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 s47F - personal privacy (Physio), Dr s47F - personal privacy (psych) & Dr s47F - personal privacy (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 s47F - personal privacy (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 s47F - personal privacy 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 s47F - personal privacy, 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 s47F - personal privacy, 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 [s47F - person] 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 s47F - person 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 s47F - personal privacy, 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/

The expert report from Prof. s47F - personal privacy states that:

- Fibromyalgia cannot be considered permanent in the same way as many health conditions, because the underlying impairment is pain and this varies considerably over time and in response to treatments and life situations.
- Fibromyalgia cannot be regarded as permanent because it is responsive to treatment (see above) and is likely to vary in intensity at different times due to a variety of factors.
- Most people continue to experience symptoms over a long period but approximately 25% improved in the long term. However, severity worsened in about 40%.

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

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

Fibromyalgia cannot be regarded as permanent because it is responsive to treatment. There is no guideline or evidence of treatment or review in determining permanency. See expert report.

What are the typical functional impairments associated with Fibromyalgia?

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

The expert report from Prof. s47F - personal privacy states that:

- While pain is the most important symptom in fibromyalgia, others "such as fatigue, nonrefreshed sleep, mood disturbance and cognitive impairment are common, but not universal.
- Ten to 30% of people with fibromyalgia will have other rheumatological conditions and people with fibromyalgia more likely have psychiatric disorders, including depression, anxiety, obsessive-compulsive disorder, and posttraumatic stress disorder.

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

The expert report from Prof. s47F - personal privacy states that:

- Specifically, people with fibromyalgia do not require lifelong support and, indeed provision of this support is likely to be harmful to them.
- While pain may interfere with daily activities to some extent the presence of pain is not a reason to avoid specific activities.

Section 25 Early Intervention Considerations

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

Early intervention considerations do not apply to Fibromyalgia.

Fibromyalgia "is likely to be minimised by early diagnosis and intervention . . . there is increasing evidence for mechanism-based management approaches to this syndrome. These are likely to be more effective if introduced early, making timely diagnosis in general practice even more important.[31]

[31] R. Kwiatek, "Treatment of fibromyalgia", Vol 40, pp. 179-183, 2017, https://www.nps.org.au/australian-prescriber/articles/treatment-of-fibromyalgia

Functional Neurological Disorder (FND) aka Conversion Disorder

Summary of FND

The U.S. National organization for rare Disorders identifies FND as follows:

- A medical condition in which there is a problem with the functioning of the nervous system and how the brain and body sends and/or receives signals, rather than a structural disease process such as multiple sclerosis or stroke.
- FND can encompass a wide variety of neurological symptoms, such as limb weakness or seizures.
- FND is a condition at the interface between the specialties of neurology and psychiatry.
- Conventional tests such as MRI brain scans and EEGs are usually normal in patients with FND. This had led, historically, to the condition being relatively neglected by both clinicians and researchers. However, it is now established that FND is a common cause of disability and distress, which may overlap with other problems such as chronic pain and fatigue.
- Encouraging studies support the potential reversibility of FND with specifically tailored treatments.
- New scientific findings are influencing how patients are diagnosed and treated which is creating an overall change in attitude towards people with FND.
- Older ideas that FND is "all psychological" and that the diagnosis is made only when someone has normal tests have changed since the mid-2000s. The new understanding, including modern neuroscientific studies, has shown that FND is not a diagnosis of exclusion. It has specific clinical features of its own and is a disorder of the nervous system functioning in which many perspectives are necessary. These vary a lot from person to person. In some people, psychological factors are important, in others they are not. [32]

Section 24 Disability Requirement Considerations

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

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

The U.S. National organization for rare Disorders provides comprehensive information on common treatment and therapy options: [33]

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

[33] ibid

Overview

FND can be hard to understand and most people haven't heard of it. Treatment should start with a clear and supportive explanation of the positive clinical features that have allowed the diagnosis to be made, even though scans and other laboratory tests may be normal.

When it goes well, understanding the diagnosis enables the patient to see that they have a genuine and relatively common condition which has the potential for improvement over time. This creates a foundation for treatment to build upon. Written information, like that available at www.neurosymptoms.org or www.fndhope.org may help individuals comprehend this complex and difficult to understand disorder.

