

CONSUMER AND CARER EXPERIENCES OF FND/CD IN AUSTRALIA

"FND is Australia's silent crisis."

Katherine Gill | E: kate@fndaus.org.au



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Abbreviations and Language used in text

Abbreviation	Term	Explanation
FND	Functional Neurological Disorder	FND is also known as Conversion Disorder, psychogenic, non-organic and/or medically unexplained symptoms.
CD	Conversion Disorder	As above
	Consumer	Refers to a person with a diagnosed FND illness
	Carer	Refers to a relative, partner or close friend who supports a person with a diagnosed FND illness
DSM	Diagnostic and Statistical Manual of Psychiatry	Classification manual for mental illnesses



What is Functional Neurological Disorder [FND]?

My otherwise healthy, vivacious 28 year old daughter was at work one morning and lost control of the right side of her body. She was rushed to a major Sydney hospital. Once evidence of stroke was cleared & FND diagnosed she was discharged the following day to her GP who had NO idea on how to treat. She has no psychiatric issues but has developed anxiety issues through this whole awful ordeal.

People with Functional Neurological Disorder [FND, also known as Conversion Disorder] experience a variety of disabling motor, sensory and cognitive neurological symptoms. Symptoms include paralysis, abnormal movements, gait disorder, balance problems, tremors, weakness, fatigue, chronic pain, black-outs, seizure-like episodes, vision disturbances/blindness, and bladder and bowel problems. The symptoms are just as disabling and distressing as similar presenting neurological diseases, such as Multiple Sclerosis, Stroke, Parkinson and Epilepsy [5, 6]. The disorder affects people of all ages and all genders but is found and/or diagnosed more commonly in females. The age of onset has a peak incidence between the ages of 35 – 50 years [7].

Functional disorders result from problems with the functioning and connectivity of the nervous system without structural damage to the nervous system. They are one of the most common diagnoses in neurologic practice [8]. It is the second most common reason for a neurological consultation, after headache. People with functional seizures make up between one quarter to one fifth of those referred to specialist epilepsy clinics [9, 10].

Functional disorders have been described as a ‘crisis for neurologists’ [1]. The condition lies in the intersect between neurology and psychiatry. Effective diagnosis and management requires collaboration between neurology, psychiatry, psychology and physical rehabilitation, including physiotherapy and occupational therapy [4, 11]. It is common, perhaps universal, for people with organic neurological diseases, such as Multiple Sclerosis, Parkinson’s Disease and Epilepsy to have a functional overlay in addition to the neurological disease. This compounds the impact of the illness and results in worse outcomes and function.

“The nature of the crisis is that there are many patients, we don’t understand the pathophysiology, we often don’t know how to make the diagnosis, we don’t know how to treat the patients, the patients don’t want to hear that they have a psychiatric disorder and they go from doctor to doctor, psychiatrists don’t seem interested anyway, and the prognosis is terrible.” [1]

Current Practices in Diagnosis and Treatment for FND

Correct diagnosis of FND requires neurology involvement. Neurologists are best placed to give and explain the diagnosis using positive signs such as the Hoover sign and tremor entrapment test [12, 13]. However, neurologists are reported to be reluctant to disclose and discuss the diagnosis with patients. Neurologists view the illness as a “*crisis for neurology*” [1], leaving them in a dilemma about how to relay the diagnosis to patients.

Studies have found that neurologists avoid discussing the diagnosis with the individual: they avoid labelling the diagnosis and avoid any mention of psychology or psychiatry [14]. There is a need within the neurology community to accept the importance of communicating the diagnosis appropriately [3]. Poor prognosis has been found to be associated with longer delay to diagnosis [15].

Current diagnostic and treatment practices are highly variable despite a growing body of international evidence that a tailored approach to diagnosis and treatment can result in major improvements in health and quality of life. Positive signs such as the Hoover’s sign and Tremor Entrapment Test are essential in supporting a phenotype based diagnosis that does not depend on exclusion of other disorders [4]. This test is commonly undertaken by neurologists. Other clinical features include sudden onset, improvement of symptoms with distraction, worsening with focused attention and excessive fatigue. Traditionally, many neurologists discontinue their involvement with the person once a diagnosis of FND is made, referring the person’s care back to the referring physician or to a psychiatrist or psychologist [16], often leaving many individuals to struggle with life changing symptoms on their own.

Clinical trials for treatment of FND are lacking but studies suggest that improvements in motor functions can be made with physical rehabilitation, and where relevant in combination with psychological interventions [4]. While research is limited, psychological interventions have the best evidence for treatment of functional seizures.

In functional disorders the nervous system is not damaged but functions incorrectly in the way messages are sent and received by the brain and body. As a result functional symptoms have potential for improvement and/or reversibility. Rehabilitation incorporating both a body and mind approach is essential to support recovery and/or self-management of the illness.

Co-morbidities

Co-morbidity with other mental illnesses, including anxiety, depression and personality disorders is common in people with FND [17-19]. A number of people report a history of childhood trauma. Adverse early life events have been linked to increased symptom severity in FND [18]. There are multiple biopsychosocial predisposing vulnerabilities for functional neurological disorder including physical injury, surgery, emotional trauma and adversity. Over 50% of individuals with non-epileptic seizures reported prior traumatic experiences, and childhood abuse is associated with increased

symptom severity [15, 18].

It has been found that around 30% of people do not identify with a psychological trauma, distress or pre-existing mental illness [20]. Many of these individuals report developing FND after injury, accidents, illness, surgery or through pushing their body through extensive exercise and physical training.

Language and Classification

Historically, FND was thought to be of psychogenic origin, and various theoretical models hypothesised that people were subconsciously 'converting' psychological trauma and conflict into physical symptoms [21], which led to the illness being named Conversion Disorder [C.D.]. The illness is known by a host of other terms, which reflect this theory including, psychogenic, non-organic or medically unexplained [3].

Many people with FND experience symptoms that present similar to epilepsy, but without changes in the electrical activity of the brain. These attacks are also known by a variety of terms including functional attacks, functional seizures, dissociative attacks, dissociative seizures, psychogenic non-epileptic seizures [PNES], pseudo-seizures and non-epileptic attack disorder [NEAD]. A common term for these 'attacks' / 'seizures' is yet to be reached, leading to a crisis in language [22].

Functional Neurological Disorder / Conversion Disorder is classified in the Diagnostic and Statistical Manual of Psychiatry (DSM-V) 300.11 under the Somatic Symptoms and Related Disorders category.

The diagnostic criteria notes

- A. One of more symptoms of altered voluntary motor and sensory function;
- B. The clinical findings provide evidence of incompatibility between the symptom and recognised neurological or medical conditions.
- C. The symptom or deficit is not otherwise better explained by, another medical or mental disorder.
- D. The symptom or deficit causes clinically significant distress or impairment in social, occupational or other important areas of functioning or warrants medical evaluation.

In the transition to the DSM V the criterion for a psychological stressor was removed as psychological stressors and life adversity are not present in a substantial subgroup of people with functional symptoms [23]. The ICD coding classifies the illness as an acute episode if the symptoms have been present for less than 6 months or persistent for symptoms present longer than 6 months.

FND has lacked ownership by both neurology and psychiatry, despite the illness historically being conceptualised as a manifestation of neurological symptoms that have arisen from a psychiatric origin [24]. Neurologists are often not well equipped to work with people with FND and they commonly diagnose people with FND and refer the person for psychiatric intervention. This fails to address the serious and disabling physical symptoms such as paralysis, weakness and gait disorder.

FND has been relatively neglected by both clinical services and research, as it falls in the intersect between physical and mental health. People with FND suffer from high levels of stigma and discrimination due to poor understanding of the disorder by both clinicians and people in the community [24]. Many people ‘fall’ into the “black hole” and “great divide” between neurology and psychiatry [19]. An integrated interdisciplinary approach involving both neurology and psychiatry taking ownership of the problem and talking a common language is urgently needed to better support people with FND.

“Because of the enormous healthcare and welfare costs associated with functional symptoms, health professionals and medical scientists need to take an active interest in keeping up to date with best practice in diagnosis and management of FND” [2].

“FND represents a unique opportunity for physical and mental health care to collaborate in the treatment of a potentially curable but significantly disabling disorder” [3].

“Functional Neurological Disorders are a neglected but potentially reversible source of disability” [4]

Brain Imaging

Brain imaging studies are beginning to shed light into the neurological deficits associated with FND symptoms. Routine testing fails to detect structural damage to the nervous system or abnormal electrical activity changes in the brain, commonly associated with epilepsy. Scans of brain activity in fMRI studies have identified dysfunction in brain areas controlling planning and initiation of movement and self-agency, along with over-activation of the amygdala. Functional MRI studies showed greater activity in limbic structures (right amygdala, left anterior insula and bilateral posterior cingulate area) and decreased activity in the left supplementary motor area (SMA) during a motor preparation task in FND patients compared to a healthy control group [25]. This indicates a possible mechanism of abnormal emotional process that is actively interfering with normal motor planning.

