FOI 23/24-1008

Scope	*Research request on "Functional Neurological Disorder" completed from the Technical Advisory Branch*

Response

As at 31 December 2023, there were 208 participants with F44.4 - Functional neurological disorder as a primary disability.

Functional neurological seizure disorder

The content of this document is OFFICIAL.

Please note:
The research and literature reviews collated by our TAB Research Team are not to be shared external to the Branch. These are for internal TAB use only and are intended to assist our advisors with their reasonable and necessary decision-making.
Delegates have access to a wide variety of comprehensive guidance material. If Delegates require further information on access or planning matters, they are to call the TAPS line for advice.
The Research Team are unable to ensure that the information listed below provides an accurate & up-to-date snapshot of these matters

Research question: Provide research on functional seizures, AKA non epileptic seizures: assessment criteria that should be met to confirm the diagnosis; functional implications of PNES e.g. How does it show up for an individual?; treatment recommendations with specific evidence on Cognitive Behavioural Therapy.

Date: 21/9/2022

Requestor: n/a review of previous TAB research

Endorsed by (EL1 or above):

Researcher: Stephanie S22(1)(a)(ii) - irrelevant mater

Cleared by: Stephanie S22(1)(a)(ii) - irrelevant mat

1. Contents

2. Summary

This research is a review of the 'Functional Seizures' research paper completed by TAB Tactical Research Team in 2019.

Functional neurological seizure disorder is listed under somatic symptom disorders in the Diagnostic and Statistical Manual of Mental Disorders, 5th Ed. While it has previously been considered a diagnosis of exclusion, advances in understanding of the disorder have enabled the development of diagnostic criteria to confirm the diagnosis. Importantly, functional neurological seizure disorder can co-occur with other neurological conditions such as epilepsy and multiple sclerosis.

Functional neurological seizure disorder predominantly affects women. Functional symptoms may result in motor deficits, sensory dysfunction and/or cognitive impairment. The prognosis for functional neurological seizure disorder largely depends on the time to diagnosis and adherence to the treatment plan. Cognitive behaviour therapy, psychoeducation, and allied health support may have a role in the treatment of the disorder.

3. Functional Neurological Seizure Disorder

Functional neurological seizure disorder (FND) is one of the most common causes of neurological disability (Medina et al, 2021). Functional neurological seizure disorder can present and feel similar to epileptic seizures, but they are a physical symptom to a psychological disturbance without any physiological connection to epilepsy and therefore sit alongside somatic symptom disorders in the *Diagnostic and Statistical Manual of Mental*

Disorders, 5th Ed. (DSM V) (American Psychiatric Association (APA), 2013; Epilepsy Action Australia, 2020; Marcolini & Tolchin, 2021).

Historically, there have been multiple names for functional neurological seizure disorder in the literature, including (Epilepsy Action Australia, 2020):

- Psychogenic non-epileptic seizure (PNES)
- Pseudo seizures
- Dissociative seizures
- Non epileptic events
- Non epileptic attack disorder (NEAD)
- Functional seizures
- Conversion disorder (psychiatric diagnosis)

The terms 'functional neurological seizure disorder' and 'functional seizure' are becoming more commonly used as they are considered more neutral than some of the earlier terms that had negative connotations for patients (Asadi-Pooya & Bazrafshan, 2020; Marcolini & Tolchin, 2021).

The true prevalence of functional neurological seizure disorder is not clear, however around 15% of presentations to general neurology clinics are attributed to functional neurological seizure disorder (Ahmad & Ahmad, 2016; Forejtova et al, 2022; Maggio et al, 2020). Patients are most commonly female, with initial presentation in their late teens to mid-twenties (Ahmad & Ahmad, 2016; Kerr et al, 2021; Marcolini & Tolchin, 2021), although motor symptoms tend to have their mean onset at ages 30-39 years (APA, 2013). Diagnosis prior to puberty is uncommon, with approximately only 1% of patients who undergo video-electroencephalography (vEEG) being diagnosed with the condition (Kerr et al, 2021).

People who experience functional neurological seizure disorder often have a history of trauma or psychological stressors such as physical or sexual abuse, neglect, and social or family conflict (Ahmad & Ahmad, 2016; APA, 2013; Marcolini & Tolchin, 2021). The condition is associated with comorbid psychiatric and psychological difficulties, poor quality of life, elevated mortality rates, and frequent use of the health system (Marcolini & Tolchin, 2021). Of note, there has been found to be a strong relationship between fibromyalgia and functional neurological seizure disorder, with one study in particular determining that out of 36 patients diagnosed chronic pain or fibromyalgia, 27 were also found to have functional neurological seizure disorder (Benbadis, 2005).

The prognosis for functional neurological seizure disorder can be poor, particularly when treatment begins more than 6-12 months after symptom onset (Gill, 2019; Gupta & Lang, 2009). Functional neurological seizure disorder can result in substantial physical disability (APA, 2013). The severity of long-term disability can be similar to that evident in people with other

significant neurological conditions such as multiple sclerosis, stroke and Parkinson's disease (APA, 2013; FND Australia, 2019).

4. Diagnosis

Functional neurological seizure disorder is often misdiagnosed for several years (Medina et al, 2021), the average delay being 7 to 10 years (Kerr et al, 2021; Marcolini & Tolchin, 2021). Possibly due to the stigma of being a psychological condition, and a fear that doctors believe the symptoms are due to malingering or fictitious disorder, patients often do not adhere to treatment after diagnosis and remain high users of healthcare (Marcolini & Tolchin, 2021; Medina et al, 2021).

Diagnosis of functional neurological seizure disorders should be based on a combination of data, including: patient history and witness observations, clinical observations, and ictal (during a neurological episode) and interictal (between episodes) electroencephalography (Asadi-Pooya & Bazrafshan, 2020).

4.1 DSM-V clinical criteria

Functional neurological seizure disorder is classified as a conversion disorder in the chapter 'Somatic Symptom and Related Disorders' in the Diagnostic and Statistical Manual of Mental Disorders 5th Edition (DSM-5). This set of diagnostic criteria emphasises the importance of making a rule-in positive diagnosis rather than an exclusionary diagnosis that was common in the past (Aybek & Perez, 2022). Table 1 outlines the diagnostic criteria for functional neurological seizure disorder.

Table 1

DSM V diagnostic criteria for functional neurological disorder

DSM V Diagnostic criteria:
A. One or more symptoms of altered voluntary motor or sensory function
B. Clinical findings provide evidence of incompatibility between the symptom and recognised neurological or medical conditions.
C. The symptom or deficit is not 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 and warrants medical evaluation.
The ICD-10-CM code depends on the symptom type:
Specify symptom type:
(F44.4) With weakness or paralysis

(F44.4) With abnormal movement (e.g., tremor, dystonia, myoclonus, gait disorder)
(F44.4) With swallowing symptoms
(F44.4) With speech symptom (e.g., dysphonia, slurred speech)
(F44.5) With attacks or seizures
(F44.6) With anaesthesia or sensory loss
(F44.6) With special sensory symptom (e.g., visual, olfactory, or hearing disturbance)
(F44.7) With mixed symptoms
Specify if:
Acute episode: Symptoms present for less than 6 months.
Persistent: Symptoms occurring for 6 months or more.
Specify if:
With psychological stressor *(specify stressor)*
Without psychological stressor

Diagnosis of functional neurological seizure disorder relies on clinical evidence that shows the symptoms of concern have not developed due to another recognised neurological disorder, such as epilepsy. Importantly, an individual can be diagnosed with both functional neurological seizure disorder and another neurological disease such as epilepsy or multiple sclerosis (APA, 2013).

