



Functional Neurological Disorder

Patient workbook

Functional Neurological Disorder workbook

This workbook has been developed to help you on your recovery journey. It is a tool which can help you to better understand Functional Neurological Disorders and where you can keep track of what you have learnt and accomplished from the various therapies.

How to get the most from this workbook

This workbook requires maximum participation in all therapeutic activities. Written reflections can also help you to understand the condition and goal of therapies, there will be spaces provided for you to reflect if you wish.

The workbook is not a stand-alone tool and must be used together with your treating team. It is designed as a visual companion to help you on your journey.



MY TURN—This symbol indicates a task for you to complete at various stages of your program. Your therapist may ask you to complete tasks at the end of a session in preparation for the next session.

Our Mission

"In the spirit of the Sisters of Mercy, the Mater Hospital offers compassionate service to the sick and needy, promote a holistic approach to health care in response to changing community needs and foster high standards in health-related education and research. Following the example of Christ the Healer, we commit ourselves to offering these services to all without discrimination."

Our Values

Care: The spirit of compassion

Mercy: The spirit of responding to one another

Dignity: The spirit of humanity, respecting the worth of each person

Quality: The spirit of professionalism

Commitment: The spirit of integrity

Made in collaboration with





You have been diagnosed with a Functional Neurological Disorder (FND) and accepted to our service.

For those who participate in our program, our treatment team is committed to giving you the highest standard of care, and to help you achieve the best possible outcomes. Our multi-disciplinary treatment program is individually tailored to each person's needs and requires your active participation. You must bring to the program a willingness to work hard and an openness to learn new strategies and then apply the principles you learn from the program to life at home.

A good level of understanding about FND can have a major impact on your outcomes, so please do read the information you are given by our team and get back to us with any questions.

Our multi-disciplinary approach requires you to attend all your referred (i.e. physiotherapy, psychology, psychiatry) inpatient/outpatient appointments you are booked in for.

You will be discharged entirely from our service if you fail to do so.

Thank you.

I, _____ agree to the above terms and conditions of care.

Signed: _____ Date: ____ / ____ / ____

Introduction

What is FND?

FND are a collection of symptoms such as blackouts, paralysis and abnormal movements that suggest the presence of an underlying neurological condition, but, none of the symptoms are explained by disease. FND is caused by a complex combination of biological, psychological and social factors on the brain.

Who is at risk?

No single mechanism has been identified as sufficient to explain the onset of FND, but rather,

several interacting factors. The table on the next page shows the biological, psychological and social factors which may contribute to FND.

Why is this happening to me?

The cause of FND is not entirely known but there are effective treatments available. This is similar to diseases like Parkinson's disease as it is not known what causes people to develop Parkinson's disease, however there are many effective treatments that are used to manage symptoms.

Table 1: Potential contributing factors of FND

Factors	Biological	Psychological	Social
Factors acting at all stages	<ul style="list-style-type: none"> • 'Organic' diseases • Female gender • History of previous functional symptoms 	<ul style="list-style-type: none"> • Emotional disorder • Personality disorder 	<ul style="list-style-type: none"> • Socio-economic/deprivation • Life events and difficulties
Predisposition (vulnerabilities)	<ul style="list-style-type: none"> • Genetic factors affecting personality • Biological vulnerabilities in the nervous system 	<ul style="list-style-type: none"> • Perception of childhood experience as adverse • Personality traits • Poor attachment/coping style 	<ul style="list-style-type: none"> • Childhood neglect/abuse • Poor family functioning • Symptom modelling of others
Precipitants (triggers)	<ul style="list-style-type: none"> • Abnormal physiological event (drug side effect, hyperventilation, sleep deprivation) • Physical injury/pain 	<ul style="list-style-type: none"> • Perception of life event as negative/unexpected • Acute dissociative episode/panic attacks 	<ul style="list-style-type: none"> • Bereavement
Maintaining factors	<ul style="list-style-type: none"> • Plasticity in central nervous system motor and sensory pathways leading to habitual abnormal movements • Deconditioning • Neuroendocrine and immunological abnormalities similar to those seen in depression/anxiety 	<ul style="list-style-type: none"> • Illness beliefs • Perception of symptoms as being irreversible • Not feeling believed • Perception that movement will cause damage • Avoidance of symptoms • Fear of falling • Hypochondriasis 	<ul style="list-style-type: none"> • Social benefits of being ill • Availability of legal compensation • Ongoing medical investigations and uncertainty • Excessive reliance on sources of information or group affiliation which reinforce beliefs that symptoms are irreversible and purely physical in nature