Evidence is now emerging for the efficacy of certain treatments, especially physiotherapy for motor symptoms and a type of psychological therapy called cognitive behavioral therapy (CBT) for attacks or seizures. Specialized types of physiotherapy and CBT have been developed for FND. Other therapies such as speech therapy and occupational therapy may also have a role depending on the symptoms.

Physical Therapy

For patients with motor symptoms such as limb weakness, gait problems or movement disorder, physical therapy from a therapist who understands something of FND can be helpful. Physiotherapy approaches are active treatments that focus on retraining movement patterns that have gone wrong. There is some evidence from clinical trials that physiotherapy designed specifically for FND can be helpful for some patients. In recent years we have learned that physical therapy for FND is different from that used for stroke or MS in many ways. For example, patients with stroke benefit from being asked to focus on the affected body part, whereas in FND that tends to make things worse. Physical therapy for FND promotes 'automatic movements' and reduces the abnormal brain patterns that have been interfering with movement.

Psychological Therapies

CBT is generally the first line of treatment for patients with dissociative (non-epileptic) seizures or attacks as part of their FND and is supported by clinical trials. Therapy includes time to learn more about their attacks and recognizing brief warning symptoms and learning techniques to regain control. For some patients it is helpful to look more widely at thoughts, emotions, and experiences that could have played a role in the development of symptoms. For those patients without anxiety and depression, psychological therapy may still be useful in regaining confidence. FND itself is often experienced as a stressful condition to manage and live with. Other types of psychological therapies can also be used depending on the individual patient, e.g. psychodynamic interpersonal therapy (PIT) or more trauma-focused work for patients who have had such experiences.

Occupational Therapy

Occupational Therapy assists patients in finding adaptations and regaining confidence in their ability to carry out daily activities in the home or workplace. Occupational therapy can help build on other therapies to contribute to a better overall quality of life.

Speech Therapy

For patients with speech symptoms as part of FND, speech therapy is an important part of treatment. Like physical therapy, the approach is different from that used, for example, after a stroke and patients benefit from seeing therapists confident in this area.

Other Therapies

There is no research-based evidence that any specific medication is beneficial for FND, but medications may be useful for other symptoms commonly occurring with FND such as pain, migraine or anxiety. Other therapies are being investigated in research studies

Not everyone with FND can benefit from treatment even if they do understand their condition and are well motivated.

When is FND 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.***

Research indicates that the condition can improve and that improvement is dependent on the individual patient's circumstances:

- Recovery is an individual process and what works for one person may not work for another, so it is important to find what is right for the individual. [34]
- FNDs are not seen as degenerative, however symptoms for people can become chronic or worsen. Recovery from symptoms is possible, or symptoms can become manageable, but may be dependent on triggers, co-existing conditions and receiving appropriate treatment. [35]
- Due to the diversity of symptoms that may present with a Functional Neurological Disorder, and the varied potential causes/triggers that can differ from person to person, treatment plans must be tailored to suit the person's individual need, with all health aspects being taken in to consideration. [36]
- Evidence is now emerging for the efficacy of certain treatments, especially physiotherapy for motor symptoms and a type of psychological therapy called cognitive behavioral therapy (CBT) for attacks or seizures. Specialized types of physiotherapy and CBT have been developed for FND. Other therapies such as speech therapy and occupational therapy may also have a role depending on the symptoms. [37]
- The symptoms of conversion disorder usually do not last long. Generally, the more quickly the symptoms start, the more rapidly they go away. If the symptoms came about in response to a clearly defined stress, the symptoms are likely to last only a short time. More severe symptoms, such as paralysis or blindness, also may not last a long time because it is harder to sustain symptoms that interfere significantly with daily activities. A less severe symptom (such as tremor) or a symptom that is repeated and limited (such as seizure) can continue or come and go, depending on the person's circumstances. [38]

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[34] FND Australia Support Services, "A pathe to recovery", [website], 2019, https://fndaus.org.au/functional-neurological-disorder-recovery, (accessed 19 December 2019)

[35] ibid

[36] FND Action, "Treatment", [website], 2019, https://www.fndaction.org.uk/treatment, (accessed 19 December 2019)

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

[38] FND Action, "Treatment", [website], 2019, https://www.fndaction.org.uk/treatment, (accessed 19 December 2019)

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

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

Available information indicates that current medical treatments and reviews are not likely to determine permanency.