Subsequent studies have found abnormal functional connectivity in the brains of people with functional disorders including increased connectivity in areas involving the amygdala and decreased connectivity in prefrontal and sensorimotor areas [26]. Studies are identifying changes in the structural volumes of brain areas involved in motor control, in people with functional disorders compared to healthy controls [27-29].

Prognosis and Disability

Prognosis for people with FND is poor. People experiencing functional neurological symptoms are at least as disabled as similar presenting illnesses associated with neurological diseases such as Multiple Sclerosis, Stroke, Parkinson's Disease and Epilepsy [5, 6]. People are commonly diagnosed with FND by a neurologist, often after years of dealing with 'medically unexplained' distressing and debilitating symptoms, yet on diagnosis they are often not referred to appropriate services to treat the distressing but potentially treatable symptoms [4].

Quality of life measures indicate that people with FND are similarly impaired as cohorts of people with Parkinson's disease and MS, but suffer from more distress [30]. Long-term follow-up studies identified that 50–90% of people with FND experience ongoing symptoms [31-33], many of which become worse, especially when treatment begins later than 6–12 months from symptom onset [34]. Studies have found that at the 12 year follow-up, the majority of patients [83%] remain symptomatic, distressed and disabled [35]. Long term disability is similar to that seen in cohorts of people with multiple sclerosis [MS], but with increased levels of pain, significantly reduced emotional wellbeing and social role functioning, compared to a similar cohort of people with multiple sclerosis [35], with both the FND and MS groups presenting considerably worse than locally acquired population based controls.

Cost / Economic Burden of FND

Recent epidemiological and economic studies are lacking, and have been hampered by changes in terminology, classification and problems with diagnosis. Previous international studies have shown that FND is associated with substantive increased healthcare utilisation and consequently increased direct and indirect costs. In a study from the USA, [36] it was found that, compared with patients suffering from organic disorders, FND patients had more primary care visits, more specialty visits, more emergency department visits, more hospital admissions, and higher inpatient as well as outpatient costs. They estimated that annual direct medical costs attributable to FNDs alone [in excess of other physical and mental health comorbidities] for the USA were \$256 billion a year [in 2005]. A similar study in England, reported to be conservative, estimated the costs of somatisation disorders for people of working age, of which FND accounts for a large component, to be £18 billion pounds in the financial year 2008 to 2009 [37].



FND in Australia: Consultation with Consumers and Carers

In December 2018 the National Mental Health Commission sponsored FND Australia Support Services Inc. to undertake an Australian consumer and carer consultation to explore the *'Experiences of FND in Australia'*. A copy of the consumer and carer survey can be found in appendix 1.

A total of 179 Australians participated in the consultation, which included 113 consumers and 66 carers. The demographics are reported in table 1. The survey was promoted through the organisation's networks and social media platforms. The distribution of survey respondents reflected the distribution of the organisations' membership base, which also reflects the FND knowledge and service base of the individual States and Territories. Around half of all survey respondents were from Queensland, which has a specialised adult program for FND. In areas where there are no services and few specialists in FND, such as the Northern Territory, Tasmania and South Australia, people are less likely to be correctly diagnosed with FND, and less likely to find their way to FND Australia Support Services networks. This is reflected in the membership of the organisation and subsequently the response rate of the survey.

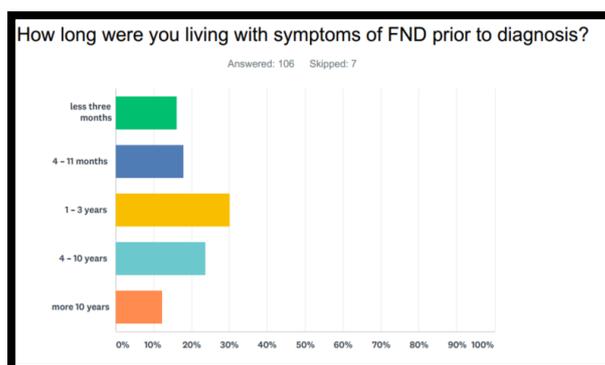
Table 1: SURVEY DEMOGRAPHICS

- 113 Australian CONSUMERS living with a diagnosis of FND participated in the survey
- 66 Australian CARERS participated in the survey
- AGE: 87% of people completing the consumer survey were aged 25-64 years
- GENDER: Approximately 90 % of consumer respondents were female
- INDIGENOUS: 5% of consumer respondents reported being of indigenous background, all of whom were living in Queensland.
- STATE: QLD 49%, NSW 22%; WA 12%; VIC, 10%; SA 5%; ACT 1%; N.T. 0% and Tas 0%
- Metropolitan 50%; Regional 30%; Rural/Remote 20%

The survey results were tabulated and themed as discussed below. The survey graphs are provided in appendix 2. **The outcomes reflect the serious underinvestment into FND knowledge translation, research, community awareness, health professional knowledge and services in Australia.**

Experience of Diagnosis

Early diagnosis with an effective therapeutic explanation of FND and early intervention, leads to the best outcomes and potential for full or partial recovery. Due to low awareness of the condition across health services, 66% of participants with FND reported living with debilitating FND symptoms for over a year prior to diagnosis. 36% of consumer survey respondents reported experiencing symptoms for over four years prior to being diagnosed with FND. Only 16% of people with FND were diagnosed within three months of the onset of FND related symptoms. Failure to diagnose the condition early after onset of symptoms, and/or poorly delivered diagnoses, can lead to iatrogenic harm, repeated testing and significantly worse outcomes [4].



- *“No one would tell me anything about the diagnosis, it was always, we don't know, and that wasn't helpful to me. No one could tell me what to do, what it meant or how to get better. I just kept being told there was nothing wrong in my tests.”*
- *“Being diagnosed much earlier would have been better so I didn't lose 6 years of my life not knowing, not being able to drive, and stuck at home by myself until my husband came home from work. I believe this then contributed to my problem because of the isolation.”*
- *“My experience was 14.5 years of the medical world not knowing about FND could have saved a lot of money spent on medical professional not knowing what I had.”*
- *“[I needed to be] given more information and support. I was referred back to GP”*
- *“Quicker diagnosis, medical professionals not disregarding my symptoms, not being discharged from hospital with no understanding of what was going on, even though I couldn't walk unassisted, not being told 'you just need to try harder' by a neurologist even though he couldn't tell me what was going on.”*

Many reported being initially misdiagnosed, with a misdiagnosis of stroke or epilepsy, being the most common. Consumers reported having to undertake their own research to understand the illness. They reported finding many health professionals uneducated about the illness, and many people experienced negative attitudes from health professionals. Respondents reported that some professionals were dismissive, condescending and rude and that they failed to believe the symptoms were real. Survey respondents reported feeling judged, due to the fact that the diagnosis falls under mental health classifications.

- *“I was told I was faking it and that it’s all on my head.”*
- *“Nobody could tell me what was going on or why and I was left to figure it out alone. I was never able to accept the symptoms were purely psychiatric either. ... Attitudes directed at me from neurologists, nurses and doctors have been largely dismissive and rude. Medical practitioners need to be better informed about the condition with updated research and findings as well as perusing more research into the condition.”*
- *“I needed “people to believe my symptoms are real and to understand that this is a neurological and psychiatric condition, not just PTSD.”*
- *“My GP said that the diagnosis meant that there was nothing wrong with me”*
- *“I was “automatically judged by the neurologist just because I had a mental health disorder”*
- *“By the time I got diagnosed by a well-informed neurologist, I had been through hell with various other specialists who basically treated me anywhere between contempt, distrust, patronising, mean, etc... implying that I was malingering or manipulative, just at my most vulnerable, when I was simply asking for help... it has been a terrible experience for me. So basically anything human could have made it more positive. Being validated and backed up has helped me start to heal my identity from the damage that was done.”*



Explanation of FND and Prognosis

Consumers felt they were not provided with a realistic prognosis and that they did not have the condition effectively explained when diagnosed with FND.

- *“I needed to be given more information, other than being told that I would wake up one day and be 'normal'. 2.5 years later I am still waiting!”*
- *“If my team of neurologists had have given me more information than "It may get better, you may need some time. There isn't anything we can really do. At least it is not MS". Instead I had to google FND while in the hospital to see what things could help me.”*
- *“If my doctor had told me it was in my hospital report. I'd spent 2 weeks in hospital having tests to work out why I was collapsing and the hospital Doctor diagnosed it and put it on my report but my GP didn't tell me. I happened to read a University book at a*

friend's house and saw it explained. So then I took that information to my GP who said... oh yes, the hospital report said that!!!"