Symptoms

The two most common groups of FND are:

Functional motor disorders:

These can include a range of sometimes debilitating symptoms, such as:

- limb weakness
- tremor (shaking)
- dystonia (abnormal posturing)
- gait disorders
- dysphagia (difficulty swallowing)

Dissociative attacks

Often referred to as non-epileptic seizures/attacks, these episodes involve altered movements, sensations or experiences that closely resemble epileptic seizures, but are not associated with electrical discharges in the brain. The most common symptoms are excessive movements of limbs, trunk and head; stiffening; tremor; muscle weakness and loss of responsiveness may also occur.

The driving force behind these attacks is **dissociation**. This is frequently a response to

mental, physical (including sensory overload) or social stressors. Dissociation can involve feeling disconnected from the body (e.g. thoughts, feeling, sensations) and/or disconnected from the surroundings. People often describe dissociation as feeling spacey, zoning out, or as though the brain has shut down. Some people may be aware of warning signs or triggers to the episodes, however, for others they can seem to happen automatically.

We avoid using the term seizures to describe these events as it may confuse health practitioners into thinking that you have epilepsy. Instead we use the term dissociative events/attacks to help distinguish between epilepsy and dissociation.

Other symptoms

When suffering from a functional neurological disorder people often have several other symptoms such as chronic pain, fatigue and difficulty with cognitive function (i.e. poor memory and problems with concentration) and sensory symptoms such as numbness and tingling are commonly described.

Meet your team

After receiving a diagnosis of FND from your neurologist you will be treated by a team of health professionals. This team has been assembled by your neurologist to give you the best possible treatment. Team members may include: physiotherapists, psychologists, occupational therapists, psychiatrists, speech pathologists and nurses. Your treatment team is very experienced in treating FND and will help you answer any questions you have.

Below you will find an explanation of each team member's role:

Allied Health Professionals

Patients with physical symptoms (disturbances with walking, weakness, problems speaking) will often need physical treatment. Allied health professionals including: speech therapists, occupational therapists and physiotherapists are vital in the recovery process.

Physiotherapists offer education, movement retraining and self-management strategies. Recent research has shown increased improvements in functional motor symptoms in people with FND who work closely with physiotherapists.

Psychosocial Occupational Therapists (OTs) focus on life activities important to you. They will work with you to help you understand how your daily activity is motivated, organised into everyday life patterns, and performed in the context of your environment. OTs also will explore meaningful activity options to assist you. If you have any leisure activities you are working on, please let your team know.

Speech Therapists work with people who have difficulty swallowing, producing clear speech, and expressing or understanding language. Speech therapists work with you to determine your goals for intervention, develop self-management strategies, and retrain skills in speech, language and swallowing.

Nurses play a critical role in FND patient care especially during inpatient stays. They provide round the clock care to you and are able to help monitor your progress outside of therapy sessions. Nurses are also able to help you reinforce positive behaviors and strategies taught to you by your therapists by guiding patients through the reflective practice model.

If you have any problems during an inpatient stay your nurse will be the first point of contact. Please let them know if you need any assistance as they will be able to help you.

Psychiatrists are medical doctors with expertise in the diagnosis and treatment of mental health conditions. They have a deep understanding of physical and mental health and how they affect each other. They are able to prescribe and monitor medication.

Psychologists can help you to better understand FND and learning strategies to help cope and manage symptoms. Many patients with FND benefit from seeing a psychologist. Your psychologist will mostly use cognitive behavioral therapy (CBT) to treat symptoms.

