

Submission
No 95

**INQUIRY INTO EQUITY, ACCESSIBILITY AND
APPROPRIATE DELIVERY OF OUTPATIENT AND
COMMUNITY MENTAL HEALTH CARE IN NEW SOUTH
WALES**

Organisation: FND Australia Support Services Inc

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Equity, accessibility and appropriate delivery of outpatient and community mental health care in New South Wales

Functional Neurological Disorder [FND]

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FND has been labelled medicine’s “silent epidemic,” a “crisis” in neurology, and psychiatry’s “blind spot” (Aybek & Perez, 2022). FND is a complex neuropsychiatric disorder, that slips between system gaps between neurology and mental health. FND is classified as a psychiatric disorder under the DSM-5 and ICD-11, yet presents with highly disabling and distressing neurological conditions. Neurologists find FND a challenging condition to discuss with patients (Aybek & Perez, 2022), and mental health services are poorly equipped to manage the disabling physical symptoms. FND is recognised as being a potentially reversible disability, yet a large percentage of people are developing lifelong permanent disability. People with FND slip through systemic gaps in services, failing to access care and treatment that could prevent long term disability.

FND symptoms disrupt daily life, many people struggle to attend school, work and engage in community life (Gill, 2019). A person living with FND is often highly dependent on their carers and many families find their capacity to work is disrupted while caring for a loved one with FND (Gill, 2019).

FND Symptoms include:

- Functional Seizures, that may appear similar to epileptic seizures
- Paralysis
- Gait Disorder – inability to walk
- Upper and Lower limb weakness
- Tremors
- Sensory changes including vision loss, severe sound sensitivity, loss of feeling in limbs
- Incontinence
- Swallowing problems and
- Speech difficulties

Treatment:

Evidence based care for FND, involves a therapeutic explanation of the diagnosis and access to a comprehensive multi-disciplinary team including psychology, psychiatry, neurology, physiotherapy, occupational therapy, dietetics and speech pathology (Espay et al., 2018).





Without access to comprehensive evidence-based care, many people will go on to develop permanent disability (Gelauff & Stone, 2016), and becoming dependent on Centrelink disability pensions, carer pensions and the National Disability Insurance Scheme. Early access to treatment improves long term outcomes and prognosis, especially for young people, whose brains are more neuroplastic.

In research conducted by our organisation, in partnership with the University of Technology, Sydney and Notre Dame University, effective management of FND was described by people with lived experience of FND, as being responsive, knowledgeable, respectful, transparent, collaborative, and trauma-informed (drafting for publication). Unfortunately, effective management was also described as rare, particularly in regional and remote areas of Australia. Clinicians report low levels of confidence and a lack of training with resulting impact on patient engagement, stigma and service utilisation (Lehn, Bullock-Saxton, Newcombe, Carson, & Stone, 2019; MacDuffie et al., 2021).

Importance of Access to Evidence-based FND Care

Poor healthcare experiences for people with FND have a negative impact on symptom persistence, overall prognosis (Robson & Lian, 2017), and increase patient costs (Lagrang, Jones, Bernard, & Lehn, 2023) and clinician knowledge about FND symptoms and care strongly mediates this.

FND Services in NSW

FND Australia Support Services is the only charity dedicated to FND patient care, education and advocacy in Australia. It remains an unfunded organisation run by a handful of volunteers living with the condition, and a few contractors. The organisation receives around 11-15 enquires per day, from people in crisis, desperately seeking treatment and living with incredible disability, financial distress and not knowing where to turn.

In 2021, the NSW Ministry of Health funded the creation of the FND Aus App, which now provides a wealth of information to help people understand their condition [FND App | FNDaus.org.au | FND Australia Support Services](#). In 2022, the NSW Ministry of Health funded the development of a pilot group program to assist people to learn strategies to reduce their symptoms and improve their wellbeing. This program has currently completed one round, with very positive feedback. Another group will be offered shortly.





The Prince of Wales has recently been awarded funding for a pilot program. [Mindgardens Functional Neurological Symptom Disorders \(FND\) Clinic | Centre for Healthy Brain Ageing \(CHeBA\) \(unsw.edu.au\)](#) There is currently an inpatient program for children with FND at Westmead Hospital [limited capacity], but no outpatient pathways for children with FND.

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Both the FND Aus group program and Prince of Wales program have no ongoing funding to continue the pilot programs. These programs, also do not meet the full spectrum of services needed for FND recovery and wellbeing for people across the state.

Co-presenting Mental Health Care in People with FND

In addition, people with FND commonly present with significant comorbid mental health conditions, including PTSD, complex PTSD, eating disorders, borderline personality disorder, other mood disorders and suicidal ideation. Many people with co-presenting mental health conditions, are excluded from community mental health services and inpatient services as a result of their FND symptoms. For example, people with seizures and tics have been excluded from DBT community intervention programs as their seizures and tics were disruptive to other patients. Inpatient mental health programs are often not equipped to meet the severe disability needs of people with FND, including wheelchair accessibility, hi-lo hospital beds, disabled bathrooms, assistance with personal care and managing FND symptoms including seizures, feeding and showering. As a result, the people with the most needs are excluded from all services, and many end up suicidal and in severe distress. Services, for example lifeline have not been equipped to understand the impact of the disability nor be able to refer people to appropriate services, due to the lack of services specifically catering to the needs of people with FND.

Service Gaps

There is an urgent need to create pathways for people presenting with FND, both inpatient and community. There exists a need to look after the whole person, including the physical disability and their mental wellbeing. Not addressing the mental health concerns of a person with FND, will likely lead to ongoing disability. In addition,



if physical rehabilitation is not available, along with access to relevant disability services, people will continue to suffer and experience significant functional decline.

There exists an urgent need for a **helpline**, to assist people on their pathway, **funding for services** across the spectrum of needs for FND as well as upskilling in FND **education for clinicians**. Because of the need for a comprehensive multi-disciplinary team, ideally **a specific FND Medicare plan**, similar to the Eating Disorder Care plan, would allow for people to access the treatment they need, prior to developing a permanent disability. The current Chronic Disease Management plan, does not meet the needs of people with FND.

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Many people with FND will eventually require the National Disability Insurance Scheme, due to long-term disability, but access to this scheme requires the person to be fully treated. Many people fail to meet this criterion, due to the lack of funded services available for them to access. Had they been able to access the required treatment services, they may well not be needing to apply for NDIS, with some people able to recover to a point that they can manage their condition in the community without the need for ongoing care. This is especially critical for young people, where research shows that 60% of young people who access comprehensive evidence-based care, going on to recover.

Lived Experience Stories

The impact of FND on people, has been presented in recent media stories including:

[Functional neurological disorder: Cruel disorder robs previously healthy teen of almost all movement - except when she is asleep | Exclusive \(9news.com.au\)](#)

[Meet the women in the fight against functional neurological disorder - ABC News](#)

[Functional Neurological Disorder \(FND\): The reality of living with it. \(mamamia.com.au\)](#)

[Functional Neurological Disorder turned Rachel's life from healthy and active to 'debilitating' pain | 7NEWS](#)



FND Australia Support Services would be happy to work with Government and the NSW Ministry of Health, to develop future pathways of care to support people with FND.

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