

Experiences of Functional Neurological Disorder

Summary Report



Australian Government

National Mental Health Commission

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Introduction

Functional neurological disorders (FND) are one of the most common diagnoses in neurologic practice and the second most common reason for a neurologic consultation after a headache.¹ FND is estimated to be experienced by around 50 people per 100,000 population.² In a recent Australian study of an outpatient neurology clinic, 15% of new presentations received a primary diagnosis of FND, whilst other studies find that up to 30% have at least some functional element as part of their symptoms.^{3,4}

Functional disorders result from problems with the functioning and connectivity of the nervous system without associated structural damage to the nervous system.⁵⁻⁹ People with FND experience a variety of disabling motor, sensory and cognitive neurological symptoms such as: paralysis, balance problems, tremors, weakness, fatigue, chronic pain, seizure-like episodes, blindness, and bladder and bowel problems.

Until recently FND has been relatively neglected by both clinical services and research, as it falls at the intersection of physical and mental health. Historically, FND was thought to be a mental illness and continues to be classified as a mental health condition under the Diagnostic and Statistical

Manual of Mental Disorders (DSM-5). Theories originally proposed that people were subconsciously 'converting' psychological trauma and conflict into physical symptoms.¹⁰ However, these theories are starting to be challenged by brain imaging research that show differences in the way the brain functions in people with FND.^{5,11} Nevertheless, research consistently shows that individuals diagnosed with FND experience significantly higher rates of mental illness such as anxiety and depression than comparable populations with neurologic disorders.²

Neurologists are often not well equipped to support the full range of symptoms of FND, and will refer the person for psychiatric intervention. However, doing so can fail to address the serious and disabling physical symptoms people with FND experience. As a result many people with FND fall into the 'black hole' between neurology and psychiatry and are left confronting high levels of stigma and discrimination by both clinicians and people in the community.^{12,13}

The following paper summarises research undertaken by FND Australia Support Services Inc. for the National Mental Health Commission to explore the experiences of consumers diagnosed with FND and their carers in Australia.

Experiences of FND in Australia: a consumer and carer survey

In December 2018 FND Australia Support Services Inc. undertook an Australian consumer and carer consultation to explore the experiences of FND in Australia.

In total, 179 Australians participated in the consultation, including 113 consumers and 66 carers. The survey was promoted through the organisation's networks and social media platforms. 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.