What are the typical functional impairments associated with FND?

According to FND Australia Support Services Inc., [39]

- Functional neurological disorder can involve a variety of neurological symptoms affecting the motor, sensory and cognitive functions of the body.
- FND symptoms arise out of a disorder in the functioning of the nervous system and not damage to the nervous system, although FND may overlap and co-exist with other neurological diseases.
- Symptoms may include, but are not limited to:
    - Bowel and bladder problems
    - Seizure-like episodes
    - Vision problems and blindness
    - Severe fatigue
    - Cognitive issues
    - Paralysis and severe limb weakness
    - Gait disorder
    - Abnormal movements
    - Tremor
    - Speech and swallowing difficulties

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

As it appears that recovery from the condition is possible, someone with FND is not likely to require supports from NDIS for their lifetime.

[39] FND Australia Support Services Inc., "What are the typical FND symptoms", [website], 2019, https://fndaus.org.au/fnd-symptoms, (accessed 18 December 2019)

Section 25 Early Intervention Considerations

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

Early intervention considerations do not apply to FND, as there is likelihood for improvement of the condition.

Next suggested steps

1. The expert reports commissioned on CRPS, fibromyalgia and CFS could be shared in full with the NAWM. Since these are comprehensive reports that are signed off by experts in the field there is no associated risk.
2. TAT could potentially commission a similar expert report on FND (conversion disorder).
3. The Agency could commission a whole package of these expert reports to assist with access determinations for specific complex conditions.
4. The information collated in this document can be used by TAT advisors to respond to TAPS access enquiries from NAWM.

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Appendix A – AAT case summary

Name	Year	Diagnosis	Outcome
s47F - person	2019	CRPS	Went to hearing and Agency lost case - Access granted. This was the first case of it is kind to go to hearing.
s47F - personal privacy		CFS, Fibromyalgia, PoTS	Hearing Oversight Committee conceded due to Agency own OT assessment noting needed assistance to access community
s47F - personal privacy	2017	CRPS	Agency conceded with advice from Counsel. Evidence supported substantially reduced functioning in mobility and self-care.
s47F - personal privacy		CFS	Hearing Oversight Committee conceded due to poor prospects advice from Counsel
s47F - personal privacy		Fibromyalgia	Conceded under Early Intervention
s47F - personal privacy		Fibromyalgia, depression	Agency conceded under s21(2) prescribed program NSW
s47F - personal privacy		CRPS	Withdrawn at Hearing
s47F - personal privacy		CRPS	Still on-foot
s47F - personal privacy	2019	CRPS	Upcoming hearing as of 28/11/19
s47F - personal privacy	2019	Fibromyalgia (also psoratic arthritis, depression/anxiety)	Upcoming hearing as of 28/11/19