Associated features that can support the diagnosis of functional neurological seizure disorder, although not specific to the disorder, include (APA, 2013):

- a history of other functional somatic symptoms or disorders, particularly including pain and fatigue
- onset that is associated with stress or trauma, either psychological or physical. Although this temporal relationship may only be true for up to 50% of individuals
- 'la belle indifference' (i.e., the lack of concern about the implications of the symptom) has been associated with functional neurological seizure disorder, but is not specific and should not be used to make the diagnosis

4.2 vEEG

Video electroencephalography (vEEG) is the gold standard method to diagnose functional neurological seizure disorder (Lopez & LaFrance, 2022; Marcolini & Tolchin, 2021). Extended vEEG evaluations enable greater diagnostic certainty to capture seizure events without epileptiform abnormalities immediately before, during or following seizures (Marcolini & Tolchin, 2021). Compared to epileptic seizure waveforms, functional neurological seizure

disorder typically demonstrates normal awake brain electrical activity during impaired or lost consciousness events (Marcolini & Tolchin, 2021). Extended vEEG can be performed in an epilepsy monitoring unit; for individuals whose episodes are infrequent, single channel electromyography can be obtained at home over weeks or months to support the diagnosis (Marcolini & Tolchin, 2021).

4.3 Clinical assessment

An accurate diagnosis is best achieved using a combination of the patient history, information from observers, physical examination, evaluation of ictal semiology with a normal ictal vEEG, and psychiatric evaluation (Lopez & LaFrance, 2022; Marcolini & Tolchin, 2021).

There is no reliable laboratory test that is sensitive or specific to the diagnosis of functional neurological seizure disorder (Marcolini & Tolchin, 2021). Currently, research suggests there may be subtle differences in the structural and functional MRI of an individual with functional neurological seizure disorder compared to a healthy control, however these results are preliminary and cannot be used in clinical diagnosis or exclusion of functional neurological seizure disorder (Marcolini & Tolchin, 2021).

5. Presentation

5.1 Functional Implications

Patients may present with motor and/or sensory or cognitive neurological symptoms (Barnett et al, 2020) that can present acutely and resolve quickly or be long lasting (Nicholson et al, 2020). This results in a wide range of possible functional impairment, including (APA, 2013; Barnett et al, 2020; Gill, 2019; Nhan & Cheah, 2020; Nicholson et al, 2020):

- Limb weakness or paralysis
- Gait disorders
- Balance problems
- Movement disorders such as tremor, jerks and dystonia
- Episodes of apparent unresponsiveness with or without limb movements, possibly resembling epileptic seizures, syncope or coma
- Dysphagia
- Communication difficulties
- Speech disturbance, including reduced or absent speech volume, altered speech articulation, prosody or fluency
- Fatigue
- Chronic pain

- Sensory symptoms such visual disturbances (e.g., double vision), cognitive symptoms (e.g., planning difficulties, mental slowness, black outs, memory difficulties), tactile disturbances (e.g., altered, reduced or absent skin sensation), or hearing disturbances
- Bladder and bowel problems

5.2 Risk and prognostic factors

The following are risk and prognostic factors associated with functional neurological seizures (APA, 2013):

- Maladaptive personality traits, especially emotional instability, are common
- There may be a history of abuse and neglect
- Stressful life events, including physical injury, are common but not universal
- Other neurological diseases that cause similar symptoms, e.g., around 20% of individuals with functional neurological symptom disorder also have epilepsy
- Individuals with functional neurological seizure disorder may show higher rates of suicidal thoughts and attempts than individuals with a recognised neurological disease
- Short duration of symptoms and agreement with the diagnosis are positive prognostic factors, whereas maladaptive personality traits, comorbid physical disease and receipt of disability benefits appear to be negative prognostic factors

5.3 Presentation of functional neurological seizures vs epileptic seizures

People with functional neurological seizure disorder experience transient episodes of altered awareness (Marcolini & Tolchin, 2021). The seizures are believed to be an involuntary coping mechanism, and people who experience these types of seizure are more likely to use maladaptive coping mechanisms to handle stress (Epilepsy Action Australia, 2020).

Differentiating functional neurological seizures from epileptic seizures can be difficult as both show alterations in behaviour, consciousness, sensation and perception (Nhan & Cheah, 2020; Thimm & Belon, 2011). The table below highlights how a person may present during a functional neurological seizure compared to an epileptic seizure (Nhan & Cheah, 2020; Thimm & Belon, 2011):

Table 2

Functional neurological seizures versus epileptic seizures

Behaviour	Functional neurological seizure	Epileptic seizure

Duration over 5 mins	common	rare
Gradual onset	common	rare
Eyes and mouth closed	common	rare
Resisting eye opening	common	very rare
Post ictal weeping/upset	occasional	rare
Post ictal nose rubbing/cough	rare	occasional
Side to side head movements	common	rare
Type of body movements	Pelvic thrusting; out-of-phase or side-to-side oscillatory movements; chaotic and disorganized thrashing; ictal stuttering; post-ictal whispering	Pelvic thrusting; quick, tonic posturing; vocalization
Respiration	often fast	ceases
Grunting sound	occasional	common
Recall for period of unresponsiveness	common	very rare
Aura	common	common
Attacks rising from sleep	occasional	common
Self-injury	occasional	occasional
Tongue laceration	occasional	occasional
Incontinence	common	common

6. Treatment

In addition to treatment options, how the diagnosis is delivered and received influences adherence to the treatment plan and therefore prognosis (Aybek et al, 2022; Marcolini & Tolchin, 2021).

6.1 Cognitive behaviour therapy

A number of randomised controlled trials support the efficacy of cognitive behaviour therapy to reduce seizure activity, improve psychosocial functioning, fewer somatic symptoms and improve quality of life (Aybek et al, 2022; Marcolini & Tolchin, 2021), however long-term follow-up generally indicated the effect did not remain significant (Aybek et al, 2022). A systematic review of 11 studies investigating the efficacy of cognitive behaviour therapy for functional neurological seizure disorder suggested moderate to large significant effects on measures of physical symptoms, and small to moderate effect sizes for mental health, function and quality of life (Gutkin et al, 2021). It was noted in this systematic review that the success of cognitive behaviour therapy depends on the patient accepting their symptoms may relate to psychological factors. Although Goldstein et al (2021) reported improvement in quality of life and psychosocial functioning at 12 months, this was not 12 months post-cessation of therapy but rather after the 12th month of therapy. Therefore, as reported by Aybek et al (2022), the effect of the therapy may decrease over time which might suggest that individuals need to have ongoing cognitive behaviour therapy for ongoing remission or decrease in symptoms.

6.2 Psychoeducation

While psychoeducation may not reduce seizure frequency, there is some evidence that it improves psychosocial functioning as they develop greater understanding of their diagnosis, acceptance and belief in the treatment plan (Aybek et al, 2022). An important consideration is this effect may not be evident for online education and self-help interventions (Aybek et al, 2022). Implementing psychoeducation to improve understanding of the diagnosis may encourage adherence to the treatment plan and increase the likelihood of better outcomes (Medina et al, 2021).

6.3 Allied health therapy

Physiotherapy is the first treatment option for patients with motor symptoms, with an emphasis on motor retraining (Aybek et al, 2022). Data from randomised controlled trials and observational studies have demonstrated efficacy of physiotherapy for functional neurological seizure disorder with improvements in gait, social functioning and quality of life reported (Aybek et al, 2022; Maggio et al, 2020). Maggio et al (2020) reports an average of 34% improvement in motor function was observed after adherence to weekly physiotherapy for an average of 7 weeks.