- *"I needed "a better understanding. Not just hey you have thing called FND. You are completely normal except you have these dissociative events. Talk to someone about re wiring your brain. You have been put on the neuropsychological waitlist but that could take 2 years. We can't give you meds. Just work out your triggers and avoid doing it. Explain what dissociative means. Don't make me feel that it's in my head by only wanting me to speak with psychologists. I don't know what can make it better it's a hard and overwhelming experience."*

80% of survey respondents reported distressing experiences in health services. People were accused of faking symptoms, putting them on for attention, having their symptoms dismissed and/or being treated 'atrociously' or 'like an idiot'. Survey respondents described negative experiences in relation to the level of compassion, knowledge and understanding of health professionals. People reported being patronised, 'spoken down to' and judged. 10% of people reported a mix of good and bad experiences and 11% of survey respondents reported positive experiences in relation to the level of compassion, knowledge and understanding of health practitioners. These were mostly associated with the few specialised FND clinics.

"I am angry and disillusioned with how FND patients are treated in emergency, GP's and Neurologist's, psych professionals, with no care, no compassion, stigma, and complete disregard for any specific care or treatment. This creates and inflicts great harm causing many to attempt suicide or suicide."

"It has been very limited and at times detrimental to my daughter's well-being. She has been accused of malingering, attention seeking, totally dismissed and even ignored. Very few professionals have even heard of the diagnosis let alone try to understand it."

On the 3rd of January a general physician at a Brisbane private hospital allowed my daughter to fall on the ground 6 times because she believed my daughter was faking. We medically discharged ourselves from that hospital. On the 12th of January we presented to a major Brisbane public hospital. The E.R. doctor told us to go home, put a mattress on the floor in the kitchen and go to the toilet in a bucket. He refused to admit my daughter who was totally paralysed. I demanded to speak to his supervisor. My daughter was then admitted to the incorrect ward and received no supervision as she required. On the 15th of January a doctor told her she had FND. The conversation lasted 30 seconds and we were discharged an hour later with a website on a post-it note. We had no treatment plan. – Carer - 2018

FND Treatment in Australia

People who have early access to an FND specialised multi-disciplinary treatment program with specialist FND knowledge, have the best chance of improved outcomes and potential for recovery. In the study only 36% of Australian consumers accessed any form of treatment for symptoms of FND in the six months post diagnosis. When people were able to access specialised treatment there were noticeable positive benefits.

- *“Once I found the right people to help me it was amazing. Suddenly things started clicking and I did not feel like it was all in my head. Suddenly I had real people understanding my symptoms and genuinely wanting to help.”*

40% of people reported they had not accessed any form of support or treatment for FND. Many referred to a lack of information and that they were not provided with an effective explanation about the diagnosis and how to treat the condition. People were ‘ping ponged’ between services and doctors, while failing to receive any appropriate care.

- *“I have received no treatment or service since diagnosis. My GP isn't supportive. Public health have not offered anything.”*
- *“Needed more info about it, instead of only told it's psychological. No follow through for physio, counselling etc...nothing! I was in hospital and symptomatic at the time of being given my diagnosis.”*
- *“I haven't gotten any care or treatment”*
- *“I have not been offered any treatment support at all. I don't have private health insurance and public system has offered nothing. As I can't work due to FND I can't afford to pay for any treatment e.g. physio etc.”*
- *“All I was told was I had FND and there was no cure or help and was not referred to anyone.”*
- *“I have never been able to access care from people who knew what they were doing and it was left to me to search things out, research myself, and then educate the professionals”*
- *“I needed a “quicker diagnosis, it took five years of tests and waiting to see medical specialists before I was diagnosed. During this time I could have easily fallen through the cracks and either seriously injured myself or even committed suicide as I couldn't take the embarrassment of what was happening and not being able to give anyone an explanation of why I do it.”*
- *“Yes there is nothing in the public health system in Victoria for FND sufferers. I have been totally dismissed”*
- *“Better explanation the first time. Rather than being handed a print out and saying this is what you have after being in ICU for 2 months fighting for each day and then told there is no help for you go home. It was horrendous the way that they handled it and treated me after they diagnosed me. No help with organising treatment after. No answers to very important questions for months after diagnosis. Better support afterwards especially for people who have never been chronically ill.”*

- *“No one can tell me where to go to get help so still suffering through on my own”*
- *“I have been pushed from pillar to post for the last four years. Poked, prodded, disrespected, ignored and generally mistreated until finding Nexus Neurology and just now getting the help I need. I now have depression due to the length of time this has taken and because of lack of treatment I have been getting steadily worse this year which I have spent mostly in bed because of pain, fatigue and non-epileptic seizures.”*
- *“I've found that neither psychiatrists nor neurologists want to treat me because they don't view it as part of their field.”*
- *“No one understands FND, so they don't know how best to treat her”*

..... there is absolutely nothing

“For a disorder getting diagnosed frequently there is really nothing out there or understanding. I refuse to go to emergency as I know how badly I would get treated, I don't say much to my GP as he has not dealt with FND before. It's a really lonely world being isolated with FND. The stigma needs to go and I'm finding a lot of people with FND were high achievers and living life to the fullest and it's all been taken away and what doesn't help is professionals saying it's all in your head, you want to be ill. For neurologists going through training FND should be taught. Emergency doctors and nurses need to be informed and this should be included in their training or on professional development days. The only support is the FND group, without that there is absolutely nothing.”

- *“I have not been able to find ANY significant treatment for my daughter.”*
- *“There is little or no treatment available to FND patients”*
- *“There appears to be no treatment available in NSW available for an adult”*
- *“There is no service in the Illawarra area as far as I know”*

“Patients are told to go home, they can't offer any care and treatment. This happens to the majority, not the minority. FND patients are in ICU because they cannot breathe or swallow. Yet these critically ill patients are not supported with basic compassion. They must be faking. Faking? And they are on ventilators? This disorder is an expensive cost to so many services with no results.”

Barriers due to Travel and Wait Periods

People reported having to travel extensive distances in order to access health professionals to treat or diagnose the condition. A number of people had moved interstate in order to access one of two specialised FND programs. These two facilities have an extended wait period.

- *“Long wait times to see specialists. Lack of trained doctors and nurses. Lack of other services.”*
- *“I am waiting for treatment since September. Laying 95% of day in bed. I have placed myself in assisted living.”*
- *“Paediatric options have been limited with long waiting lists”*
- *“I had to travel from Rockhampton to Brisbane once a week to see my treatment team, as there are no neurologists or any medical health professionals in Rockhampton that know about FND.”*

Geographical distance makes it very hard to access appropriate services”

- *“No treatment available had to move 1000 km away to receive appropriate medical treatment”*
- *“I only see one FND specialist- it's a 12 hour return journey, and he's happy to see me once every 6 months. How am I to progress and get better?”*
- *“Distance and expense has limited us greatly in getting better care”*

Wait periods for initial appointments and treatment was causing people to decline and become disabled while waiting to see specialists.

- *“It took 4 years to see a FND trained specialist. To see some specialists, particularly the FND trained who were able to provide a diagnosis; the waiting period to get an appointment was up to 2 years. My mum's symptoms got worse and she suffered a lot waiting.”*
- *“Waiting lists are ridiculously long and getting referrals to specialist is really difficult”*
- *“Zero follow-up from the dr that diagnosed her. Long wait times for allied health”*
- *“Very long wait list to get into the system”*
- *“The waitlist for these specialised medical professionals are enormous. Once receiving treatment, they were great, but just waiting to see them is a hassle.”*
- *“Long waits and lots of phone calls to get an appointment just to get diagnosis. They don't seem to have many options in relation to treatment either.”*
- *“It has taken us 2 and a half years to now surround ourselves with providers that know and understand. We have been through many many providers that have been very unsupportive.”*

Service Level Gaps and Barriers to Treatment

Knowledge:

People with FND reported significant gaps in the level of health professionals' knowledge, compassion and understanding of FND. Participants reported a significant lack of knowledge and understanding amongst health professionals, emergency departments, paramedics, allied health practitioners, General Practitioners and other doctors including neurologists and psychiatrists. Many people were treated as though they were *'faking'* their symptoms or *'attention seeking'*. People referred to being *'dismissed and patronised by neurologists'*, being *'pushed from doctor to doctor'* and having *'nurses snigger and ill treat me because they were ill-informed about the condition which then prolonged getting proper help and made my FND worse'*.

Lack of knowledge of FND across the health professions led to a delayed diagnosis and treatment.

- *“I needed knowledgeable doctors and physical therapy programs offered straight away to prevent [me] becoming permanently disabled.”*
- *“Everyone just says I don't know anything about that and passes you on.”*
- *“So far my experience is the medical profession seems to be very much in the dark about FND”*
- *“Most of the Medical Profession has no idea or understanding of FND!!!”*
- *“No one knows how to treat the condition. I feel like a practice mannequin where people try*

anything and everything with no real thought."