Appendix B – Previous TAT advices

HPRM Record	Title	Diagnosis	Key passages of outcome / recommendation
When searching HPRM for 'chronic regional pain syndrome':			
NED18/241094	ADV 2018 3098 ACC eligibility not met for participant with complex regional pain syndrome, functional neurological disorder and chronic fatigue 20181218 RTO573	CRPS, FND, CFS	Suggested access be revoked as the participant does not meet eligibility for "other physical" disability under s24 and s25 of the NDIS Act.
NED17/308149	ADV 2017 0550 ACC prospective participant with Benign joint hypermobility syndrome and chronic regional pain syndrome 20170926 LM0044	CRPS, plus other	Participant did not meet S24 or S25 access criteria, and should be made ineligible for the NDIS. If the participant would like to appeal the decision, they should be encouraged to provide further information relating to all their conditions (including PTSD, Anorexia nervosa migraine syndrome), treatments, prognosis, and how they impact on her functional capacity.
NED17/276004	ADV 2017 1097 ACC Review of access for a 21 year old woman with speculated diagnosis of chronic regional pain syndrome 20170905 CM0093	CRPS	The participant does not meet the access requirements set out in Section 24 and/or 25 of the NDIS Act (2013) and her access should be revoked. Access should be revoked in the instance that further information cannot be provided to meet S24 1 (b) and 1 (e) as per the table above.
NED17/70647	ADV 2016 1790 ACC Review of access for a potential participant with Chronic Regional Pain Syndrome (CRPS) and fibromyalgia. 20170602 LM0044	CRPS, fibromyalgia	In relation to her CRPS, participant does not meet S24 1b, 1c, 1e or any of the S25 early intervention criteria. In relation to her condition of Fibromyalgia, participant does not meet S24 1b, 1c, 1e or any of the S25 early intervention criteria. In relation to her condition of Shoulder Tendinopathy, participant does not meet any of the S24 or S25 criteria.
NED17/48791	ADV 20160869 ACC - Participant with Fibromyalgia Chronic Fatigue Syndrome Complex regional Pain Syndrome (CRPS) Dysphagia PTSD Depression Anxiety	CFS, fibromyalgia, CRPS, PTSD, anxiety, depression	Under section 24 and 25 of the NDIS Act 2013 a prospective participant needs to meet all listed criteria to meet the disability or early intervention requirements. Participant does not meet the following: Fibromyalgia / Chronic fatigue syndrome: S24 1c, 1e and S25 criteria Complex regional Pain Syndrome (R foot): S24 1a, b, c, e or S25 criteria Dysphagia (difficulty swallowing): S24 1b, e or S25 criteria Hearing loss: S24 1c, d, e or S25 criteria

HPRM Record	Title	Diagnosis	Key passages of outcome / recommendation
			Psychosocial conditions: S24 1c, 1e or S25 criteria
NED17/48293	ADV 20161485 ACC - chronic reflex sympathetic dystrophy (also called complex regional pain syndrome CRPS) and a range of comorbid conditions 20170324 LM0044	CRPS, plus other	Does not meet S24 or S25 access criteria and should be made ineligible to the NDIS.
NED17/9641	ADV 20161047 ACC Review of access for participant with chronic regional pain syndrome 20170127 LM0044	CRPS, brachial plexus plexopathy, psychoscial	Does not meet Section 24 or Section 25 eligibility requirements and it is recommended that her access to the NDIS revoked. Participant does not meet the following criteria: Brachial plexus plexopathy – S24 1(b) and 1 (e) or any of the S25 criteria of the NDIS ACT Chronic Regional Pain Syndrome – S24 1(b) and 1(e) or any of the S25 criteria of the NDIS ACT Depression / anxiety – S24 1(a), 1(b), 1(c), 1(e) or any of the S25 criteria of the NDIS ACT
When searching HPRM for 'fibromyalgia': Note: there are approximately 40 advices relating to fibromyalgia. Only recent or primary disability ones have been listed below.			
NED19/306629	ACC 2019 3107 51 year old with Myalgic Encephalomyelitis (Chronic Fatigue) Fibromyalgia and Postural Tachycardia Syndrome 20191115 KTU174 (002)	ME/CFS, fibromyalgia, PoTS	Based on the information provided, the participant has a disability resulting from a combination of Myalgic Encephalomyelitis (chronic fatigue), Postural Tachycardia Syndrome (POTS) with postural intolerance, treatment resistant Cerebral Spinal Fluid leak and Fibromyalgia (24.1.a), that these impairments are permanent (24 1.b) and affects her capacity for social and economic participation (24 1.d). Whilst she seems to have some functionality, exertion exacerbates her fatigue and further reduces her capacity which satisfies that she has a substantially reduced functional capacity (24.1 c) and that she is likely to require lifetime supports (24.1 e). On the basis of available information it is considered that that the participant meets section 24 access eligibility criteria to become a participant in the NDIS as set out in The NDIS Act 2013 and the NDIS (Becoming a participant) Rules 2016.