Support from a speech therapist may be necessary for individuals who demonstrate speech, language and swallowing impairments, however the efficacy and long-term outcomes after speech and language therapy for individuals with significant impairment does not appear well studied (Barnett et al, 2019).

A professional education paper by Nicholson et al (2020) has offered recommendations for the role of occupational therapy for patients with functional neurological disorder. Occupational therapy can provide practical support to overcome the effects of disability on activities of daily living. This may include education, vocational rehabilitation, assistive technology assessment,

and strategies to overcome functional motor, visual and cognitive impairment (Nicholson et al, 2020).

6.4 Neuromodulation

Research into the efficacy of neuromodulation for functional neurological seizure disorder is limited but emerging, therefore included in this research paper. As part of a systematic review, Oriuwa et al (2022) analysed data from one paper investigation the effects of TMS on functional seizures. All participants (N = 7) received high frequency repetitive stimulation of the right temporoparietal junction for 30 sessions over 30 weeks, and all experienced a significant decrease in weekly seizure frequency. At 3 months follow up, 4 participants had sustained remission in seizure activity.

6.5 Medication

Antiseizure medications have no role in the treatment of functional neurological seizure disorder, and may actually increase morbidity due to side effects (Lopez & LaFrance, 2022). While individuals with functional neurological seizure disorder may be prescribed medication for other psychological disorders, such as antidepressants, there is currently no medication to prescribe specifically for the symptoms of functional neurological seizure disorder.

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Research Request – Central Sensitivity Syndromes and Functional Neurological Disorder

Brief	Information to assist Assessors from NAWM with their decisions for access requests relating to these specific conditions.
Date	Due 24 December 2019
Requester	Katrin S22(1)(a)(ii) - Irre – Assistant Director TAT
Researcher	Aanika S22(1)(a)(ii) - Irre
Cleared by	

Contents

Please note:

The research and literature reviews collated by our TAT Research Team are not to be shared external to the Branch. These are for internal TAT use only and are intended to assist our advisors with their reasonable and necessary decision making.

Delegates have access to a wide variety of comprehensive guidance material. If Delegates require further information on access or planning matters they are to call the TAPS line for advice.

There are already a significant number of resources, including commissioned expert reports and external specialist publications and clinical guidelines, which are available to NDIA staff to use in delegate decision making.

This paper aims to bring these resources together as a starting point and provide any additional information as required.

Scope of this document

The National Access and Workload Management Branch (NAWM) have requested assistance from TAT with assessing access for prospective participants with Chronic Regional Pain Syndrome, Functional Neurological Disorder aka Conversion Disorder, Chronic Fatigue Syndrome & Fibromyalgia.

- *Note: While the Disability Related Health Supports (DRHS) policy has not changed any of the established NDIS access criteria or legislation, the fact that 1) Participants can now receive DRHS through the NDIS and 2) A planner must now plan for the 'whole of person', means that the 'most appropriate funder/provider' proviso (under s34.1.f) no longer eliminates the typical types of supports that the NDIS could potentially fund for this cohort.*
- *This is causing an increase in access requests being made for these health conditions, based on their diagnosis and lived/reported significant functional impairment(s)*

The symptoms and experiences of people with these health conditions are individual and often complex, consequently it is often challenging for medical experts to determine a diagnoses.

Even once a diagnosis has been made, it remains difficult for NDIS access assessors to apply the Access - disability requirements criteria, particularly to determine permanency and the need for NDIS supports for life, compared to mainstream health treatment and supports.

Also, as the pathophysiology *[the disordered physiological processes associated with disease or injury]* of these conditions are still poorly understood, it is challenging for access assessors to determine whether these cohorts have exhausted all evidence-based, clinical, medical or other treatments.

- None of these conditions are included on the List A, B, C or D for common conditions that meet NDIS Access – disability requirements.
- While the outcomes of AAT hearings are not intended to set a precedent, the NDIA legal team's application of the access legislation against these health conditions in AAT cases is the only direction the NAWM have to guide their decision making.

Previous AAT Cases

The majority of these AAT cases were relating to access and were deemed 'access not met'. Generally, it was only in severe cases that access was met, where permanency and functional impairment were established through expert reports.

See APPENDIX A for full summary of AAT cases relating to these conditions to date.

Previous TAT advices

There are several previous TAT access advices relating to these health conditions. Most of these advices are from 2017 & 2018.

These TAT advices highlight that CRPS, CFS, FND, fibromyalgia, along with, Postural tachycardia syndrome (PoTS), depression, anxiety and other psychosocial disability, Lyme's disease & lupus often present as complex comorbidities.

See APPENDIX B for full summary of TAT advices relating to these conditions.

Central sensitivity syndromes / Central regional pain syndromes – Common co-morbidities

Physicians often experience difficulty diagnosing patients who present with reported chronic pain and multiple other non-specific symptoms. This is because reported and observed symptoms may result in multiple diagnoses.

The nomenclature of 'central regional pain syndrome' or 'central sensitivity syndrome', or their variations, are increasingly used to collectively refer to all chronic pain disorders with a common pathophysiology.

An advocacy website called **Central Sensitivity Syndrome Survivor's Guide** comprehensively summarises this

> "Central Sensitivity Syndrome or Central Sensitization Syndrome (CSS) is a comorbid syndrome marked by "central sensitization" in which holds overlapping features that can cause significant disability. Such over lapping conditions are Fibromyalgia, Myofascial Pain, and Chronic Fatigue Syndrome. The biophysiologic mechanisms of these conditions are multifactorial; neuroendocrine abnormalities with central sensitization, however, seem most important. Though psychological distress is present in these patients, keep in mind this is not a psychiatric illness. Management is mostly supportive and includes patient education, psychological support, behavioral modification, physical exercise, and various serotonergic and noradrenergic medications. Like Chronic Fatigue Syndrome and Fibromyalgia, there is a higher preponderance of females with this condition than men. Accumulated recent data support the hypothesis that all these disorders share a common biophysiologic mechanism of neurohormonal dysregulation caused by perhaps neuroendocrine or adrenaline. It seems the most important neurologic aberrations comprise central sensitization, which involve molecular, chemical, and functional changes in the central nervous system, resulting in an amplification and spread of pain, and intensification of other sensations".
>
> "The concept that several of these related conditions should be grouped under the unified heading of "Central Sensitivity Syndrome" was first presented by Dr. Muhammad Yunus, rheumatologist, professor of Medicine at the University of Illinois College of Medicine at Peoria, and pioneer in fibromyalgia research. Dr. Yunus discovered that many of these conditions (e.g., fibromyalgia, myofascial pain syndrome, irritable bowel syndrome, chronic fatigue syndrome, headaches and restless legs syndrome) shared several characteristics, including pain, poor sleep, fatigue, extreme sensitivity to stimuli, and an absence of abnormal tissue structure. The connecting thread for these conditions appears to be central sensitization, which simply means that the central nervous system has an exaggerated response to stimuli"[1].

Dr Muhammad B. Yunas's critical literature review from 2007 titled '*Fibromyalgia and Overlapping Disorders: The Unifying Concept of Central Sensitivity Syndromes*' can be found here.