- *"Once diagnosed with FND no one wants to do much to help"*
- *"I was extremely fortunate in that the diagnosis was made by an expert FND neurologist. The only negative was the 10 months prior with a GP and psychiatrist not knowing what was wrong."*
- *"Lack of knowledge. Being told there was nothing wrong with me"*
- *"Health professionals need to have "knowledge of the condition. Medical streams need to take responsibility, not being pushed back and forth between them. Not having to see three neurologists before finding one that actually agrees they should continue to be involved in treatment. Not that there is a recognized treatment."*
- *"In general all my Drs responses are they need to look up FND as they don't know anything about it, so generally have low expectations of any positive outcomes"*
- *"The medical field knows little about this condition so it's very hard to find a medical professional who will take you on, or who properly understands or even knows how to treat it."*

A number of people referred to having to educate the practitioners they were seeing for FND.

- *"I've had to teach just about every doctor and nurse I have had contact with in the past eight years what a non-epileptic seizure is and what is causing them."*
- *"I have had to explain and show websites for GP to gain knowledge about FND"*

Many professionals who lacked knowledge in FND failed to offer genuine concern and compassion for the disabling and distressing symptoms, and failed to offer follow up care, treatment and support.

- *"I am treated like an idiot and the neurologist seems to find it amusing that I get paralysed from the neck down"*
- *"The paramedics thought I was faking my symptoms and told me so, or assumed I was on drugs when I wasn't. I have never had a physician explain my condition to me. I have had to do all the research myself and fight to have a treatment plan."*
- *"People don't believe I am sick and no longer trust me or want to help"*
- *"GP's generally have no understanding of FND. I was humiliated and made to feel like I was a whinger and had no reason to be having symptoms. It was very distressing. Also, when I have been in other hospitals and had a non-epileptic seizure I have been told that I need to stop it and that I can control it, which I can't. Some hospital staff can be very cruel and judgemental."*
- *"I have been treated atrociously by Emergency Room doctors. These doctors know nothing about FND and insult me every time I present with an issue, even if it is not FND related. I have been sent home completely paralysed, unable to toilet or shower, unable to eat or drink properly, unable to even move around my home. The ER doctors did not care. ER doctors and nurses need better training because currently they are preventing FND patients from receiving the care that they need. Additionally, while in a neurological ward I was dismissed by nursing staff. I had collapsed mid-seizure and was hanging half off my bed for over 90 minutes. No nursing staff noticed me. Nurses were directed to sit with me during my seizures. When I came to, I was called a liar, a drama queen and sick in the head. Even after this, when nurses were told to check on me every 15 minutes and document this in my chart, this never happened. I felt like I was not taken*

seriously because my problem was "just" functional. This perception needs to be changed."

Financial Barriers to Care and Treatment

Many people referenced financial barriers to treatment, with no services being offered in the public health system.

- *"I have been unemployed and on Newstart for 5 years. I can't afford to access therapists to help me."*
- *"I can't get any info on treatment plans/options that may be helpful. I can't afford a wheelchair so I'm severely isolated at home and I'm on a disability pension and can't afford to go through the private system for help"*
- *"Unless you have money to privately see specialists you do not get help"*

Low Levels of Satisfaction with Diagnosis, Access to Treatment and Quality of Care

People reported significant gaps and barriers in gaining a diagnosis, access to treatment and the quality of care for treatment of FND. When asked to rate their satisfaction in these areas on a scale of 0 – least satisfied to 100 – most satisfied, the satisfaction outcomes were rated extremely low. Participants rated their satisfaction with their experience of obtaining a **diagnosis** at a median of 25 and mean of 37 [range 0 to 100]; they rated their satisfaction with **access to treatment** at a median of 15, mean of 28 [range 0 to 100] and their satisfaction with their **quality of care and treatment** for FND at a median of 23, mean 32 [range 0 to 100]. Higher ratings were from people who had accessed the few specialised FND programs.

- *"Doctors nurses and other staff need to be aware of the condition and to give me information and referrals so I didn't have to source myself. Like many I was told I was faking it and I chose to be this way. It was all in my head etc."*
- *"I was "told to not come back to the hospital because there is nothing they can do. More info would have been nice too"*
- *"I experienced abuse at the hands of nurses in a private and public hospital. I was deprived of water, my phone and yelled at over and over in a private psychiatric hospital to 'STOP IT' while on the floor, after I had fallen off the commode. They thought I was malingering. They didn't seem to know the difference between FND and Munchausen's. The [hospital] said I could no longer go inpatient anymore as they didn't know what to do anymore, and the OP clinic didn't understand FND, then private turned me away too once I had too many admissions. Interstate inpatient at the Mater Brisbane has not been possible due to being too unwell, plus cost barriers even though that has been my only hope many times."*

Rural, Regional and Remote areas

People living in **rural, regional and remote areas** experienced even greater barriers in access to care and treatment.

- *“No specialised services within 3.5 hour drive. Lack of services for rural and teenagers.”*
- *“I live in a regional town and a neurologist only comes down once a month. This makes it really difficult to get an appointment. There is no local specialist with experience treating FND.”*
- *“I live in a rural area. There are not any neuro-physiotherapists or neuro-psychologists in this area. My GP had not heard of FND and my psychologist says it’s just trauma- but despite being psychologically treated for PTSD there is no improvement in FND symptoms”*
- *“I have to travel an hour or more to see my psychologist and physiotherapist. I have had 2 appointments in Sydney (3 1/2 hours away). Travel is extremely difficult”*
- *“I live in a rural area. There is no treatment here and limited awareness of the condition. I cannot afford time off work to travel weekly to Melbourne so I suffer in silence”*
- *“Due to the rural area I live in, I have had access to no support. It has taken over 2 years to find a local supportive GP, psychologist and physiotherapist.”*
- *“Treatment is difficult to obtain as any specialists that treat FND are 4 hour round trip away in the city. And I rely on others now for transport and the trio is very draining on me”*

National Disability Insurance Scheme [NDIS]

While FND often leads to significant physical disability and functional limitations, in addition to psychosocial disability, the number of people with NDIS packages was low. Only 10% [n=9] of consumers reported having a NDIS Package. 20% of survey respondents had applied for NDIS and were denied. The issue over whether or not FND was a permanent condition was reported as reasons for denial. Other people experienced barriers applying to NDIS related to requiring a permanent visa, but needing help to organise this. Over 30% of respondents reported the process was too daunting and overwhelming to apply, and the stress of applying would worsen their condition. 14% of consumers and 16% of carers reported not knowing what the NDIS is. For those who had received a NDIS package [n=9] the size of the packages ranged from less than \$10,000 to more than \$150,000, with the most common package size [n=3] ranging from \$75,000 to \$100,000.

Many people reported being in the process of applying for NDIS, but many reported barriers to applying.

- *“I feel the stress of the interview and being denied would cause my symptoms to be triggered”*
- *“No, not applying is part of us believing this is just temporary.”*
- *“Still going through the process and dealing with idiots who don't understand my needs. The stress of applying is hard and need lots of reports from people who don't understand my condition. Even though I have had the illness for a long time it is hard to prove permanency because they don't know if we will ever get better”*
- *“I don't know what it is really or how to get it.”*
- *“My psychologist says I need to apply but I can't read or write very well and I get very overwhelmed so I need someone to help me. But my support person is not willing to help so I haven't started the paperwork yet”*
- *“I was told by medical professionals to not bother as I would be rejected”*

- *“No, we have been told we're not eligible because the illness "is recoverable" and may not be long term so have not bothered trying to apply.”*
- *“Previous experience with my daughter being with NDIS for autism has shown me that the NDIS is too dysfunctional, and without clear guidelines for this condition I see applying only as a headache best avoided”*

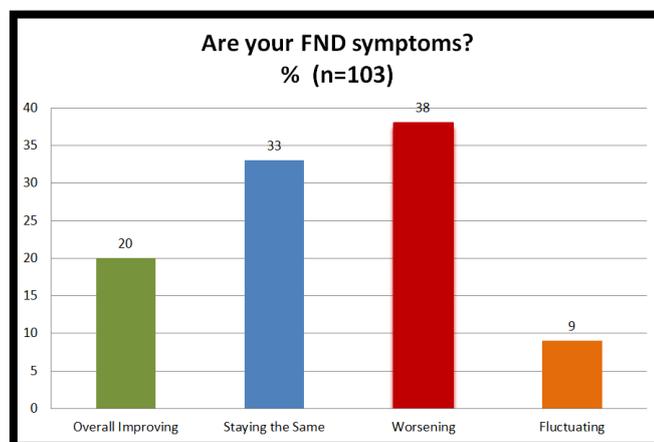
Is Recovery Possible?

