11 strategies that can be helpful are Sensory Grounding Techniques, which aim to keep
12 people present in the moment and focus attention to prevent dissociation.[41] Some
13 examples include noticing the detail in the environment (e.g. colours, textures,
14 sounds); cognitive distractions (e.g. word games, counting backwards); sensory
15 based distractors (e.g. flicking a rubber band on the wrist, feeling a textured item).

16

17 **Common Problems Associated with FND**

18 *Hypersensitivity*

19 Many people with FND report hypersensitivity to touch, light, sound and movement.
20 Specific terms have been used to describe these problems, including sensory
21 modulation difficulties, sensory defensiveness and sensory over-responsiveness.
22 [27, 49] These symptoms are not unique to FND, in fact they are also common in
23 people with other diagnoses, such as migraine, chronic pain and fatigue. It is
24 important to address hypersensitivity as it can become a maintaining factor, resulting
25 in avoidant behaviours, limiting participation in functional activities and exacerbating
26 other symptoms and disability.

27

28 The experience of hypersensitivity can influence the pace and intensity at which
29 treatment can be delivered and should therefore be carefully assessed and
30 considered as part of triage and treatment planning. UK group members outlined
31 that sensory hypersensitivity (for people with FND) tends to be addressed within
32 function by encouraging graded exposure to various sensations experienced within

1 the persons day-to-day routine. The UK group also endorsed gradual minimisation
2 of compensatory techniques such as use of sunglasses when indoors for
3 photophobia or the use of headphones or ear plugs for auditory sensitivity or the
4 more content-specific misophonia, as these are thought to perpetuate and
5 exacerbate hypersensitivity. In some settings in the USA, treatment and assessment
6 of sensory modulation difficulties are based on the Jane Ayers Theory of Sensory
7 Integration.[50] The Adolescent/Adult Sensory Profile (AASP) assessment tool can
8 be used to direct the development of a personalised sensory exposure regimen.
9 This regimen may combine compensatory strategies to inhibit and grade exposure to
10 sensory sensitivities alongside sensory-based activities to better regulate emotional
11 responses, improve cognitive functioning and increase functional participation.

12

13 Hypersensitivity of the skin or allodynia is a common secondary consequence of
14 “fixed” functional dystonia (as are other trophic changes associated with complex
15 regional pain syndrome).[39] Unchecked, hypersensitivity can lead to problems
16 associated with learnt non-use (e.g. further pain and hypersensitivity, muscle atrophy
17 and discomfort associated with over-use of the unaffected side). OTs can encourage
18 graded use of the affected limb whilst gradually reducing protective postures. For
19 instance, promotion of arm swing in walking, weight-bearing in sitting or standing,
20 bilateral upper limb use in activity. Graded exposure to different sensory experiences
21 may help to normalise sensation, for example, wearing clothing on the affected limb,
22 applying moisturiser, washing up in warm water.

23

24 *Anxiety*

25 Although not universal, anxiety is common in FND and may act as a symptom
26 precipitating or perpetuating factor. Some people may experience the physiological
27 and somatic consequences of anxiety (e.g. racing heart rate, tight chest, etc) without
28 recognising the experience emotionally. This has been described as panic without
29 panic or alexithymia.[51] OTs can help to address anxiety through education by
30 describing the physiological process of anxiety and its physical impact on the body.
31 The concept of a fight or flight response may be useful for patients who do not
32 identify as feeling anxious. OTs can help people identify how anxiety interacts with

1 FND symptoms to impede involvement in daily activities and implement anxiety
2 management strategies. This can include breathing techniques, progressive muscle
3 relaxation, grounding strategies, visualisation, distraction, thought re-framing,
4 mindfulness, integrating activities of enjoyment, regular cardiovascular exercise and
5 supporting the person to undertake an anxiety provoking task in graded steps.