In 2007 Yunas concluded that the concept of CSS seems viable and it "based on mutual associations among the CSS conditions as well as the evidence for central sensitizations among several CSS members… [and that] CSS is an important new concept that embraces the biopsychosocial model of disease. Further critical studies are warranted to fully test this concept. However, it seems to have important significance for new directions for research and patient are involving physician and patient education. Each patent, irrespective of diagnosis, should be treated as an individual

[1] CSS Survivor's Guide, "Central Sensitivity Syndrome (CSS) - Central Sensitization", [website], 2019, http://css.dewarlorx.com, (accessed 18 December 2019)

considering both the biological and psychosocial contributions to his or her symptoms and suffering[2].

The proposed members of the CSS family include: Fibromyalgia, Chronic Fatigue Syndrome, Irritable Bowel Syndrome (IBS), Tension type headache (T-T Headache), Migraine, Temperomanibular disorders (TMD), Myofascial pain syndrome (MPS), regional soft-tissue pain syndrome (RSTPS), periodic limb movements in sleep (PLMS) multiple chemical sensitivity (MCS), Female urethrl syndrome (FUS), Interstitial cystitis (IC), Post traumatic stress disorder (PTSD)[3].

This publication has comprehensive information on the mutual associations amongst these CSS conditions.

A research publication from 2011 highlights how fibromyalgia is commonly linked with other regional pain syndromes such as tempromandibular disorder (TMD), irritable bowel syndrome (IBS), interstitial cystitis (IC), headache, chronic low back pain, and chronic neck pain.

This publication states that:

> "A persuasive body of evidence now demonstrates that sensitization represents a unifying pathophysiological mechanism among these painful disorders. It has been proposed that these syndromes have more in common than previously thought, specifically that they are characterized by a dysregulation of peripheral afferents and central nervous system pathways. Given the shared pathophysiological mechanisms, these disorders have been coined "central sensitivity syndromes" (CSS)"[4].

Another publication from 2015 discussed how central sensitization are a collective group of disorders stating that: "There is considerable overlap among syndromes such as fibromyalgia, chronic fatigue, irritable bowel syndrome, chronic pelvic pain, and chronic daily headache"[5].

Diagnoses, Self-diagnoses, and Symptoms that May Suggest Central Sensitization Syndrome (Especially If Copious)[6]	
Abdominal bloating	Immune deficiency (self-diagnosed)
Abdominal pain, chronic abdominal pain	Interstitial cystitis, painful bladder syndrome
Adrenal insufficiency (self-diagnosed), adrenal fatigue	Irritable bowel syndrome
Alopecia, hair loss, trichotillomania	Joint pains
Anxiety	Low testosterone or hypogonadism (with normal test results)
Atypical facial pain	Lupus (self-diagnosed)
Atypical or non-cardiac chest pain	

[2] Yunus, MB, 'Fibromyalgia and Overlapping Disorders: The Unifying Concept of Central Sensitivity Syndromes', The University of Illinois College, 2007, https://www.ourcpc.com/wp-content/uploads/2016/03/Yunus-central-sensitivity-2007.pdf, accessed 9 December 2019, p.339.

[3] Ibid, p. 341.

[4] L. Kindler et al., "Central Sensitivity Syndromes: Mounting Pathophysiologic Evidence to Link Fibromyalgia with other Common Chronic Pain Disorders", Pain Manag Nurs., Vol 12, No 1, pp. 15-24, 2012, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3052797/

[5] ibid

[6] ibid

Autoimmune disorder (self-diagnosed)	Lyme disease, chronic Lyme disease (self-diagnosed)
Autonomic disorder (self-diagnosed)	Meniere disease
Black mold, toxic black mold (self-diagnosed)	Morgellons disease (self-diagnosed)
Brain fog, fibrofog	Multiple chemical sensitivities
Burning mouth syndrome	Multiple drug allergies or intolerances (self-diagnosed)
Burning tongue	Multiple food allergies or intolerances (self-diagnosed)
Candida or chronic yeast infection	Myofascial pain syndrome
Chiari malformation	Palpitations
Chronic low-back pain	Panic disorder, episodes, attacks
Chronic non-specific light-headedness	Pelvic pain, chronic pelvic pain, premenstrual syndrome
Chronic pain	Polycystic ovary syndrome
Chronic pelvic pain	Porphyria (self-diagnosed)
Chronic prostatitis	Post-deployment syndrome
Chronic tension or migraine headaches	Post-traumatic stress disorder
Chronic testicular or scrotal pain	Postural orthostatic tachycardia syndrome (POTS)
Chronic whiplash-associated disorders	Pseudotumor cerebri
Chronic widespread pain	Schamberg disease, soft tissue tumors
Complex regional pain syndrome	Sick building syndrome
Delusions of parasitosis	Sjögren syndrome (blamed for multiple symptoms)
Depression or bipolar disorder	Temporomandibular disorders, temporomandibular joint pain
Dizziness	Thyroid disease (with normal test results, usually self-diagnosed)
Edema or swelling complaints not evident on examination	Tinnitus
Ehlers–Danlos syndrome	Vulvodynia, vulvar vestibulitis
Fatigue or chronic fatigue	
Fibromyalgia, myalgic encephalitis	
Hormone imbalance	
Hyperventilation	
Hypoglycemia (self-diagnosed)	

While Functional Neurological Disorder (FND) is not considered under the Central Sensitivity Syndrome (CSS) umbrella of conditions, chronic pain is a common symptom of patients with FND and overlaps with these CSS conditions due to the neurological dysfunction factor.

The U.S. National Organization for Rare Disorders states that:

> "Anxiety and depression can sometimes cause physical symptoms which overlap with FND symptoms. For example, panic attacks can present with symptoms such as pins and needles

in the fingers or mouth and depression often causes poor concentration or fatigue. Anxiety and depression are common in patients with FND but many patients do not have such problems.

Chronic pain is also common in patients with FND including fibromyalgia, which is also related to disturbed nervous system functioning. Pain disorders are also usually associated with fatigue, sleep disturbance, and poor concentration. Migraine and chronic headaches are also common.

Other functional disorders including irritable bowel syndrome, or overactive bladder syndrome are more common in patients with FND"[7].

Similarly to FND, Chronic Fatigue Syndrome (CFS) does not fit neatly under the Central Sensitivity Syndrome umbrella, but is closely associated with many of the conditions and symptoms common in CSS patients and one aspect of the pathophysiology of CFS is an altered central nervous system conditioning[8].

In 2002, the Royal Australasian College of Physicians (RACGP) published CFS Clinical Guidelines which state that:

- "Fatigue is a central feature of many clinical syndromes, including CFS, fibromyalgia, irritable bowel syndrome, major depression, anxiety and somatoform disorders. These syndromes also share other, non-specific symptoms, including musculoskeletal pain, sleep disturbance, neurocognitive impairment and mood changes. Fibromyalgia, in particular, is a closely related syndrome, differing mainly in its relative emphasis on musculoskeletal pain rather than fatigue"[9].

[7] NORD, "Functional Neurological Disorder", [website], 2019, https://rarediseases.org/rare-diseases/fnd, (accessed 18 December 2019)

[8] The Royal Australian College of Physicians, "Chronic fatigue syndrome: Clinical practice guidelines — 2002", MJA, Vol 176, p. 32, 2002, https://www.mja.com.au/system/files/issues/cfs2_2.pdf

[9] ibid, p.28.

Chronic Regional Pain Syndrome (CRPS)

Expert report

In June 2018 the Technical Advisory Team commissioned a report on CRPS from three experts in the field – Dr Anne Daly (Physio), Dr Philippa Frances (psych) & Dr Will Howard (pain management specialist). The report was intended to assist with specific TAT AAT CRPS access cases, but offers a holistic snapshot of the condition.