HPRM Record	Title	Diagnosis	Key passages of outcome / recommendation
NED19/246638	ADV 2019 2864 ACC 37 year old with Fibromyalgia 20191030 KTU174	fibromyalgia	While it is recognised that the participant has a physical impairment due to fatigue and chronic pain which results in reduced functional capacity, there is insufficient information to confirm that it is likely to be permanent (24.1 (b)) or that she experiences substantially reduced functional capacity across any domain (24.1 (c)) and is likely to require lifetime NDIS supports (s24.1 (e)).
NED19/199129	ADV 2019 0454 ACC Access decision for a 51 year old with Osteoarthritis, Carpel Tunnel Syndrome, Tennis Elbow, Greater Trochanteric Pain Syndrome, Fibromyalgia and Adjustment Disorder 09202019 RST221	PoTS, fibromyalgia, plus other	In relation to the s241b criteria, while it is acknowledged that s47F - personal privacy has a number of conditions that may be likely to be permanent, it cannot be considered that she meets the s241b permanency criteria at this stage. In addition it cannot be considered that her conditions result in substantially reduced functional capacity (24 1.c) or that she is likely to require NDIS supports for her lifetime (24 1.e).
NED19/190096	ADV 2019 0749 EML ACC 48yr prospective participant with fibromyalgia and chronic fatigue syndrome 20190905 KHM067	Fibromyalgia, CFS	Access met. Based on the available information XX meets Section 24 access criteria. The information provided satisfies that XX has a permanent impairment which results in physical disability (24.1 a and b). It is also satisfied that XX has a substantially reduced functional capacity across the domains of mobility and self-care as evidenced by her need for equipment alongside person to person supports to complete these activities (24.1.c). This impairment also affects her capacity to participate in his community (24.1.d and she will require NDIS supports for her lifetime.
NED19/156637	ADV 2018 8452 ACC adult chronic fatigue syndrome lyme disease fibromyalgia asthma depression access review 20190731 RTO573	CFS, fibromyalgia, lymes, depression, plus other	Based on the information provided the prospective participant does not meet criteria 24.1(b) of the NDIS Act 2013 for permanency. The information confirms that the prospective participant experiences Depression, Anxiety and PTSD, according to recent Psychologist report, however the report from Neurologist dated 20 March 2019 advises "he does not describe himself as overtly anxious or depressed but he does worry about his future". Further, symptoms associated do not meet criteria 24.1(c) of the

HPRM Record	Title	Diagnosis	Key passages of outcome / recommendation
			NDIS Act 2013 for substantially reduced functional capacity. As such, it is not likely the prospective participant will require lifetime support of the NDIS and does not meet section 24.1(e) of the NDIS Act 2013.
NED19/16753	ADV 2018 5354 ACC Myasthenia Gravis inflammatory myopathy fibromyalgia 20190220 CCQ988	Fibromyalgia, depression, Myasthenia Gravis, inflammatory myopathy, osteoporosis, Grave's disease.	There is currently insufficient information available to determine whether or not the prospective participant meets the S24 or S25 NDIS access criteria. Specifically, it is not considered that any of the S24 or S25 criteria are met for the conditions of Fibromyalgia, inflammatory myopathy, osteoporosis, Graves disease or depression as there is no information available relating to these conditions. In relation to the condition of Myasthenia Gravis it is not considered that S24 1b, 1c, 1e or any of the S25 criteria is met.
NED19/6632	ADV 20184320 ADL AT CPAR HWB THER supports for participant with schizoaffective disorder where supports pertain to other conditions inc fibromyalgia and chronic fatigue syndrome 20190123 KRN451	Psychosocial, CFS, fibromyalgia	This advice as about R&N supports relating to fibromyalgia and CFS, when the participant's primary disability was psychosocial.
NED18/249425	ADV 2018 3274 ACC Secondary disability access Fibromyalgia chronic pain and multiple physical conditions 20181220 CCQ988	Fibromyalgia, CRPS, plus other	Under section 24 and 25 of the NDIS Act 2013 a participant needs to meet all listed criteria to meet the disability or early intervention requirements. On the basis of the information available at this time, the participant does not meet S24 1b, 1e or any of the S25 criteria in relation to her fibromyalgia and chronic pain conditions.
NED18/232900	ADV 2018 3086 ACC Access ineligibility for participant with fibromyalgia 20181212 RTO573	fibromyalgia	From the information provided it cannot be considered that the participant meets the NDIS eligibility criteria under Section 24.1(b) and (e), and Section 25.1(a)(i), (b), (c)(i), (c)(ii), (c)(iii) and 3(a) of the *NDIS Act 2013.*
NED18/194100	ADV 2018 1632 ACC Review of access degenerative musculoskeletal disorder fibromyalgia and complex PTSD 20181009 CCQ988	Fibromyalgia, PTSD, degenerative musculoskeletal disorder	There is insufficient information to consider that the participant meet the NDIS eligibility criteria (S24 and S25) at this time, however it is possible with further information as outlined above, that the participant may meet for the condition of degenerative musculoskeletal condition.