While FND is thought to be treatable, only 20% of consumers surveyed, reported some improvement in their symptoms over time. Those who reported improvement did not report full recovery, although the survey was communicated through networks associated with the organisation so are more likely to have reached people still affected by FND.

- *“Up and down on any given day or month. Very gradually improving in some areas.”*
- *“Occupational therapists and psychologists taught me how to manage my symptoms. Any improvement is mostly because I have learnt to manage and pace myself.”*
- *“Wax and wane you do your best to get as strong as you can till you go backwards again but never coming back to what you were as we say a new kind of normal”*
- *“They have improved but not to any real advance”*
- *“They have improved but have now stopped progressing”*

One third of consumers surveyed reported their FND symptoms as staying the same, while 38% reported worsening symptoms over time. 9% of consumers described how their symptoms would fluctuate.

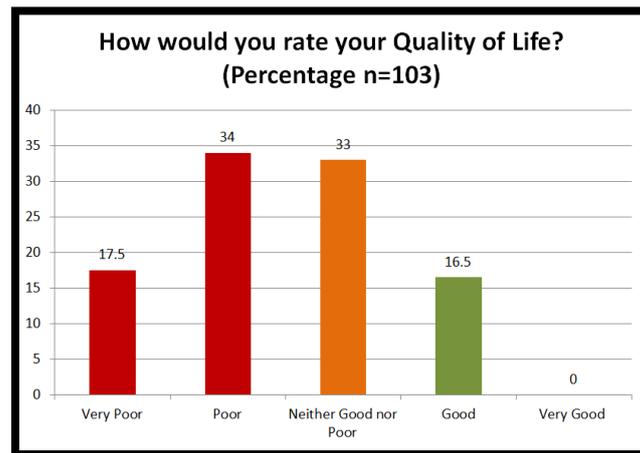
- *“Symptoms are changing and fluctuating”*
- *“Bit like a roller coaster, they come and go”*
- *“Some symptoms have stayed the same. Some have improved. Others have changed. Others appear to have gone away at present.”*
- *“it's a mixture of both improving some days, staying the same and worsening”*
- *“I have good days and bad days.”*



Impact of FND on Daily Living

Quality of Life with FND

The survey outcomes highlighted the serious life changing impact FND had on the life of people and families affected by FND. Overall consumers rated their quality of life poorly. No one stated they had a very good quality of life, and only 16% of people rated their quality of life as good. Over 50% of people with FND rated their quality of life as poor or very poor.

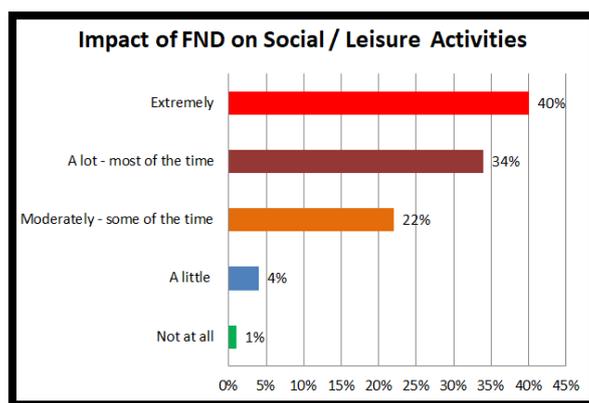


- *“My symptoms are so severe that my life is spent in bed 90-95% of the time.”*
- *“Due to the seizures I had long periods where I was unable to drive, so I was housebound. Fatigue [is] a huge problem for me. Bone aching tiredness and fatigue that is not helped by sleeping is exhausting and impacts on every area of my life. It has also impacted my mental health significantly!!”*

Social Isolation

99% of survey respondents reported that FND affected their engagement in social and leisure activities to some extent. 75% of people reported that FND impacted a lot or extremely on their social and leisure activities. 90% of people found that FND negatively impacted on their ability to maintain friendships and relationships.

- *“I used to horseride and miss it dearly. Can no longer horse ride due to pain and fatigue.”*
- *“Because of the lack of work it is difficult to access the community and engage in hobbies.”*



Many people commented on the isolation they experienced due to the disabling physical symptoms of FND, and reported losing friends due to the illness.

- *“Extreme isolation”*
- *“Sensitivity to bright lights and loud sounds makes it difficult to be out in public”*
- *“Due to my symptoms I struggle to leave my home. I live in a highset house so I can go weeks with not leaving my house. This makes life very hard I struggle on a daily basis doing the most basic tasks.”*
- *“Can’t even afford to get things I need such as a wheelchair so am extremely isolated.”*
- *“I have had no social engagement since diagnosis, and I am basically house bound”*
- *“I never go out anymore due to pain and feeling ill and being jerky. I don’t speak to my friends about it in fear they will abandon me. It’s very lonely and isolating. I was a very social out going person whom was never home.”*
- *“I’ve lost friends and a relationship through this illness. So those that are left are stars.”*
- *“I have no friends. I have no family support except my Mum.”*
- *“not able to maintain friendships when you are housebound and can’t walk”*
- *“Can no longer engage with my kids’ school. I’m so lonely.”*
- *“Transport is difficult to go see people and I fatigue quickly.”*
- *“I am a very social person I can hardly go out anymore. I sometimes need friends to pick me up or they have to come visit me. But then of course there are my really bad days when I will not let anybody see me when I cannot walk properly.”*
- *“Friends have dropped off like flies. My limitations mean I cannot do what they do. Accommodating my limits can only be tolerated in small quantities. I don’t ask and they don’t call. I went from being the social butterfly organiser to nothing. This is one of the hardest things to deal with, adjust and accept.”*
- *“I have actually had people abuse me. Treat me differently also I have lost friends over it.”*

Some reported that they only left the house for medical appointments

- *“I have no friends. I have no social life. I only leave the house to go to medical appointments.”*
- *“I rarely leave the house except to attend doctor’s appointments”*

Mental Wellbeing

FND was reported to negatively impact on the mental wellbeing, to some extent, in 98% of survey respondents. FND negatively impacted the mental wellbeing of 60% of people most of the time or extremely impacted the mental wellbeing of people affected. People reported becoming depressed and in some cases suicidal, due to the impact of FND on daily living, the time taken to get a diagnosis, the challenges of adapting to a disabling illness, and the attitudes to the illness amongst the health professionals and in society.

- *“Mental health team should be made to follow up on everyone. This is a huge thing to absorb, and having depression, I tried to commit suicide a couple of times because I didn’t think I’d ever get better.”*
- *“Deep depression BECAUSE of losing my life and abilities to this condition. Suicidal”*
- *“I go through depressive episodes, hopelessness, anxiety, etc.”*
- *“I am so depressed. I am lonely. Lost. Scared. Have bleak outlook of future. Feel like I have aged and all that is left is planning for health needs and old age style needs.”*
- *“It is hard enough adapting to such a disabling illness but having to deal with the discriminating and harmful attitudes in society, in the health profession and in the workplace is what does even more damage. It is a very distressing and debilitating illness and things need to change before we lose more people to suicide. I have been left suicidal because of the way people have treated me over the illness. They would not treat me this way if I had had a spinal injury, which is considered to be a real condition.”*

One respondent wanted the focus taken off mental illness.

- *“It would help if the emphasis was taken off mental illness. It is not the cause. FND isn’t a mental illness. This just makes it stigmatised and creates barriers to treatment and for communicating with others.”*

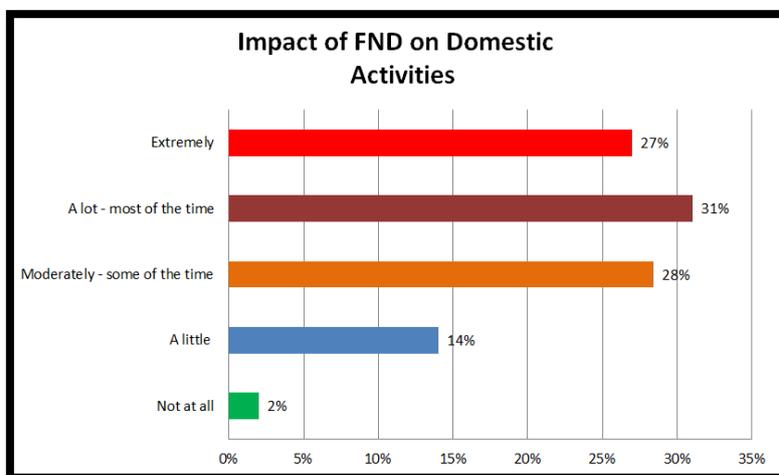
Activities of Daily Living

FND symptoms impacted on people’s ability to independently self-care [87% of people affected to some extent] and engage in basic domestic activities [98% of people affected].