6

7 *Fatigue and Pain Management*

8 People with FND often experience pain and/or fatigue. These can be disabling
9 symptoms and should therefore be considered as part of any intervention. Evidence
10 for the management of pain and fatigue in other long-term conditions currently exist
11 and can be adapted for use in FND.[52, 53]

12

13 *Psychological Trauma*

14 A systematic review found that serious adverse life events are more common in
15 people with FND compared to the general population.[54] Of note, childhood neglect
16 was found to be a greater risk factor than physical or sexual abuse. Importantly,
17 adverse life events were not universal, and even if present, may be relevant to some
18 but not all as also evidenced by a recent case controlled study exploring pre-
19 disposing risk factors for functional limb weakness.[55] For some people,
20 addressing the impact of adverse events (e.g.in in Post-Traumatic Stress Disorder)
21 may be a necessary part of treatment. For others, a more symptom focused
22 intervention may be appropriate. The group felt that addressing the sequelae of
23 psychological trauma is not a generic OT role. Some OTs have sufficient experience
24 and qualifications to manage difficulties that arise from serious mental health
25 problems, but this usually is the result of additional training and accreditation.
26 However, people sometimes disclose information about traumatic events during OT
27 intervention. It is therefore important that therapists have the skills to listen and
28 contain the person's distress. Using reflexivity to acknowledge one's own limitations
29 within the context of your professional role is imperative. There are some OTs who
30 may feel more capable in managing trauma due to their skill set and practice setting
31 (e.g. mental health or neuro-psychiatry settings). Less experienced clinicians should

1 be encouraged to seek supervision and support. Knowing who to refer on to if a
2 person discloses trauma (and consents to onward referral) is important and clear
3 lines of how to do this should be established.

4

5 *Risk Management*

6 People with FND often disengage from usual activities due to a perceived risk to
7 their personal safety, (e.g. fear of having a DS upon leaving the house). It is an OTs'
8 role to help manage risk and increase independence by enabling people to engage
9 in activities through a process of supported positive risk taking. This concept is
10 explored in a recently published guidance document for occupational therapists in
11 the UK, 'Embracing risk; enabling choice'.^[56] The identified principles can be
12 applied to working with people with FND and the group endorses its guidance.
13 Further information is available in the extended online document.

14

15 *Disability Management*

16 *Care*

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

21 *Benefits*

22 People with FND are entitled to health and social care benefits / insurance but many
23 find the systems involved difficult to navigate. It may therefore be necessary and
24 appropriate for OTs to support applications for benefits and insurance claims. This
25 may involve liaising with agencies, supporting the completion of paperwork and
26 advocating on the person's behalf regarding the potential benefit of undergoing
27 specialist rehabilitation (e.g. a letter outlining treatment options and the evidence
28 base). A simple "to whom it may concern" letter, describing a person's diagnosis,
29 articulating the finer details of the condition (e.g. variability of symptoms), impact on
30 function and their support needs can be a valuable tool to help people negotiate with

1 relevant agencies. When patients are on the cusp of eligibility for benefits and
2 undergoing treatment, an open discussion about whether they wish to defer
3 application until they see the outcome of treatment may be appropriate.

4 *Housing*

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

13

14 *Relapse Prevention / Staying Well Plan*

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

21 1. What have you learnt about your condition?

22 2. What makes your symptoms worse? / What might trigger setbacks?

23 3. What are the most helpful management strategies that you have learnt?

24 4. What were the unhelpful coping strategies that were making it difficult for you to
25 improve?

26 5. What can you do if you notice that your symptoms and function are getting worse?

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

29

1 *Concluding Treatment*

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

10

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

20 See Box 2 below for a summary of the intervention principles for OT and FND
21 suggested in this document.

22

23 **Box 2. Summary of intervention principles for Occupational Therapy and 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.

1

2 **LIMITATIONS**

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

12

13 **CONCLUSIONS / SUMMARY**

14 FND is a complex condition that has far reaching consequences on physical and
15 psychological health, occupational participation and quality of life. Current best
16 practice is for multi-disciplinary rehabilitation, of which OT is a part. However, there
17 are few resources available to help guide OT assessment and intervention. Here we

1 provide recommendations for OT assessment and intervention for people with FND,
2 considering their journey from acute presentation to support in the community. The
3 information within this document highlights the important role of OT in helping people
4 with FND and may have relevance for other professional groups. Future research
5 should seek to test the individual components of these recommendations and
6 explore the potential for cost benefit.

7

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9

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17

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6 Nil

7

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10

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