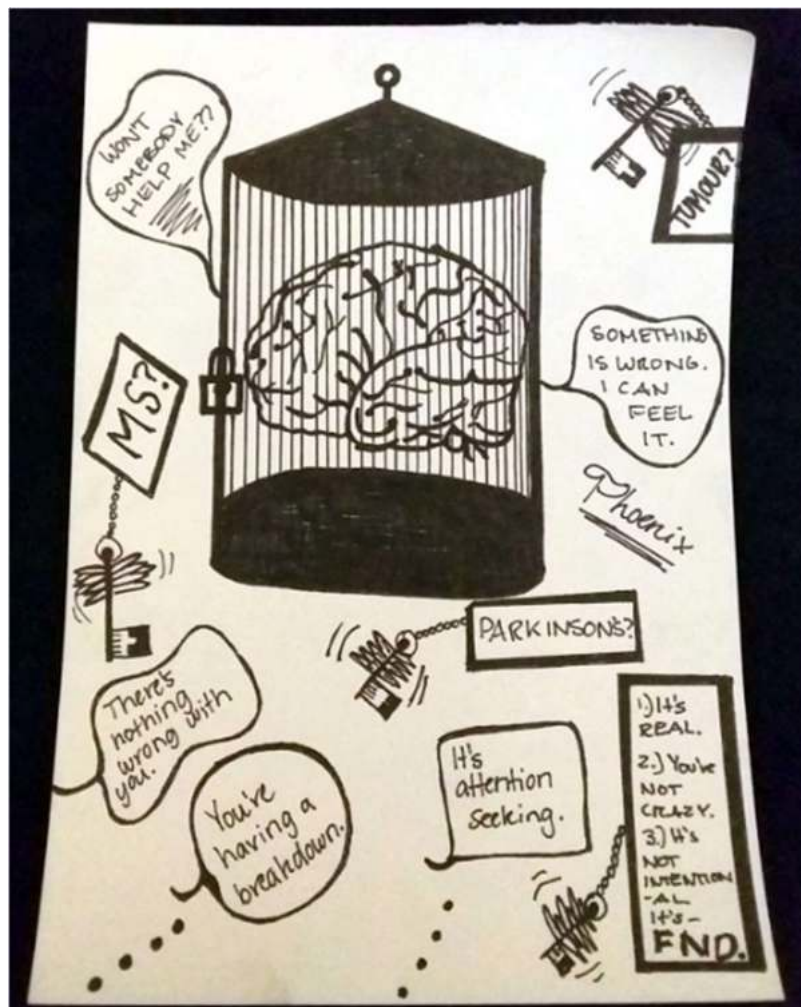


Figure 1: Artwork by Laura, FND Consumer, visualising her experience with FND

Diagnosis

A general physician at a private hospital allowed my daughter to fall on the ground six times because she believed my daughter was faking. We medically discharged ourselves from that hospital.

[Nine days later] we presented to a major 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...

[Three days later] 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.

FND Carer

Failure to diagnose the condition early after onset of symptoms, poorly delivered diagnoses and repeated testing compound the harm caused by the condition and lead to significantly worse outcomes for people with FND.⁴ Only 16% of people surveyed reported receiving a diagnosis within three months of the onset of FND related symptoms, rising to 34% within 12 months. However, the majority (66%) reported living with debilitating FND symptoms for over a year prior to diagnosis and over a third (36%) for over four years.

In addition to delays in diagnosis, survey participants reported low levels of satisfaction with the experience of obtaining their diagnoses overall. Many referred to a lack of information, noting that they were not provided with an effective explanation of the condition, realistic prognosis or treatment options at the time of diagnosis. Such experiences of diagnosis are consistent with international research in this area¹⁴ and a key area for potential improvement as communication of diagnosis is recognised as a critical first step in therapeutic success.⁴

Living with FND

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.

FND Consumer

Current diagnostic and treatment practices are highly variable despite a growing body of international evidence that a tailored approach to diagnosis and treatment of FND can result in major improvements in health and quality of life. However, the literature also recognises that the prognosis for people diagnosed with FND remains poor,¹⁵ a fact attributed to the combination of under recognition of FND, poorly delivered diagnoses and lack of availability of knowledgeable therapists.⁴ In such circumstances, people experience functional neurological symptoms that are at least as disabling as other neurological diseases such as Multiple Sclerosis, Stroke, Parkinson's Disease and Epilepsy and are often not referred to appropriate services to treat their distressing but potentially treatable symptoms.^{4,15-17}

Overall survey respondents reported significant pain and grief associated with their experience of FND. Whilst the pain directly associated with the

symptoms of FND was significant, responses indicated that it was the compounding effects of stigma, professional misconceptions, unavailability of treatment services and overall lack of broader supports that were the most harmful to consumer's mental and emotional wellbeing.

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... They would not treat me this way if I had had a spinal injury, which is considered to be a real condition.

FND Consumer



Figure 2: Artwork by Leanne, FND Consumer, visualising her experience with FND.

FND prognosis: access to treatment and quality of care

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... what doesn't help is professionals saying it's all in your head, you want to be ill...The only support is the FND group, without that there is absolutely nothing.

FND Consumer

Early diagnosis with an effective therapeutic explanation of FND and early intervention from providers with specialist FND knowledge, leads to the best outcomes and potential for full or partial recovery. Effective management requires collaboration between neurology, psychiatry, psychology and physical rehabilitation, including physiotherapy and occupational therapy^{4,18}. However, many neurologists discontinue their involvement with consumers once a diagnosis of FND is made, instead referring the person's care back to the referring physician or to a psychiatrist or psychologist, often leaving many individuals to struggle with life changing symptoms on their own.¹⁹

I've found that neither psychiatrists nor neurologists want to treat me because they don't view it as part of their field.