This report has all the information a NAWM team member would require to assess access and provides answers to the following questions:

1. *What is the aetiology of this condition?*
    a. *Terminology:*
    b. *Diagnosis*
    c. *Clinical Presentation*
2. *What is the impairment, if any?*
3. *What medical and allied health specialties are involved in:*
    a. *Diagnosis:*
    b. *Treatment of this condition:*
4. *What treatment options are clinically indicated for this condition? What are the indications and likelihood of success for each treatment? Please comment on details and dosage of any recommended treatments including frequency and duration as appropriate.*
    a. *Physical therapies*
    b. *psychological therapies*
    c. *Medications*
    d. *Interventional therapies*
    e. *Implanted therapies*
5. *Is this condition results from an impairment, what is the likelihood that this impairment will be permanent?*
6. *Are individuals suffering this condition likely to require lifelong support? If so, what types of supports are likely to be required?*
7. *Would symptom management through interventions such as medication change, pain management, exercise programs etc. reduce the functional impact of the diagnosis and associated disability?*
8. *How prevalent is the incidence of CRPS being diagnoses as a stand-alone condition as opposed to being diagnosed as part of comorbidity?*

This full report is embedded in APPENDIX C for reference.

Information additional to the expert report are listed below.

Summary of CRPS

Greta Palmer - Pain specialist and anaesthetist at the Royal Children's Hospital and Royal Melbourne Hospital provides the following information on CFS via the NPS MedicineWise website:

- CRPS is an uncommon chronic pain condition.
- The syndrome occurs spontaneously or is triggered by injury, such as a strain or sprain, a distal fracture or surgery. The upper limb is affected more in adults and the lower limb in children. Usually, the pain is out of proportion to any preceding injury.
- In CRPS type I there is no evidence of nerve damage. This was formerly called reflex sympathetic dystrophy or Sudeck's atrophy.
- In complex regional pain syndrome type II there is a history of nerve injury. This was formerly called causalgia.
- CRPS is a painful debilitating condition in a limb. It is associated with abnormalities in skin, bone, and the autonomic, sensory and motor nerves.
- The features are limb pain, allodynia, hypersensitivity, hyperalgesia, abnormalities of the vasomotor, sudomotor and motor systems, and trophic changes, with reduced use of the affected limb. The diagnosis is clinical and one of exclusion.
- The emphasis of therapy is graded rehabilitation and movement of the limb with physiotherapy and occupational therapy. Psychological therapies should be offered if a patient is making no or slow progress in the acute phase, and to all patients in the chronic phase as depression can occur.
- The goal of pharmacotherapy is to assist functional improvement. The early phase may be managed with simple analgesia. Antineuropathic drugs including tricyclic antidepressants and antiepileptic drugs may be added. Other treatments with some evidence of effectiveness include corticosteroids, calcitonin and bisphosphonates[10].

See full complex regional pain syndrome fact sheet written by Greta Palmer - Pain specialist and anaesthetist Royal Children's Hospital and Royal Melbourne Hospital.

Better Health Channel – Victoria have also published a Complex regional pain syndrome (CRPS) fact sheet which was written by professionals at the Austin health – Pain Management service.

Section 24 Disability Requirement Considerations

What are the common evidence based clinical, medical and other treatments for CRPS?

- ***See 5.4 of the NDIS (Becoming a Participant) Rules 2013.***

A management update on neuropathic pain, which was published in the Australian Family Physician in 2013 states the following regarding current evidence based recommended treatments for neuropathic pain:

[10] Palmer, G, 'Complex regional pain syndrome', June 2015, NPS MedicineWise, https://www.nps.org.au/australian-prescriber/articles/complex-regional-pain-syndrome, accessed 26 November 2019.

"With only a few evidence-based clinical trials for treating CRPS, treatments are extrapolated from studies of other neuropathic conditions. An older, randomised double-blinded, placebo-controlled trial showed limited improvement with gabapentin. Less rigorous trials and case studies have shown some benefit using non-steroidal anti-inflammatory drugs (NSAIDs), opioids, baclofen, calcitonin, corticosteroids, bisphosphonates, dimethyl sulfoxide, IV immunoglobulin therapy and TCAs, while intravenous lignocaine temporarily reduces spontaneous evoked pain. Some benefit has been reported using anti-TNF antibodies (infliximab). Treatment options for complex CRPS are outlined in *Table 4 (below)*".

"There is little evidence for invasive procedures, particularly in the early treatment of CRPS. Sympathectomy does not provide lasting analgesia and may worsen the pain. Spinal cord stimulation produces short-term improvement in refractory cases and could be considered in combination with behavioural and physical therapies. Current treatment of CRPS is directed toward restoration of function using pharmacological, psychological and physical therapies. In practice, first line pharmaceutical agents to consider are opioids, antidepressants, gabapentinoids, carbamazepine and corticosteroids"[11].

Table 4. Treatment options for complex regional pain syndrome[17]

Some evidence	No evidence (worth considering)
Bisphosphonates	NSAIDs
Gabapentin	Opioids
Corticosteroids	TCAs
Topical 50% dimethyl sulfoxide	SNRIs
Anti-TNF antibodies (infliximab)[15]	Sodium channel blockers
IV immunoglobulin therapy	

When is CRPS permanent or likely to be permanent for the disability requirements? Does this condition ever improve?

- ***See S24.1(b) of the NDIS Act 2013 & 5.3 of the NDIS (Becoming a Participant) Rules 2013.***

Regarding permanency, the MayoClinic provide the following information highlighting that improvement or permanency is entirely dependent on the individual patient's circumstances:

- "Symptoms may change over time and vary from person to person. Pain, swelling, redness, noticeable changes in temperature and hypersensitivity (particularly to cold and touch) usually occur first.
- Over time, the affected limb can become cold and pale. It may undergo skin and nail changes as well as muscle spasms and tightening. Once these changes occur, the condition is often irreversible.

[11] Votrubec, M & Thong, I, 'Neuropathic pain: A management update', Australian Family Physician Vol. 42, no. 1/2, January/February 2013, https://www.racgp.org.au/download/Documents/AFP/2013/March/201303votrubec.pdf, accessed 29 November 2019.

- Complex regional pain syndrome occasionally may spread from its source to elsewhere in your body, such as the opposite limb.
- In some people, signs and symptoms of complex regional pain syndrome go away on their own. In others, signs and symptoms may persist for months to years. Treatment is likely to be most effective when started early in the course of the illness"12.

The CRPS Network Australia provide advice to people with CRPS and

- "It is important to keep a positive attitude. Remission is possible and attainable.
- It may take 12 – 18 months to stabilise your CRPS and for many people, who are diagnosed within 3-6 months of the inciting event, their symptoms are completely resolved within this time frame"[13].

The expert report by Daly, Frances & Howard (Appendix C) highlights that "there is enormous variation in the prognosis of CRPS. Many people recover in the first six to twelve months. After this time there is a diminishing chance of recovery. Once there are significant signs of joint fibrosis (stiffening of joints) or muscle dystonia it is the authors' experience that it appears to be unlikely that there will be significant improvement. Again it is the authors' experience that in these severe cases, the clinical pathway is then further deterioration over another one to two years with stabilisation occurring by the end of year two or three. At this time it would appear that any impairments will be permanent".

What type of medical treatment and review is required to determine permanency?

- **See 5.6 of the NDIS (Becoming a Participant) Rules 2013.**

Diagnosis of complex regional pain syndrome is based on the Budapest Diagnostic criteria.