CBT is a short term, practical style of talk therapy that involves identifying patterns of behaviors (what you do), cognitions (thoughts and interpretations) and emotions that contribute to and worsen symptoms.

Sessions typically address:

- Education about symptoms
- Techniques for interrupting warning signs at the start of an episode and strategies for managing symptoms when they occur
- Working to increase participation in activities that have been avoided or discontinued because of symptoms, mood or anxiety
- Tackling unhelpful thoughts that may influence symptoms, self-esteem, mood and anxiety

The table following shows how thinking can have an impact on FND:

Table two: Example of changes in thoughts and behaviours of patients with FND accompanied by a good understanding of their symptoms.

	Dissociative attacks	Functional weakness
Old thought	"Oh no! What is happening to me? Do I have epilepsy? Am I going to die during one of these attacks?"	"Do I have multiple sclerosis? I'm going to end up in a wheelchair!"
Old behaviour	Avoid social interactions, tendency to succumb to attacks as a way of getting rid of warning symptoms.	Seeing many specialists, not doing much just in case symptoms worsen.
New thought	"I'm having a dissociative attack—these are not harmful for me and I can see if I can manage this.""	"It's a strange diagnosis but seems like I have the potential to get better."
New behaviour	Tries distraction techniques during warning signs to negate attacks.	Gradually exercises, learn to expect flare ups, good days and bad days.

Medications

It is important to remember that there is no magic pill to cure FND and generally pharmacological (tablet) therapy is not helpful in the treatment of FND. One situation where it can be beneficial is in treating high levels of depression anxiety (which can reduce the effectiveness of therapy).

Medications can also help to reduce high levels of pain which can then enable you to participate in therapeutic sessions more actively.

It is important to let your doctor know if you are taking any medications.



MY TURN: What are the names of my treating team and their roles?

Team member	Name	Role

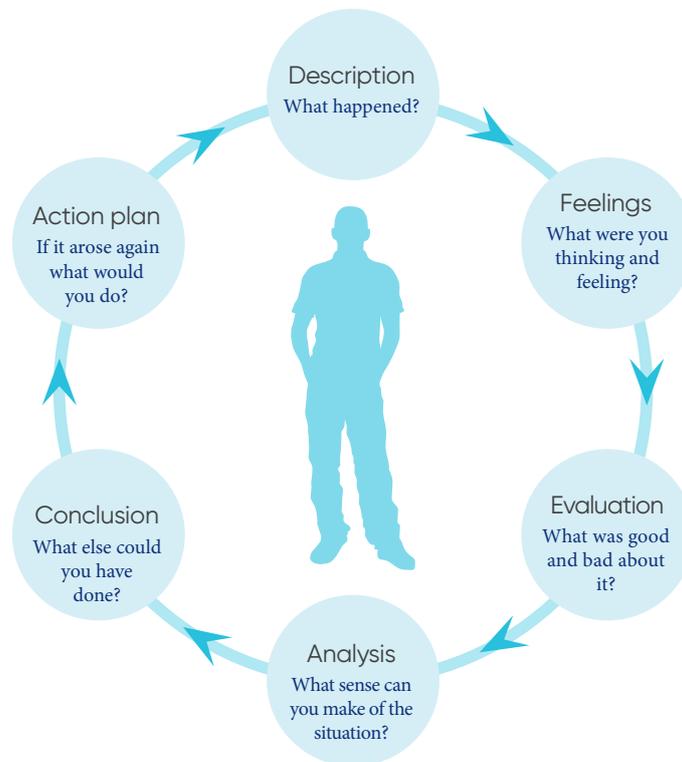
Reflective thinking

Below is the reflective cycle model. If you experience a flare up of FND symptoms we will assist you by talking to you using this model.

The aim of this reflective process is to try and uncover or discover what is triggering the symptoms flare-ups and to try and find good strategies which can help to stop or alleviate symptoms. It is often helpful to write down your reflections as they can help you to see patterns in your symptoms.