FND Consumer

Survey findings indicated that the full range of recommended multidisciplinary interventions are not currently available to Australians diagnosed with FND. Only 36% of surveyed Australian consumers accessed FND related treatment in the six months after diagnosis and 40% reported that they had never accessed any form of support or treatment for FND.

Participants reported a significant lack of knowledge and understanding amongst non-FND specialised health and allied health professionals, and many reported needing to educate practitioners they were seeing for FND. Others cited significant additional stress resulting from interactions with professionals who did not show genuine concern and compassion for the disabling and distressing symptoms consumers were experiencing or offer appropriate follow up care, treatment and support. They

reported being 'ping ponged' between services and doctors, with no-one willing to take responsibility for their management and care, resulting in further deterioration of their conditions. Responses such as the following were common:

I have been pushed from pillar to post for the last four years. Poked, prodded, disrespected, ignored and generally mistreated until finding [neurology service] 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.

FND Consumer

Experiences such as these are consistent with the international FND literature which recognises that "partly because of under recognition or poorly delivered FND diagnoses and lack of availability of knowledgeable therapists, the prognosis of FND remains collectively poor, with disability persisting or even worsening over time."⁴



Figure 3: Kate and physiotherapist Catriona demonstrating FND treatment using an auto bike.

Participants highlighted the following significant barriers to receiving treatment:

- **Clinical knowledge of health professionals during both diagnosis and treatment.** Distressing experiences with health service professionals were reported by 80% of survey respondents who described being accused of faking symptoms or ignored because ‘it’s all in your head.’ Only 21% of respondents reported having at least some positive experiences in relation to the level of compassion, knowledge and understanding of health practitioners, most of which were associated with one of the few specialised FND clinics.
- **Absence of any specialised FND services.** People reported having to travel extensive distances in order to access specialised health professionals to treat or diagnose their condition and a number of people had moved interstate in order to access one of two specialised FND programs. Such impacts were further compounded for people living in rural, regional or remote areas.
- **Waiting periods for specialised services.** Where specialised treatment services were available, wait periods for initial appointments and treatment were extensive, and people’s conditions deteriorated while waiting to see specialists.
- **Financial barriers to treatment.** Survey participants reported that there are no treatment services currently offered to individuals diagnosed FND in the public health system.

In the short term such barriers left consumers without support and treatment options and, in the longer term, left consumers distressed and reluctant

to approach health services for assistance when their symptoms deteriorated.

Although FND is considered treatable, only 20% of consumers surveyed reported some improvement in their symptoms over time and none reported full recovery. Comparatively, one third of consumers reported that their FND symptoms stayed the same, 38% as worsening and 9% as fluctuating over time.

NDIS

FND often leads to significant physical disability and functional limitations, in addition to psychosocial disability. However, the number of survey respondents with an individualised funding package under the National Disability Insurance Scheme (NDIS) was low. Only ten percent of consumers reported having a NDIS package, whilst many others were in the process of applying but facing significant barriers to success. A further 20% of respondents reported their applications had been denied, with the key consideration reported to be whether or not FND is a permanent condition.¹

Over 30% of respondents reported the NDIS application process was too daunting and overwhelming to attempt, and that the stress of applying would worsen their condition. For those who had received an NDIS package, the size of the packages ranged from less than \$10,000 to more than \$150,000, with most ranging from \$75,000 to \$100,000.

¹ Whilst FND is considered potentially reversible, long-term follow-up studies have identified that 50–90% of people diagnosed will experience ongoing symptoms.^{15,20} Many of these will become worse, especially when treatment begins later than 6–12 months from symptom onset, as is common with long delays to diagnosis and access to services.²¹ Furthermore, international research suggests a large majority of people (83%) are still experiencing symptoms and remain distressed and disabled some 10 years or more after initial diagnosis.²²

Beyond the symptoms: factors that compound the impact of FND on consumers and their carers

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.