HPRM Record	Title	Diagnosis	Key passages of outcome / recommendation
NED18/177140	ADV 2018 0860 ACC Review Access Lupus Fibromyalgia Chronic Fatigue Syndrome Sjogrens 20180831 CCQ988	Fibromyalgia, lupus, CFS, Sjogren's Syndrome, sensory processing disorder, chronic headaches, chronic constipation, anxiety and depression, Type 1 latent onset autoimmune diabetes.	Based on the available evidence XXX does not meet the following criteria at this time: • Systemic Lupus Erythematosus (SLE) – does not meet any of the S24 or S25 criteria at this time • Fibromyalgia – does not meet any of the S24 or S25 criteria at this time • Chronic Fatigue Syndrome (CFS) - does not meet S24 1b, 1c, 1e, 2 and any of the S25 criteria • Sjogren's Syndrome – does not meet any S24 1a, 1c, 1d, 1e, 2 or S25 criteria
NED17/359595	ADV 2016 1432 ACC Review of access Persistent depressive disorder lower back pain and Fibromyalgia CHG151 20171115	Fibromyalgia, chronic pain, depression	Under section 24 and 25 of the NDIS Act 2013 a prospective participant needs to meet all listed criteria to meet the disability or early intervention requirements. In this case, based on the available information, it is considered that the participant does not meet the following: Psychosocial disability – Does not meet S24 1c) or 1e), nor does she meet S25 1b), 1c) i, ii, iii or iv). Fibromyalgia, and lower back pain - Does not meet S24 criteria 1b), 1c) or 1e), nor does she meet S25 1a) i, 1b), or 1c) i, ii, iii or iv).
When searching HPRM for 'functional neurological disorder':			
NED18/87417	ADV 2017 2596 AT Q6 Edge HD PWC with Spex seating adult with Functional Neurological Disorder access not met 20180327 JB0080	FND	There is insufficient information available to determine if the participant meets section 24 (1.b,c,&e), 24 (2) and section 25 as per the table and paragraph above. However there is also insufficient evidence to confirm that the participant's access should be revoked at this stage. Additional information is required to determine if the participant meets the access requirements to be a participant of the NDIS. Information from medical or allied health professionals should include a comprehensive outline of the participant's diagnosis, treatments to date, recommended treatments and prognosis and information outlining the impact of her impairments on her functional capacity.