Nurses will use this model when you have flare ups. It is important that you understand this process and why nurses are asking you questions when you experience symptoms.

Figure one: The reflective cycle model. This is a useful tool that patients can use to see patterns in their symptoms



When I am not getting better

Unfortunately it is not guaranteed that every patient with FND will respond well to treatment. There are various factors that may influence your progress. A significant factor for poor recovery is a lack of understanding or acceptance of the diagnosis of FND.

A good grasp of the diagnosis of FND greatly increases your chance of recovery, but it is important to remember there are patients who understand their diagnosis and comply with their therapy programs and are still unable to achieve all their goals.

To maximise the benefit of treatment:

1. Develop a good understanding of FND
 - Ask questions
 - Read and follow up on information provided by your team
 - Use the resources available (see pages 16 and 17)
2. Engage in all therapy sessions
 - Daily planners are used for you to organise sessions and plan your day

Goal setting

Just as your symptoms took time to develop, it may take time to move beyond it. The key is to develop a set of goals that you can achieve in a step-by-step way.

- First, **identify your goals**. Goals should be **SMART** (**S**pecific, **M**easurable, **A**ttainable, **R**ealistic, **T**imely). For example, 'to go for a 2km run by four weeks time'.
- Next, it's important to **establish a series of small steps** that will lead you from your present level of activity to the achievement of your goal. Using the previous example: it might be that the person can presently walk but feels fatigued and in pain after walking 1km, and they will establish an exercise program to increase the distance walked by 50m a week.
- As part of this process, it will be important to realise **there will be occasional flare-ups**. This often occurs when your activity level has increased by too much. In these situations, you will need to remind yourself that **most likely** there was no further injury and that with adequate management strategies (as guided by your team), you will be able to continue your exercises. **Pacing education** will be provided to by your team to avoid these flare-ups as much as possible.



MY TURN: What are my SMART goals?

Timeframe	Goals



MY TURN: My action plan

Setting and achieving goals can be difficult. To assist with this, your team will help you create your action plan.

My action plan

Goal—Something I WANT to do:

Break it down into smaller, manageable steps:

- 1.
- 2.
- 3.

What is this first step towards this goal that I will do **this week**?

1. WHAT:
2. WHEN:
3. HOW MUCH:
4. HOW OFTEN:

What are my **barriers** and **obstacles**?

My action plan

Plan to **overcome** barriers and obstacles:

1.

2.

3.

Confidence rating of PLAN on a scale of 0-10:

1

2

3

4

5

6

7

8

9

10

How will I follow up the **plan**?

If the plan is unsuccessful **what** can I do to **problem solve**?

1.

2.

Pacing yourself

People with functional symptoms often have fatigue, weakness or pain which can be made worse by exercise. The common phrase “No pain, no gain” doesn't always apply now. To overcome this, your team will help you gradually increase the amount of activity you do. If you have had these symptoms for a long time, it may take some time to recover.

What often goes wrong is that increasing activity without guidance may lead to increasing symptoms. Understandably, this can make you believe that you must be making your condition worse or causing damage to your muscles.

When this happens, it is important to remember that you're not causing damage if you do it under the guidance of your therapy team. Yes, activity can make the symptoms worse; but no—you're not causing any damage. Understanding and interpreting this when you have pain and fatigue can be difficult, so it is important to discuss with your team.

Getting better may mean dealing with symptoms that may change from day to day, morning to evening. A very common problem in rehabilitation is a tendency to do too much on a good day and then feel much worse later that day or the next day.

You will probably experience good and bad days. The bad days may even feel as though you are 'back to square one'. However remember all the progress you have made so far.