CRPS Network Australia provide an example of a Budapest Criteria here.

An issue with the Budapest CRPS test is that it is based on excluding other diagnoses, that is, the final diagnostic criteria is to confirm that 'there is no other diagnosis that better fits'.

The 2013 management update on neuropathic pain states the following regarding diagnosis and clinical presentation for CRPS:

> *"Complex regional pain syndrome (CRPS) is rarely seen in general practice. Diagnosis is based on a cluster of clinical criteria affecting the somatosensory and autonomic nervous systems. However, CRPS remains a classification enigma: both neuropathic and other non-neuropathic pathophysiological processes have been suggested. Early recognition in primary care, implementation of treatment and referral to a pain service will help minimise function loss, chronicity and disability.*
>
> *A patient with CRPS typically presents with severe pain on movement, with skin colour and temperature changes, and sweating and swelling that occurs in a regional distribution. Reduced movement, weakness and tremor may also occur. Clinical signs include vasomotor and sudomotor (relating to sweat glands) changes, motor signs, pain, allodynia, hyperalgesia*

[12] Mayo Clinic, "Complex regional pain syndrome", [website], 2019, https://www.mayoclinic.org/diseases-conditions/complex-regional-pain-syndrome/symptoms-causes/syc-20371151, (accessed 18 December 2019)

[13] Network CRPS Australia, "Complex regional pain syndrome", [website], 2019, https://crpsnetworkaustralia.org.au/information-for-new-patients, (accessed 18 December 2019)

and reduced range of movement and strength. Later clinical signs include trophic changes (nails, skin, hair) and osteoporosis. In CRPS-I, recognised precipitating events include fractures, sprains or post-surgery. CRPS-II may develop after major peripheral nerve injury"[14].

"There is no specific test for CRPS. Plain X-rays (cortical thinning and bone loss), bone scans (abnormal third phase increased peri-articular uptake), temperature differences, quantitative sensory testing and MRIs are used both clinically and in research. However, only 'objective measurement of temperature differences' has a high sensitivity and specificity.

Criteria for clinical diagnosis is continuing pain disproportionate to an inciting event, coupled with three of four symptoms plus at least one sign from the following: sensory, vasomotor, sudomotor, motor/trophic, and with no other diagnosis that better explains the patient's symptoms and signs. Differential diagnoses to consider are unilateral vascular disease, post-traumatic neuralgia, metabolic, autoimmune or neoplastic disorders, neuropathies or psychiatric somatoform disorders[15].

What are the typical functional impairments associated with CRPS?

The expert report from Daly, Frances and Howard lists that CRPS may result in loss of or damage to the following functions:

- Mental functions e.g. energy and drive functions, sleep, attention, memory, emotional functions, perceptual functions, higher level cognitive functions
- Sensory functions e.g. pain, light touch, temperature
- Neuromuscular and movement related functions e.g. mobility of joint, muscle power an tone, involuntary movements, balance and coordination
- Functions of skin and related structures e.g. skin temperature, sweating, nail and hair growth.

Is someone with CRPS likely to require supports from the NDIS for their lifetime?

As outlined in the expert report by Daly, Frances and Howard, after approximately three years whatever resulting functional impairment the person has is likely to be permanent. Whether their functional impairment is severe enough the meet the NDIS access requirements is entirely dependent on their individual circumstances.

[14] Votrubec, loc cit.

[15] Ibid.

Section 25 Early Intervention Considerations

How do early intervention access considerations apply to people with CRPS?

Early intervention considerations do not apply to CRPS. Any services that a person with CRPS would receive before the condition is considered permanent would be considered time-limited health treatments.

Chronic Fatigue Syndrome (CFS)

Expert report

In January 2018 the Technical Advisory Team commissioned a report on Chronic Fatigue Syndrome from an Australian expert in the field – Dr Andrew Lloyd, MD FRACP. The report was intended to assist with specific TAT AAT Chronic Fatigue access cases, but offers a holistic snapshot of the condition.

This report has all the information a NAWM team member would require to assess access and provides answers to the following questions:

Preamble

1. *What is the aetiology of this condition?*
2. *What is the impairment, if any?*
3. *What medical and allied health specialties are involved in: a) Diagnosis and b) Treatment of this condition?*
4. *What treatment options are clinically indicated for this condition? What are the indications and likelihood of success for each treatment? Please comment on details and dosage of any recommended treatments including frequency and duration as appropriate.*
5. *Is this condition results from an impairment, what is the likelihood that this impairment will be permanent?*
6. *Are individuals suffering this condition likely to require lifelong support? If so, what types of supports are likely to be required?*
7. *Would symptom management through interventions such as medication change, pain management, exercise programs etc. reduce the functional impact of the diagnosis and associated disability?*
8. *How prevalent is the incidence of Chronic Fatigue Syndrome being diagnosed as a stand-alone condition as opposed to being diagnosed as part of comorbidity?*
9. *Other comments:*

This full report is embedded in APPENDIX D for reference.

Information additional to the expert report are listed below.

Summary of CFS

CFS is often referred to as myalgic encephalomyelitis and sometimes it is abbreviated as ME/CFS.

In addition to fatigue for more than 6 months that is not relieved by sleep and interferes with activities of daily life, patients suffer other symptoms such as cognitive impairment, muscle and joint pains and sore throat.

Diagnostic criteria for chronic fatigue syndrome:

- Unexplained, persistent fatigue that is not due to ongoing exertion; is not substantially relieved by rest; is of new onset (not lifelong); and results in a significant reduction in previous levels of activity.
- Four or more of the following symptoms are present for 6 months or more:

- impaired memory or concentration
- postexertional malaise (extreme, prolonged exhaustion and sickness following physical or mental activity)
- unrefreshing sleep
- muscle pain
- multijoint pain without swelling or redness
- headaches of a new type or severity
- sore throat that is frequent or recurring
- tender cervical or axillary lymph nodes[16]

RACGP Clinical Guidelines - CFS

In 2002, a Chronic Fatigue Syndrome Working Group, which convened under the auspices of the Royal Australasian College of Physicians (RACGP) published a comprehensive article Clinical Practice Guidelines on CFS. The publication was sponsored by the Commonwealth Department of Health and Ageing and was published in the Medical Journal of Australia. The article is comprehensive (40 pages) and addresses the following topics:

- What is chronic fatigue syndrome?
- Evaluating people with fatigue
- Managing patients with CFS
- CFS in children and adolescents
- Social and legal issues

The NDIA acknowledges that there is conflicting evidence regarding the permanency and best management of ME/CFS.

Currently, the NDIA continue to use these RACGP Chronic Fatigue Syndrome Clinical Practice guidelines on diagnosis and management, as these are the accepted national guidelines.

It is understood that these guidelines are in the process of being updated but until this occurs, the current guidelines continue to be the accepted document of reference for the NDIA. It should be noted that NDIA does not have input into the guidelines as they are related to health practice.

It is recommended that all TAT advisors refer to this document in full.