FND Consumer

Survey outcomes highlighted the serious life-changing impact FND had on the life of people and their families leading to significant costs and losses, personally, financially, psychologically and socially. Over 50% of people with FND rated their quality of life as poor or very poor whilst only 16% reported their quality of life as good and none reported it to be very good.

Carers reported the same frustrations as consumers in terms of seeking a diagnosis, medical care and treatment. In addition to these frustrations, caring for a loved one with FND had significant wide-reaching negative impacts on the mental, physical and financial wellbeing of carers themselves. For some *“Caring has been a full time activity when FND was at its worst”* (FND Carer).



Figure 4: Amelia, FND consumer.

Mental wellbeing

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.

FND Consumer

FND had at least some negative impact on the mental wellbeing of 98% of respondents and 60% reported such effects were present most of the time. 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, financial stressors associated with the loss of employment and lack of available financial support and the attitudes to the illness amongst the health professionals and in society.

Carers also reported negative impacts of FND on their mental well-being with 95% reporting being negatively impacted to some extent. Of these, 33% of carers reported that their 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”* and described experiencing strain, distress and helplessness in caring for a family member with FND.

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.

FND Carer

Physical wellbeing and impact on activities of daily living

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.

FND Consumer

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).

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.

FND Consumer

Meanwhile, 85% of carers reported that caring for a person with FND has impacted on their physical wellbeing, to some extent, often due to the physical labour required to care for a person with FND e.g. pushing or lifting a wheelchair and lifting an adult person.



Figure 5: Cassandra, FND Consumer.

Employment and financial wellbeing

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.

FND Consumer

For 98% of the consumers surveyed, symptoms of FND impacted their ability to work or study to at least some extent and for 70% of people this meant not being able to work or study at all. Only 7% of surveyed people with FND were working full time.

Almost all consumer respondents (95%) reported struggling financially because of the impact of FND on their ability to work and 89% of carers reported that caring for a person with FND had a negative impact on their financial well-being affecting their ability to work and job security.

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 because he loses a day of pay.

Significant financial impacts – including losing businesses, homes and in some cases ending up homeless – were reported by 20% of consumers and 7% of carers. Multiple respondents admitted that the financial strain associated with FND alone had led them to consider or attempt suicide.

Consumers noted that Centrelink payments were difficult to live on or gain access to in the first place. Furthermore, the cost of treatment and support was financially inaccessible for many with people reporting being 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(s).

Social wellbeing and inclusion

The combination of debilitating FND systems and lack of support services has left many people with FND extremely isolated. FND impacted a lot or extremely on 75% of respondents' social and leisure activities. Some participants reported that they only left the house for medical appointments, while 90% of people reported that FND negatively impacted on their ability to maintain friendships and relationships.

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... This is one of the hardest things to deal with, adjust and accept.

FND Consumer



Figure 6: Amelia, FND Consumer.

Respondents reported that their symptoms left them unable to leave the house without assistance. Many people reported being unable to drive, yet their symptoms and fatigue also made public transport difficult to manage and other modes of transportation were financially unfeasible and assistance hard to come by, further entrenching their social isolation.

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... there have been times when I have had to cancel appointments because I could not drive and had no other options or backup available to me.

FND Consumer

Conclusion

The research conducted by FND Australia Support Services Inc. provides insight into the views and experiences of consumers and carers living with and affected by FND in Australia. The survey results suggest that improvement in the following four key areas has potential to substantially improve the quality of life experienced by people living with and affected by FND:

- Greater understanding and recognition of FND amongst mental health and health professionals, especially those providing emergency care or involved in communicating the diagnosis.
- An interdisciplinary approach to FND diagnosis and treatment with input from consumers, neurology, psychiatry, psychology and physical rehabilitation services.
- Greater access to knowledgeable health and mental healthcare services.
- Greater recognition of FND and its impacts by government support services.

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