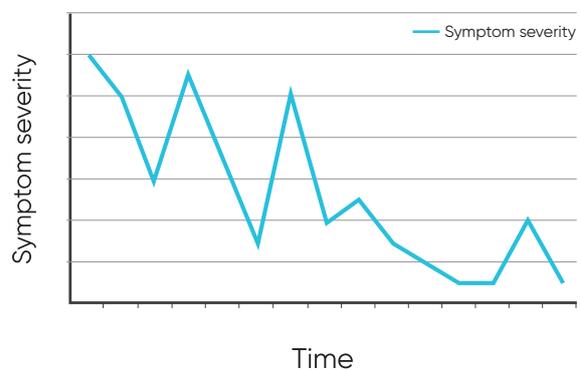
It is predicted that you will experience 'flare ups' as you try to improve with your therapy team. The aim is for each flare up to be not quite as bad as the last one with slow gradual improvement in between.

When your symptoms get worse again, it is understandably demoralising, but it is common as people try to recover from a debilitating illness.

The graph shows what happens when you are slowly improving overall with rehabilitation.

Some days you may experience worse symptoms than the day before, but over time you symptoms will get better and you may experience them less often.

Figure two. Improvement of symptoms over time



Taking the next step and pacing yourself

It is important not to overdo or underdo it and to understand how pacing works for you.

The more activity you do over time, the fewer symptoms you will get over this time. This may be weeks, but if you have the symptoms for months or years, this may be much longer due to negative 're-wiring' of the nervous system over time. This is known as **neuroplasticity**. The remarkable ability of the nervous system to alter its structure and function in response to internal and external factors is what your therapy provided by your multi-disciplinary team is based on.

(Adapted from *What is Functional Weakness* at www.neurosymptoms.org—Dr Jon Stone, Consultant Neurologist)



MY TURN: Pacing myself

In the table below write the activities you expect to be doing today and what limits you could apply to these activities, to prevent doing too little or too much (see the examples provided).

Activity/Exercise	How will I PACE myself?
Example: push ups	Example: I will do five push ups and take a rest. I will try and do this three times throughout the day



MY TURN: Planning my day

A useful strategy in pacing is organising your day. This can help get to an idea of work and rest balance. Plan your day using the daily planner below.

Time	Activity	Jobs/tasks
07:00		1.
08:00		2.
09:00		3.
10:00		4.
11:00		5.
12:00		
13:00		
14:00		
15:00		
16:00		
17:00		
18:00		
19:00		Notes:
20:00		
21:00		
22:00		

Additional resources

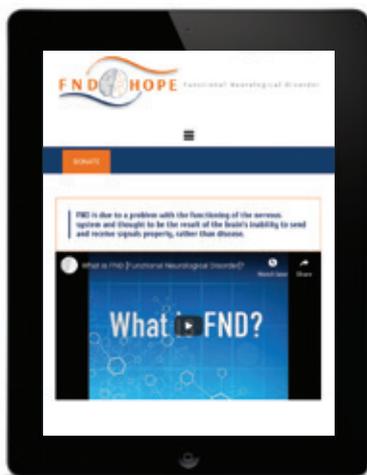
Free online self-help information has been developed in recent years for patients with FND symptoms.



Site one: The site www.neurosymbols.org was developed in Edinburgh in 2009 by Dr Jon Stone (consultant neurologist and honorary senior lecturer in Edinburgh with specialty interest in FND) and contains a wide range of information for patients with FND.



Site two: Another site www.nonepilepticattacks.info is developed to provide information specifically for patients suffering from non-epileptic attacks in 2011 by Sheffield hospital in the United Kingdom.



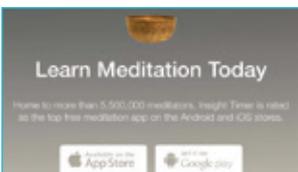
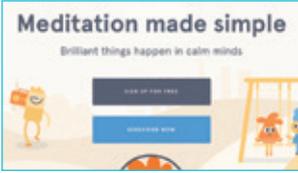
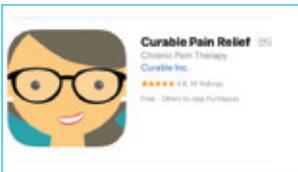
Site three: Additionally in 2012, the site www.fndhope.org was established. Contents of the website were written by patients, caregivers and doctors/researchers with the common goal of promoting understanding and better care for patients with FND.