HPRM Record	Title	Diagnosis	Key passages of outcome / recommendation
NED18/200062	ADV 20181860 ACC Review of access for participant with functional neurological disorder LM0044 20181026	FND	On the basis of the available information, it cannot be confirmed that XX meets S24 1b or 1c, or the S25 criteria, however there is also insufficient information to confirm that her access should be revoked. 2. As XX's plan has expired, a new plan incorporating provision of reasonable and necessary supports should be approved. 3. Further information should be requested as outlined above during the planning period. If information cannot be obtained to establish if XX' impairments are permanent, consideration into the appropriateness of an independent assessment may be required.
NED18/241092	ADV 2018 3098 ACC eligibility not met for participant with complex regional pain syndrome, functional neurological disorder and chronic fatigue 20181218RTO573	CRPS, FND, CFS	Based on the information provided the participant does not meet s24.1(c)(e) and 25.3(a) of the NDIS Act. As such the participant does not meet the eligibility criteria for access, or early intervention, to the Scheme. It is considered that the participant's support needs are best met by the health and mental health service systems as per the recommendations of the Neurologist and Orthopaedic Surgeon.
NED19/17532	ADV 2018 5321 ACC 17 year old prospective participant with Functional Neurological Disorder 20190221 CCQ988	FND	While it is possible that the prospective participant will meet the s24 NDIS access criteria, further information will be required in order to be satisfied that s241b is met. Specifically information relating to the specific treatment inventions completed and whether or not there was any improvements as a result of these interventions over the course of her multi-disciplinary inpatient and outpatient treatment program.
NED19/36281	ADV 2018 6190 ACC initial access review adult conversion disorder functional neurological symptoms disorder anxiety depression dec 20190322 RTO573	FND, psychosocial	The Delegate should uphold access not met decision for functional neurological disorder/conversion disorder as not having met criteria under section 24 or 25 of the NDIS Act.
NED19/38699	ADV 2018 6316 ACC initial access adult functional neurological disorder dec 20190401 RTO573	FND	Based on the available information the prospective participant does not meet criteria for early intervention under section 25 of the NDIS Act for functional neurological disorder. There is insufficient information to determine her condition is permanent under parts 1(a)(i)(ii), and if supports are more