- *“As a mother I struggle daily with cooking and cleaning. Having a restricted driver’s license and living in a rural area means I no longer socialise. I barely am able to drive 2 km just to get children to bus stop daily.”*
- *“Need full time care can’t care for my family or house”*
- *“I am down to one shower or two on a good week. I can barely wash my hair as my arms are too weak and painful.”*
- *“I cannot prepare my own food, I only shower once every 10 days, I require assistance to toilet. I cannot do anything for myself. I am 100% reliant on others.”*
- *“I can no longer cook, do basic housework, or do the grocery shopping, occasionally need*

assistance with basic personal care.”

- *“I live in assisted living. Meals are bought to my bed as I can't sit at table. Cleaning my room is done for me.”*
- *“I can't cook, I can't shop, I can't clean. I'm 100% reliant on others to do everything for me.”*



Community Access

FND symptoms and the resulting disability, impacted on people’s ability to access the community and travel. 95% of people reported FND had some impact on their ability to access the community and 68% reported that their ability to access the community was impacted extremely or most of the time due to symptoms of FND. Many people reported being unable to drive [losing their license for medical reasons] were struggling with costs of taxis and were denied taxi vouchers. Many people reported being in wheelchairs and/or unable to walk. Public transport was difficult for people to manage. Respondents reported experiencing blindness, in a wheelchair and unable to leave the house without assistance, but *‘assistance was difficult to come by’*. The barriers in community access led to isolation and dependence on others in order to leave the house.

- *“He cannot travel. He stopped driving soon after he started having seizures. FND has also given him motion sickness, so car travel is hard. Public transport is impossible. His movement disorder means he walks ‘funny’ so even a walk down the street is both painful & exhausting. His seizures mean he cannot fly.” – Carer*
- *“In a wheelchair and visually impaired. NDIS would not fund transport to use a taxi as I was under 18. Can no longer leave my house without assistance. Cannot catch school bus. Live rurally 10km from school so parents have to drive me and some wheel chair taxi use.”*
- *“I don’t go near public transport. I have very limited ability to walk long distances due to muscle weakness and fatigue. I have restricted driving capacities and am very conscious of staying within safe limits to get myself to appointments and home safely. There have been times where I have had to cancel appointments because I could not drive and had no other options/back up available to me.”*

- *“Unable to leave the house (I'm now wheelchair bound) unable to drive so rely on someone to take me out.”*
- *“Travel has become a financial burden. I can't drive and bus isn't always safe.”*
- *“I am now unable to drive due to non-epileptic seizures. My son drives me everywhere. I was catching cabs for some time after I'd stopped driving but now I'm too unwell to go out most of the time and if I do venture out I don't feel safe alone.”*
- *“When I am in a flare I am unable to drive. I'm unable to take public transport. I'm 100% reliant on others to help me get around outside the house.”*
- *“Due to the seizures I had long periods where I was unable to drive, so I was housebound.”*

Employment and Financial wellbeing

Employment and FND

70% of people with FND reported not being able to work or study at all and only 7% of people with FND were working full time. 98% of people reported that symptoms of FND, impacted to some extent, on their ability to work or study.

- *“I had a collapse at work and was on sick leave and shortly thereafter, I was made redundant. I'm reluctant to apply for work due to prospects of continuing collapses.”*
- *“Due to symptoms I am unable to work, so my work was unable to renew my work contract.”*
- *“My employer refused to have me back until I could provide medical clearance.”*
- *“I have had periods where I have needed to be in a wheelchair which creates huge barriers in every area of my life. I had a really good job but I had to leave due to FND, as I was having multiple non epileptic seizures a week at work, and I also had very bad brain fog, cognitive delays, trouble walking etc. etc. I still haven't been able to find a job after being forced to leave due to FND symptoms interfering with work.”*
- *“I have had to cease employment and study due to FND”*
- *“I had to resign due to discrimination.”*
- *“I have also been told by my employment that I cannot return until I am completely cleared for all duties.”*
- *“My health has improved but I had to quit my job and only recently got a new job with minimal hours and income.”*
- *“I was a teacher but with my issues they could find no way of employing me in any capacity.”*
- *“I am not able to work because of disability discrimination.”*
- *“I was too unwell / symptomatic to return to work. After a few months after symptoms started I resigned.”*

Study and FND

Symptoms of FND also impacted on study and schooling.

- *“stopped me from going to school too many symptoms and days off”*
- *“Was not considered for additional support at school until 18 months of having vision equivalent to being legally blind.”*
- *“I had to withdraw from a Counselling Course (Cert 3) and I had to shut down my business. My mental fog, poor concentration and memory issues made it impossible to study or work.”*
- *“I was unable to declare my condition in the workplace for fear of being made redundant. In the end, I became too fatigued to stay at work. I then tried to keep my skills up by completing a diploma but became too ill and needed to stop.”*
- *“I had to withdraw. They were helpful, but couldn't solve my underlying problem”*

Support for work and study

A minority of survey participants were supported and accommodated to continue engaging in work and study.

- *“It's impacted a lot but as I'm stubborn I do it anyway and pay for it with symptoms. I get assistance from workmates as I work in an inclusive environment. Uni assist me with disability support”*
- *“Work: not supportive or accommodating (told me I couldn't go back until I was completely better). Uni: Very Supportive and Accommodating”*
- *“QUT Disability Services have been incredible to me in helping me find ways to continue to study and achieve well.”*

Financial Strain

95% of people were struggling financially because of the impact of FND on their ability to work, Centrelink payments were difficult to live on and to access. The cost of treatment and support was financially inaccessible for many, and 20% of people had catastrophic financial impacts that included losing businesses, homes and in some cases ending up homeless. People reported being financially unable to purchase wheelchairs that were required and struggling to pay day to day bills. Many had drawn on their super, used up their savings and maxed out their credit card. Not being able to afford a wheelchair to access the community led to people being extremely isolated. A couple of respondents reported that the financial strain had led to suicide attempts.

- *“Where I was working is very understanding of my I'll health but I am unable to return due to my condition and they are unable to accommodate me and my needs at all. This makes a huge financial stress as we have lost my income, added treatment expenses and no financial help is available to us at all.”*
- *“If I can't get benefits or get a job soon I could soon lose my home. I had no idea how hard it is for people in wheelchairs until I ended up in a wheelchair”*
- *“We are struggling with our mortgage and day to day bills”*
- *“Been living off savings and lost them all; living off borrowed money and Credit card;*

considering drawing on superannuation to get cash flow happening”

- *“Potentially on the verge of losing house as I have not been able to work since I ended up in a wheelchair”*
- *“Lost everything both my and my hubby’s incomes. We were about to buy a home and we lost my husband’s business.”*
- *“Having to sell our farm - which is our home and livelihood....loss of home and employment.”*
- *“I’ve had to pay for all treatments with no Medicare or other supports. Without a job, this has impacted the whole family negatively, adding stress that really isn’t helpful.”*
- *“Nearly ended up homeless. Salvation Army helped me as much as they could.”*

CentreLink

- *“It took ages as the Centrelink didn’t know about getting DSP through the NZ Aus agreement, took 18 months to get the pension and was in serious hardship. Had to sell up house.”*
- *“I don’t know what Centrelink needs or wants to prove I can’t work.”*
- *It took nearly two years for me to receive DSP. The process was extremely stressful going through tribunals etc. Having to cease working was devastating.*
- *“I’m on Newstart which helps, but the worry of Centrelink making me look for work is bad. Everything I do makes me fatigued, then I have extra spasms.”*
- *“Unfortunately I find myself in the WorkCover system so that does not help and adds another layer of distress”*
- *“I was basically abandoned by my employer and later WorkCover insurance company; Centrelink wants me to wait till WC issues are resolved, so no support there either.”*

The Costs of FND

Respondents reported significant losses and pain associated with the illness and the loss of independence associated with the illness. People had become isolated from their friends, in some cases their families. They had missed out on vital schooling and the ability to engage in desired activities such as dancing, horse riding, sports and creative activities. People reported being under severe financial strain, that impacted every aspect of life. The loss of employment and the ability to work impacted people significantly, and was referenced by the majority of survey respondents. The symptoms impacted their ability to engage in activities they previously enjoyed, and their ability to be with friends and family.