Useful videos and apps



MY TURN: My learning

Tick the videos you have watched and apps you have used and write down any reflections or thoughts you have.

YouTube videos/apps		My reflections and thoughts	
<input type="checkbox"/>		<p>Neuroplasticity (Sentis) https://youtu.be/ELpfYCZa87g</p>	
<input type="checkbox"/>		<p>Understanding pain and what to do about it (Live Active) https://youtu.be/C_3phB93rvl</p>	
<input type="checkbox"/>		<p>Tame the Beast – Rethinking persistent pain (tamethebeast.org) https://youtu.be/ikUzvSph7Z4</p>	
<input type="checkbox"/>		<p>Sensitive Sensory Lights (Neuro Orthopaedic Institute) https://youtu.be/uF6JMIRepGU</p>	
<input type="checkbox"/>		<p>Insight Timer Meditation app Available on the App Store and Google Play</p>	
<input type="checkbox"/>		<p>Headspace: Guided Meditation app Available on the App Store and Google Play</p>	
<input type="checkbox"/>		<p>Curable Pain Relief app Available on the App Store</p>	



MY TURN: Maintaining progress

Your team will be working with you on setting strategies to manage your symptoms. Towards the end of the program you will be encouraged to reflect on these strategies.

Maintaining progress

What made me vulnerable to developing my FND?

What triggers my symptoms (events, situations, mood etc.)? What are my warning signs?

Are there things that make it worse? What thoughts or beliefs keep it going?

What are the most important things I have learned about my FND?

What coping strategies have been helpful?

Maintaining progress

How have things improved?

Re-rate goals and targets

The things that I would like to work on/achieve in the next 6 months are ...

Wellbeing plan/review date

What can I do to prevent a setback? Do I need to set aside a time to check in on how I am managing my symptoms and review progress towards goals?

What can I do if I have a set-back or relapse?

What are my support options?

In case of a set-back...

How can I make sense of this?

What events/triggers led up to this setback? How did I react to this? What did I do? What did I think? What did I feel?

What have I learnt from it?

Was this a high-risk situation? Are there things that I can identify are difficult? What helped and what didn't?

With hindsight, what would I do differently?

When I think/feel _____ what could I do instead?



MY TURN: In the case of set-back or relapse

Understanding why you experience a set-back or relapse can help you understand your symptoms better. Use the space to reflect after a flare up of symptoms.

Understanding set-back or relapse

How can I make sense of this?

What events/triggers led up to this setback? How did I react to this? What did I do? What did I think? What did I feel?

What have I learnt from it?

Was this a high-risk situation? Are there things that I can identify are difficult? What helped and what didn't?

In hindsight what would I do differently?

When I think/feel _____ . What could I do instead?



MY TURN: My on-going plan

Your team will work with you during the program. Write down the names of your team managing your ongoing care and when you will see them next.

Team member	Next appointment
Medical Officer (s)	
Allied Health	
Psychologist	
Other	



MY TURN: My diary

Keeping a diary of your reflections and achievements is a great way for you to visualise your progress. The spaces below can be used to reflect when you have achieved your goals and how you felt when achieving them.

My diary

Date:

What happened?

What did I achieve?

Date:

What happened?

What did I achieve?

Date:

What happened?

What did I achieve?



MY TURN: My diary

Keeping a diary of your reflections and achievements is a great way for you to visualise your progress. The spaces below can be used to reflect when you have achieved your goals and how you felt when achieving them.

My diary

Date:

What happened?

What did I achieve?

Date:

What happened?

What did I achieve?

Date:

What happened?

What did I achieve?



MY TURN: Notes

Use this space to make any further notes or thoughts you may have.

Notes



MY TURN: Notes

Use this space to make any further notes or thoughts you may have.

Notes



MY TURN: Notes

Use this space to make any further notes or thoughts you may have.

Notes

Mater Misericordiae Ltd,
Raymond Terrace, South Brisbane Qld 4101
P 07 3163 1110

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