The RACGP clinical guidelines state that:

- *"Fatigue can be defined as a pervasive sense of tiredness or lack of energy that is not related exclusively to exertion. It is a common complaint in the community and is usually transitory. If fatigue is prolonged beyond six months, is disabling, and is accompanied by other characteristic constitutional and neuropsychiatric symptoms, then a diagnosis of chronic fatigue syndrome (CFS) should be considered".*
- *"CFS" is a descriptive term used to define a recognisable pattern of symptoms that cannot be attributed to any alternative condition. The symptoms are currently believed to be the result of disturbed brain function, but the underlying pathophysiology is not known. Therefore, CFS*

[16] Kreijkamp-Kaspers, S, et al., 'Treating Chronic Fatigue Syndrome: A study into the scientific evidence for pharmacological treatments, Australian Family Physician, vol.40, no.11, November 2011, https://www.racgp.org.au/download/documents/AFP/2011/November/201111kkaspers.pdf, accessed 10 December 2019.

cannot be defined as a specific "disease" entity at present. Indeed, there is growing evidence that the disorder is heterogeneous, and it will probably prove to have no single or simple aetiology. It is important for practitioners to appreciate the distinction between disease, illness and disability. Diseases are defined and categorised according to our contemporary understanding of causal mechanisms and pathophysiology. As new knowledge emerges, disease definitions and terminology change. Illness, by contrast, is the subjective experience of suffering and, as such, can only be defined by reference to the sick person. Disability is the functional impairment — physical, psychological and social — caused by disease and illness. Even though an underlying disease process cannot presently be defined in patients with CFS, the suffering and disability caused by the illness can be very considerable — in many cases comparable to that seen in multiple sclerosis and rheumatoid arthritis. It is therefore important that doctors acknowledge the reality and seriousness of the suffering and disability experienced by people with CFS. Our goal as physicians is not only to identify and treat disease, but also to help relieve suffering and disability, whatever the cause"[17].

Section 24 Disability Requirement Considerations

What are the common evidence based clinical, medical and other treatments for CFS?

- ***See 5.4 of the NDIS (Becoming a Participant) Rules 2013.***

The RACGP clinical guidelines state that:

- "No single pharmacological treatment has been shown to be effective for people with CFS.
- Cognitive–behaviour therapy may be effective for some people with CFS.
- Physical and intellectual activities should be "paced" according to the individual's functional capacity.
- Graded exercise may be effective for some people with CFS.
- Antidepressant drugs may provide symptomatic relief of pain, sleep disturbance, and depressed mood in people with CFS"[18].

See page 38-42 of clinical guidelines for more information.

The clinical guidelines emphasise a multidisciplinary approach.

- "People who are persistently housebound with severe disability arising from CFS may require the assessment and advice of a team, including specialists in rehabilitation medicine, pain management, physiotherapy, occupational therapy, and social work"[19].

A wide variety of pharmacological treatments are used for chronic fatigue syndrome, however the evidence for effectiveness is very limited. A 2011 study published In the Australian Family Physician

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[17] Chronic Fatigue Syndrome Clinical practice Guidelines, Royal Australasian College of Physicians, Medical Journal Australia, vol.176, May 2002, p.23, https://www.mja.com.au/system/files/issues/cfs2_2.pdf, accessed 6 December 2019.

[18] Ibid. p.38.

[19] Ibid, p.37.

recruited ninety-four CFS patients and investigated the immunological biomarkers they filled out in a questionnaire assessing the medicines they were taking. Additionally, evidence from randomised clinical trials was sought in biomedical databases. The results found that "the 94 CFS patients used 474 different medicines and supplements. The most commonly used medicines were antidepressants, analgesics, sedatives, and B vitamins". The study identified 20 randomised controlled trials studying these medicines in CFS patients as of 2011[20].

A systematic overview was conducted in 2015 with the purpose of answering 'What are the effects of selected treatments for chronic fatigue syndrome?' The researchers searched Medline, Embase, The Cochrane Library, and other important databases up to November 2013[21].

This overview examined information relating to the effectiveness and safety of four specific interventions: antidepressants, cognitive behavioural therapy, corticosteroids, and graded exercise therapy. The overview found that graded exercise therapy has been shown to effectively improve measures of fatigue and physical functioning and cognitive behavioural therapy is effective in treating CFS in adults. It also concluded that it is still unknown how effective antidepressants and corticosteroids are in treating CFS, but Tricyclics in particular have potential therapeutic value because of analgesic properties[22].

For children the recommended treatments/interventions are cognitive behavioural therapy and graded exercise therapy[23].

When is CFS permanent or likely to be permanent for the disability requirements? Does this condition ever improve?

- ***See S24.1(b) of the NDIS Act 2013 & 5.3 of the NDIS (Becoming a Participant) Rules 2013.***

Diagnosis is established through the exclusion of other diseases causing fatigue. . . Currently, no curative treatment exists for patients with chronic fatigue syndrome. The therapeutic approach to this syndrome requires a combination of different therapeutic modalities[24].

Regarding prognosis, the same publication states that:

- "There is an average time of 5 years from the beginning of the symptoms to the diagnosis of the syndrome, with total recovery rates between 0% and 37%, and improvement between 6% and 63%. Younger patients and those without concomitant psychiatric diseases show the best prognosis, although other studies have estimated that the rates for both groups are similar"[25].

Regarding prognosis and permanency, the overview from 2015 (mentioned above) provides the following statistics:

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[20] Kreijkamp-Kaspers, loc cit.

[21] Cleare, AJ, et al., Chronic fatigue syndrome', BMJ Clinical Evidence, September 2015, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4585442/, accessed 10 December 2019.

[22] Ibid.

[23] Brigden, A et al., 'Practical management of chronic fatigue syndrome or myalgic encephalomyelitis in childhood', May 2018, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5947766/, accessed 12 December 2019.

[24] Fernandez, AA, et al., 'Chronic fatigue syndrome: aetiology, diagnosis and treatment', BMC Psychiatry, vol. 9, October 2009, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2766938/, accessed 6 November 2019.

[25] Ibid.

> "Studies have focused on people attending specialist clinics. A systematic review of studies of prognosis (search date 1996) found that children with CFS had better outcomes than adults: 54% to 94% of children showed definite improvement in symptoms (after up to 6 years' follow-up), whereas 20% to 50% of adults showed some improvement in the medium term (12–39 months) and only 6% returned to premorbid levels of functioning. Nevertheless, one prospective follow-up study suggests that, even after long illness periods, around 50% of patients can return to part- or full-time work. Despite the considerable burden of morbidity associated with CFS, we found no evidence of increased mortality. The systematic review found that a longer duration of illness, fatigue severity, comorbid depression and anxiety, and a physical attribution for CFS are factors associated with a poorer prognosis. Another review found a median full recovery rate of 5% (range 0–31%), and the median proportion of patients who improved during follow-up to be 39.5% (range 8–63%). Good outcome was associated with less fatigue severity at baseline, a sense of control over symptoms, and not attributing the illness to a physical cause"[26].

The available research on ME/CFS indicates that, due to the natural progression of the condition, some individuals may recover without intervention over weeks to months. It cannot be considered that every person diagnosed with ME/CFS will go on to have a permanent and lifelong impairment.

Regarding children, a UK based review from 2017 found that:

> "Reported outcomes vary, but the prognosis in children and young people is more optimistic that in adults. Four small studies (n=15–31) from the 1990s report that between 50% and 94% of children make a good or complete recovery at 13–72 month. The largest trial to date demonstrated that most children with CFS/ME will recover within 6 to 12 months if they receive internet-delivered CBT as treatment.For those who do not receive specialist care, recovery is much slower with less than 10% recovering at 6 months"[27].

What type of medical treatment and review is required to determine permanency?

Relating to 5.6 of the NDIS (Becoming a Participant) Rules 2013.