People reported that FND had life changing impacts, and had led to significant costs and losses, personally, financially. They reported losing:

- *‘everything, independence, self-worth, financial stability, I’ve lost me’.*

- *"it has impacted my life in every way possible and rapidly losing hope"*
- *"I have had to re-evaluate my entire future. I now have no hopes for the future."*
- *"FND has cost me my friends, my family, my work, my husband's work, my finances, and the dream of having a home of our own. It has cost me my dreams of travelling and exploring the world with my kids."*
- *"I have lost friends, my job, I cannot drive. My family suffers daily watching me deteriorate. It has just about cost me everything"*
- *"lost my Self-esteem and confidence, career, time, my marriage has suffered"*
- *"I have lost everything. My independence, profession self-worth, financial stability. I've lost me"*
- *"Lost My health. My life. My sanity. My work. My savings. My plans. My dreams. My future."*
- *"my life, my career, my friends, the ability to do things to go outside, do sports, go to the gym. I would be as disabled as a person who is a paraplegic and yet it is not recognised as such, and the emotional turmoil that goes with this is really bad, sometimes you get suicidal and you just want the scientists to hurry up and work out what is really going wrong in the brain and nervous system"*
- *"I have days where I cannot get out of bed I have no confidence in meeting a new partner I don't like to commit to any plans when I get invited out as I never know if I am going to be ok. I feel very lonely and feel like really people don't understand. I see it hard to see a future"*
- *"In every possible way family, husband and wife, employment, being a mother, Caring for my home, unable to care for my pets, self-care, sense of self."*
- *"I've lost my fire for life. There isn't even much of a flicker of my old self. I have no money, no independence, no dignity at times, don't have the equipment I need such as a wheelchair, almost all my friends have gone, extremely isolating to be in so much agony 24/7"*
- *"Can't work=can't make \$\$\$ = cant fund retirement, kids school, house payments and up keep, wife is stressed and is considering leaving me. So the future looks purity shit house"*
- *"I lost my job, driving license, friends and I rarely see my family due to distance. I am unable to tolerate heat and overheat easily which causes seizures. I don't leave the house and haven't in 4 years. I am unable to maintain any kind of relationship due to my life restrictions."*
- *"It's completely changed my life. I cannot always drive, travel, work or do things I use to do. I have had to be resilient and try to remain positive which has been hard"*
- *"I have gone from being fiercely independent despite my Complex PTSD. To not being able to take care of my home or myself. I struggle doing basics. The future will be Me not leaving my house at all"*
- *"What future. I wanted to be a nurse. I can't. I have wasted 18 months of my life because I was 4 weeks out from graduation on my final practical and boom. Can't lift my arms. Have episodes daily. I don't see a future atm."*
- *"Had to stop teaching, leave a job I loved and was highly skilled at. Cannot read or play an instrument or do anything that takes mental concentration and multiple skills to achieve for longer than 5 mins - fatigue, migraine set in. Cannot drive because of non-epileptic seizures; cannot walk when fatigued, without stick and physical support"*
- *"no jobs, relationships re friends, study can't get to school so i have left, feel like i don't have much future in what i am interested in."*

- *“There are many more things I cannot do than there are things that I can do now. I am a different person than before FND. I have lost all confidence in myself”*
- *“From a fully functioning person who participated in society to more or less a recluse. I can just see a bleak future especially with the medical services not being available and Centrelink not recognising our illness we are in limbo just trying to survive each day”*
- *“I have no life. I can’t go out as I need a wheelchair and can’t afford 1, I struggle to look after my own basic daily needs, I am isolated, I am totally unable to engage in any of my hobbies. There is no light looking forward with this it’s a painful struggle every day and that’s what my “future” is”*
- *“I have lost everything. My job, house, belongings, wife, kids, family and all my friends”*
- *“I do not know if I will ever walk again. I don’t believe I will ever be able to work. I am worried we will lose our family home. FND has systematically ruined my life.”*
- *‘It’s cost me my early adulthood. Romantic and friend relationships. Work and Study. I think the most I’ve lost is dignity, having mother and younger sister have to bath me, change me.’*
- *‘My independence; my ability to work and contribute to my family, to work in the community, to read novels, to play an instrument, to talk and sing, to walk without support, my dignity when I have to get taken to the toilet and/or fed because I’m paralysed, to physically connect with friends, to attend community events, to leave the house, to drive, to swim without being supervised in case I have a seizure. It has cost me my mental health and my low weight. Medical appointments are hugely expensive and I lost huge chunks of my life waiting on doctors lists just to be seen. I lost me while trialling medication that made my FND worse to be told it was just my anxiety. I lost my self-belief - it must be just all in my mind, I must be faking, I just need to be more positive. I have lost my purpose, my dreams and my life’s work. This is what FND has cost me.’*
- *“Can’t learn anything new or retain new information. Speech. Writing. So employment opportunities are very low and I have become a WHS concern”*
- *“I can never work in a demanding and well-paying job like the one I had before FND hit hard. So it has changed the course of my life. It also impacted on my relationship with my partner and was a contributing factor to us separating. Financially it has ruined me. I no longer own my home and am in debt. My future seems quite bleak right now because I don’t know when “I will be able to work and earn decent money again, and this impacts my emotional wellbeing as well because I don’t feel like a contributing member of society. I feel like a loser and a bludger, and no one understands how the symptoms can vary from day to day so I also face stigma and ignorance which is distressing.”*
- *“NOTHING is the same as it was prior to FND. Physically, financially, emotionally, fulfilling my role as wife, mother, employee have completely gone. My children have lost their mother. My husband no longer has a wife, but a disabled person he feels obligated to be with. I can’t cope with thinking of the future, just surviving one day at a time, hour by hour. With the lack of research into this disorder there isn’t much hope of treatment in the future.”*
- *“I wanted to finish studying at uni and work as an occupational therapist, I have had to quit my part time study. I cannot drive anymore. I cannot care for my children on my own anymore and my husband now has had to quit work to help, so his work also impacted which has also impacted our finances significantly and of ever owning our own home.”*
- *“At first it stopped my life completely. The chronic fatigue was so severe I could only shower*

and I would become breathless with this one daily living activity. I had very little savings and super due to my age and being the sole provider for my children all of their lives. I was put on Newstart and if not for my elderly mother, I would have been homeless living in my car, I could not afford share accommodation either. So my life as I knew it had been replaced with enormous loss and extreme hardship in every way. My hopes for the future in working another 15 years were gone. I had to live with my elderly mother for 2 years, then apply for public housing. I grieved for a year at the devastation this disorder caused me. I now live in chronic severe hardship and live frugally. I live a very isolated life. I am always at risk of relapse. I can't afford any luxuries, I can't use too much electricity, I can't shop for fresh fruit and very little meat and vegetables. I exist for the most part on toast..... We are in crisis."

- *"The biggest problem I'm facing is how truly disabling this is, but how sometimes I'm gifted and capable and that somehow gives people the impression that my need is not severe. I choke, I mess myself, etc... without support, I'm unable to do anything but wish for death. With support, I'm able to just barely survive and get some glimpses of beauty through a great deal of pain. With the right level of support, I still believe I could thrive.....Please help me and others get the high level of support some of us need (very high in my case) /and/ still be able to shine."*

Impact on Carers: Caring for a Person with FND

Carers reported the same frustrations as consumers in terms of seeking a diagnosis, medical care and treatment. The burden of caring for a loved one with FND had a significant impact of the wellbeing of carers and had wide reaching impacts. For some *"Caring has been a full time activity when FND was at its worst"*

Carer's Mental Wellbeing

95% of carers reported that caring for a loved one with FND negatively impacted their own mental well-being to some extent. 33% of carers reported mental wellbeing was extremely affected or affected most of the time. People reported caring for a loved one with FND caused *"A lot of stress and worry which seems never ending"*.

Many carers were consumed with caring for their loved one with FND

- *"I am my husband's full time carer. I cannot leave him alone, let alone leave him with our 3 small children so I can have some time out."*
- *"A vast majority of my time is now utilised to care for my daughter. As a carer, it is as present as every breath that I take. It is there 24/7 because my daughter could need my help all day, every day. So how can I not be present for her? Everything else stops. Everything fits in with scheduling how best to keep her symptoms as less impacting her as possible. We plan our day by the hour. Our life is hour by hour as dictated by FND."*

Carer's mental wellbeing suffered with the strain, distress and helplessness in caring for a family member with FND.

- *"My mum's condition has put a lot of stress on our relationship. Spending so much of my time, cooking, cleaning, driving her to appointments, caring for her when she needs support during/after a seizure makes it hard to maintain our mother/son relationship because it's getting more and more a patient/carer relationship."*
- *"There is also a distress of seeing my daughter crumble before my eyes and the feeling of helplessness in not being able to change what is happening. I am there to support her in every way but it is the helplessness that is overwhelming."*
- *"I developed a cannabis and tobacco problem trying to cope with looking after my mother. I haven't had a job since as IV been suffering from severe PTSD, depression and anxiety. Been suicidal as well. It has broken me"*
- *"Relationship with my wife continues to be under strain as she is not coping with the lack of support for the FND condition and its symptoms."*
- *"I gave up my life in Perth sold my house worth of furniture and came to care for her. Lost my mind my mental health has declined. I ended up in a mental health service."*
- *"Watching my daughter lose her independence has been heartbreaking."*
- *"It is hard to watch her world become smaller and smaller."*
- *"100 percent most devastating thing IV witnessed"*

"The hardest part of caring for my daughter is seeing her going from a well-adjusted adolescent starting to find her way in life, to a young person having to fight hard just to be able to attend school and participate in everyday family life."