The expert report from Dr Lloyd states that:

> "Given that there is no evidence for any curative intervention (as above), the key issue regarding permanence of impairment due to chronic fatigue syndrome relates to the natural history of the condition. When followed prospectively from acute infections such as glandular fever, the great majority of individuals recover without intervention over weeks to months, but approximately 10% will meet diagnostic criteria for chronic fatigue syndrome at six months. When the chronic fatigue syndrome has been present in a stable, non-improving pattern, despite evidence-based management (as above) for 5 years, the Australian expert guidelines indicate that the condition should be regarded as permanent for medico-legal purposes. In this context, the only additional consideration relates to the severity of the impairment. As described above, chronic fatigue syndrome is an entirely subjective illness (that is there are no abnormal findings on history, examination or laboratory investigation), yet it is clear that the level of disability associated with chronic fatigue syndrome is

[26] Cleare, loc cit.

[27] A. Brigden et al., "Practical management of chronic fatigue syndrome or myalgic encephalomyelitis in childhood", Arch Dis Child. , Vol. 102, No 10, pp. 981-986, 2017, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5947766/

commonly comparable to or greater than conditions such as rheumatoid arthritis. A small subset of all patients do suffer from both severely disabling and very prolonged (greater than 5 years) chronic fatigue syndrome – these patients may be housebound or even bed-bound as a result of the illness and despite best available evidence-based management" (see Appendix D).

What are the typical functional impairments associated with CFS?

The common functional impairments associated with CFS generally fall under the mobility, self-care, self-management and social interaction categories.

The expert report by Dr Lloyd highlights impairments to physical and cognitive functioning.

Is someone with CFS likely to require supports from the NDIS for their lifetime?

The key types of support the expert report highlight are assistance with daily living:

- "Patients typically require practical support to maintain independent living (assistance with shopping, cooking, cleaning) and travel (to/from medical appointments). This would rarely include the need for assistance with personal hygiene".

Section 25 Early Intervention Considerations

How do early intervention access considerations apply to people with CFS?

Early intervention considerations do not apply to CFS. Any services that a person with CFS would receive before the condition is considered permanent would be considered time-limited health treatments.

Fibromyalgia

Expert report

In January 2018 the Technical Advisory Team commissioned a report on Fibromyalgia from an Australian expert in the field –Professor Ian Cameron, MB BS PhD (Medicine), FAFRM (RACP). The report was intended to assist with specific TAT AAT Fibromyalgia access cases, but offers a holistic snapshot of the condition.

This report has all the information a NAWM team member would require to assess access and provides answers to the following questions:

10. *What is the aetiology of this condition?*
11. *What is the impairment, if any?*
12. *What medical and allied health specialties are involved in: a) Diagnosis and b) Treatment of this condition?*
13. *What treatment options are clinically indicated for this condition? What are the indications and likelihood of success for each treatment? Please comment on details and dosage of any recommended treatments including frequency and duration as appropriate.*
14. *Is this condition results from an impairment, what is the likelihood that this impairment will be permanent?*
15. *Are individuals suffering this condition likely to require lifelong support? If so, what types of supports are likely to be required?*
16. *Would symptom management through interventions such as medication change, pain management, exercise programs etc. reduce the functional impact of the diagnosis and associated disability?*
17. *How prevalent is the incidence of Fibromyalgia being diagnoses as a stand-alone condition as opposed to being diagnosed as part of comorbidity?*
18. *Other comments:*

This full report is embedded in APPENDIX E for reference.

Information additional to the expert report are listed below.

Summary of Fibromyalgia

There is no cure for fibromyalgia, but symptoms can be managed.

Better Health Channel list that:

> "Fibromyalgia is a condition in which people experience symptoms that include widespread pain and tenderness in the body, often accompanied by fatigue and problems with memory and concentration. Fibromyalgia affects two to five per cent of the population, mainly

women, although men and adolescents can also develop the condition. It tends to develop during middle adulthood"[28].

Section 24 Disability Requirement Considerations

What are the common evidence based clinical, medical and other treatments for Fibromyalgia?

- ***See 5.4 of the NDIS (Becoming a Participant) Rules 2013.***

Better Health Channel notes that there is no cure of fibromyalgia, but there are effective management and treatment options that reduce symptoms and list the following management options:

- *"**Education** – you need to understand your condition in order to manage it well. The more you know about your condition (for example, what triggers flares, how to manage pain and fatigue) the more control you'll have. Understanding your fibromyalgia means you'll be able to make informed decisions about your healthcare and play an active role in its management*
- ***Exercise** – regular physical activity has lots of general health benefits. It can also help you manage the symptoms of your condition. When you start exercising regularly you should notice an improvement in the quality of your sleep, an increase in energy levels, a reduction in fatigue, and improvements in your overall strength and fitness*
- ***Learn ways to manage your pain** – there are many things you can do to manage pain, and different strategies will work for different situations. For example, heat packs can help ease muscle pain, cold packs can help with inflammation, gentle exercise can help relieve muscle tension. Try different techniques until you find what works best for you*
- ***Stress management and relaxation** – stress may aggravate your symptoms. Things you can do to manage stress include planning your day and setting priorities, using relaxation techniques such as going for a walk or listening to music and avoiding people and situations that cause you stress*
- ***Balancing rest and activity** – plan your activities to make the most of your energy by alternating periods of activity with rest. Break large jobs down into small achievable tasks so that you don't overdo things*
- ***Staying at work** – it's good for your health and wellbeing. Talk to your doctor or allied healthcare professional about ways to help you to get back to or to stay at work*
- ***Sleep** – it's important to get a good night's sleep when you have fibromyalgia. Poor sleep, both quantity and quality, can aggravate your symptoms*
- ***Massage** – can help with muscle relaxation and stress management*
- ***Nutrition** – eating a balanced diet can help provide you with better energy levels, help to maintain your weight, and give you a greater sense of wellbeing*

[28] Better Health Channel, 'Fibromyalgia', March 2017, https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/fibromyalgia, accessed 28 November 2019.

- ***Support from others*** *– contact musculoskeletal australia for information about peer support group locations and contact details.*
- **Medication** - combined with other strategies, medication may be used to manage pain, reduce stress or promote sleep. There are different types of medication that your doctor may recommend:
    - Pain-relievers (analgesics) – medications such as paracetamol can provide temporary pain relief
    - Creams and ointments – can be rubbed into the skin over a painful area to provide temporary pain relief
    - Anti-depressant medications – may be used in small doses to reduce pain and help you sleep"[29].

A research publication from 2015 lists the following non-pharmacologic treatment options for Fibromyalgia:

- Patient education
- Cognitive behavioral therapy
- Biofeedback
- Mind–body techniques
- Meditative movement therapies (tai chi, yoga, qigong)
- Paced breathing/meditation
- Complementary therapies (myofascial release massage, acupuncture)
- Creative work (art, music, dance therapy)
- Workbooks (anxiety, post-traumatic stress disorder, behavior modification)
- Water-based exercise
- Graded aerobic exercise
- Strength training
- Hypnotherapy
- Chiropractic manipulation
- Transcutaneous electrical nerve stimulation
- Sleep hygiene[30]

When is Fibromyalgia permanent or likely to be permanent for the disability requirements? Does this condition ever improve?

- ***See S24.1(b) of the NDIS Act 2013 & 5.3 of the NDIS (Becoming a Participant) Rules 2013.***

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[29] Better Health Channel, 'Fibromyalgia', loc cit.

[30] K. Fleming and M. Volcheck, "Central Sensitization Syndrome and the Initial Evaluation of a Patient with Fibromyalgia: A Review", Rambam Maimonides Med J., Vol 6. No 2, 2015, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4422459/