- *"After living with, and caring, for my mother for months and months, with doctors having no idea what was wrong, I started doing my own research and I made the diagnosis. More help needs to be available. I suffered from depression after caring for my sick mother and have come very close to ending my own life from the heartache I have endured watching my mum suffer."*
- *"I am constantly worrying about her. Every time the phone rings I worry there is another problem"*
- *"Since becoming my mum's carer in 2014 it has been very distressing and difficult to take care of her. Watching my mum in agony and misery every day, seeing her have 4-6 seizures most days and seeing her not able to do the simple things she enjoys is constantly upsetting me."*
- *"The stress and concern and constantly advocating for her is extremely exhausting and frustrating within the medical system and Centrelink."*

A number of carers reported concerns as to how their adult children would manage after they were gone.

- *"I hold very grave concerns for the future of my daughter as I grow older - and closer to the inevitable future end of my life."*
- *"I worry about what will happen when I am not around, especially as she lives alone. She is such an intelligent person and should be in a worthwhile job."*
- *"I'm 71 when I die my daughter has no one to look after her & no one to help support her mentally physically & financially"*

Carer's Physical Wellbeing

- 85% of carers reported that caring for a person with FND has impacted on their physical wellbeing, to some extent, often due to manual handling e.g. pushing a wheelchair, lifting an adult person and lifting a wheelchair.
 - *"Finding it harder as I get older. Lifting a wheelchair in and out of cars numerous times a day is difficult, assisting with car transfers now she has no feeling in either leg and can't push up into a car."*
 - *"Lifting the wheelchair has made my back hurt, pushing her in it has been difficult at times."*

Carer's Financial Wellbeing

87% of carers reported that caring for a person with FND affected their ability to work. Many carers were unable to work, had to reduce their work hours and were regularly taking leave due to the impacts of FND on their loved one. Work absences were impacting on their job security and caused some carers to lose employment.

- *"Inability to work a full day when child is in FND symptoms, no chance of promotion, inability to travel for work and being placed on performance management all because of a lack of understanding of the seriousness of the condition and the need to care for the child during some severe FND symptoms"*
- *"When she is at school we have calls almost every day to come and pick her up - this makes it very difficult to maintain working. My husband is a casual worker so does not get paid for time he misses when he has to take her home and cannot come to appointments in Melbourne because he loses a day of pay."*
- *"I am constantly needing to take time off work"*
- 89% of carers reported that caring for a person with FND had a negative impact on their financial well-being. 7% reported catastrophic impacts including having to liquidate their business and sell their home.

- *“We will only be able to survive for a short period before having to sell our home as I cannot earn enough to pay mortgage, doctors’ bills, prescriptions, and general living expenses. We are using up our savings at the moment.”*
- *“Apart from large financial costs associated with seeing medical professionals, there is also an emotional stress placed on myself and the family. This has affected my work and earlier in the year caused me to have sick leave for the first time in my working career.”*
- *“I have no social life, I’m a carer not a husband, it’s cost me my business, my house, debts are mounting.”*
- *“I find it difficult financially as my daughter has moved back home. She wants to work but becomes exhausted easily and just can’t”*
- *“I can't work, she can't work. I am a single person who had a successful career we are currently living off my savings as there is nothing available to us in relation to services or funding to assist.”*
- *“Caring for a loved one with no financial support is stressful. Cost of physio, medications, doctors, social workers, massages, equipment and home modifications are not covered. It is tiring and restrictive and changes and impacts the family dynamics. It also restricts social interactions for the patient and cares and family.”*
- *“I need to sell my business & move closer to care full time. She has a toddler & has been told she cannot drive, fly. I live 1500KLM away”*

What People with FND most Need

Survey respondents were asked to identify what services and supports could best meet the needs of Australians with FND. 92% of consumers reported training and education of Health Professionals was most needed; 85% of consumers noted a need for community awareness of FND and 82% of consumers wanted support services and an equal 82% wanted research into the condition and treatment options.

People reported needing access to care and treatments, with professionals who know what the condition is and how to manage and treat the symptoms. People wanted information about the condition and understanding from health professionals; they needed information on treatment options. People wanted professionals to know and understand the condition so they did not have to explain and inform the doctors about the condition they are trying to get help for. People needed access to services and disability aids to manage around the house and the community. They needed help dealing with Government services such as Centrelink and NDIS, who often failed to recognise the condition.

“Being believed by the Medical Profession & not slapped in the face & told to ‘get out of bed & stop wasting our time because there is nothing physically wrong with you’. Many are still being treated this way now. More affordable access to Neuro Rehab not just 6 weeks a year. Allow the Mental Health Care Plan to be implemented at least twice a year. Giving people ongoing support & ensuring that Fnd is placed on the list as a real condition for NDIS & Centrelink”

Recovery Needs Identified by Australians with FND

- *“I need health professionals who are accessible, affordable and understand this condition. I need access to walking aids and home assistance and things such as physio, massage and psychology.”*
- *“Access to FND treatment that is specifically for young people that I can access without constant travel (possibility upskilling locals workers with info from experts) experts that are not focused on trauma and anxiety. A meaningful plan of treatment that focuses on my personal situation not generalisations.”*
- *“Time and space to talk and process what's happening. More investigations into my other health concerns and not just assuming it's all FND or anxiety. I need the doctors to stop downplaying the seriousness of FND. It has a huge impact on my life and ability to function.”*
- *“It needs to be accepted as a real illness and there needs to be somewhere where people with the illness can go.”*
- *“Answers and treatments that work by medical practitioners who have a profound understanding of FND.”*
- *“Paramedics to receive training for people who experience non epileptic seizures, a Neuro-Psychiatric inpatient facility.”*
- *“A Specialised program customised to my needs physically”*
- *“Would like a person that you could ring for advice and as support”*
- *“I need a wheelchair to get me out of bed and into the sunshine for an outing. Carers. Trauma therapy from being disabled. Neurophysiology, EMDR. Sensory therapy from over load. I want to walk again!”*
- *“The ability to be admitted as an inpatient if I feel that I need it, the ability to not be scared of how I will be treated if I go to hospital, the ability to have proper pain relief given to me without being called a junkie, the ability to be taken seriously by medical professionals, the ability to live my life without needing to educate every medical professional I encounter on what is wrong with me.”*
- *“Information, compassion, access to services, and mostly a lack of judgment”*
- *“I’m not sure I wasn’t aware I had options”*
- *“Anything! Any care, any rehab, any support”*
- *“Educated GPs, doctors, specialists and nurses that know what FND is. Then refer me to the relevant treatments!”*
- *“More real life stories of success and support with others”*
- *“A good doctor that understands FND and not just needing to look it up!”*

WHAT CARER'S REPORT NEEDING

- *“Having the diagnosis explained, having a treatment plan and medical staff that didn’t treat her as a faker, telling her to grow up and stop wasting doctor’s time”*
- *“Earlier diagnosis, information on treatment options and where to get help. The neurologist just said ‘we can’t help you any further”*
- *“Treating specialists having some understanding of FND”*
- *“Medical professionals to be aware of this condition and accessibility to appropriate treatment.”*
- *“Better education and awareness on the part of medical professionals. A clear list of resources to assist with treatment. Being sent home with ‘it’s up to you and your subconscious to get better’ when you can barely walk, talk or eat is unacceptable”*
- *“Many health professionals do not know what FND is, so it is hard to get targeted therapy”.*
- *“Prior to my daughter receiving her FND diagnosis we knew nothing about it. It has been a complete nightmare. We have had to access many different medical professionals, received conflicting information and have been left bewildered and very confused. This is Australia – not some third world country. Our loved ones deserve better. We as carers deserve better. It is disgraceful.”*
- *“This disorder needs to be brought into the limelight. Doctors need to get educated on how to help and treat this disorder. Centrelink needs to recognise the disability and long-term care packages need to be established.”*
- *“Help line, better access to understanding what this all means. I am feeling quite overwhelmed at the moment with very little understanding of what the journey ahead will entail.”*
- *“Specialised services that are compassionate and open minded. Training for local services in the country as travel to the cities takes such a toll on those with FND and financially it is also not sustainable to travel regularly to the city. Also training for those in the education system as a lot of time and energy has been used trying to get support and discriminatory actions have adversely affected her health.”*
- *“To be listened to. To not be dismissed. For any medical professionals to do their job properly and be properly educated.”*
- *“I need services to listen and not ignore. I need them to educate myself and the person i care for. I would like them to read the information sheet on FND and not roll their eyes”*
- *“Better understanding and knowledge universally from the medical professionals and general public if at all possible”*
- *‘Knowing that they can access proper support & treatment in a timely manner. The past 6 months have been a complete nightmare for my family. We have all suffered through lack of proper support & help.”*

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