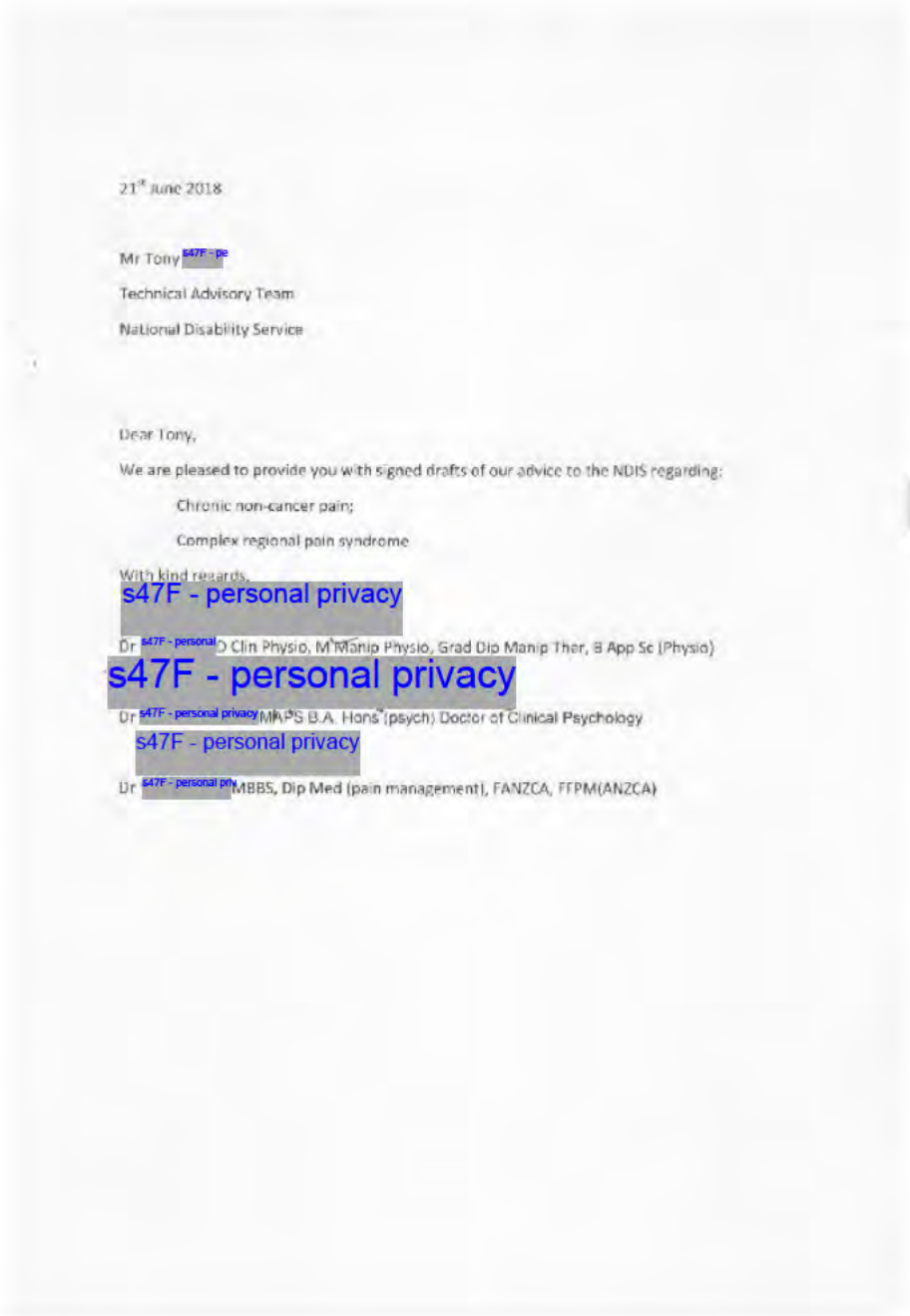
HPRM Record	Title	Diagnosis	Key passages of outcome / recommendation
			appropriately funded through mainstream services as set out under section 25(3).
NED19/175892	ADV 20188377 HMOD Funding request for home modifications for a 22 year old female with functional neurological disorder 20190822 DSS550	FND	This advice was about vehicle and home modifications.
NED19/183942	ADV 2019 1088 EML ACC 33yr prospective participant with CRPS and functional neurological disorder 20190828 KHM067	FND, CRPS, oedema syndrome and anxiety	there is currently insufficient information to satisfy that she meets all section 24 eligibility requirements and further information should be sought as outlined in the opinion section above.
NED19/191070	ADV 2019 0455 ACC Adult with Functional Neurological Disorder and Chronic Pain 20190904 KTU174	FND, CRPS	There is currently insufficient information to satisfy that she meets all s24 eligibility requirements and further information should be sought regarding the treatments and interventions undertaken to address these conditions.
NED19/196505	ADV 2019 0751 ACC Adult with functional neurological disorder paraplegia depression and leukaemia 20190909 KTU174	FND, psychosocial, non-organic paraplegia	On the basis of information available, it cannot be considered that s47F - perso meets the s24 or s25 criteria at this time. Further information should be sought regarding the scope and outcomes of treatments undertaken to date, future interventions recommended, and the expected prognosis of s47F - personal p paralysis/conversion disorder/major depressive disorder/leukaemia.
NED19/197244	2019 1901 ACC TAT Advice 25 year old with Functional Neurological Disorder 20190917 KTU174	FND	Access met. On the basis of available information it is considered that that s47F - personal privacy meets section 24 access eligibility criteria to become a participant in the NDIS as set out in The NDIS Act 2013 and the NDIS (Becoming a participant) Rules 2016.
When searching HPRM for 'chronic fatigue syndrome': Duplications listed above not included.			

HPRM Record	Title	Diagnosis	Key passages of outcome / recommendation
NED17/46967	20161468 Access for a prospective participant with Chronic Fatigue Syndrome (CFS) 20170331 LM0044	CFS	In regards to her condition of Chronic Fatigue Syndrome, XX does not meet S24 1b, 1c, 1e or any of the S25 criteria.
NED17/47508	ADV 2016 1203 ACC CHC review of access decision for chronic fatigue syndrome Access not met 20170403 RH0022 (002)	CFS	XX does not meet Section 24 1(b), (c) and (e) and does not meet any of the early intervention criteria as outlined in Section 25.
NED19/190109	ADV 2019 0894 EML ACC 18yr prospective participant with POTS ME Chronic Fatigue Syndrome 20190905 KHM067	ME/CFS, PoTS	Whilst it is satisfied that XX has a disability as a result of Postural Orthostatic Hypotension and ME/Chronic Fatigue Syndrome it is not satisfied that this results in an impairment which is likely to be permanent (24.1 b) and will require lifetime NDIS supports (24.1 e).
NED19/88232	ADV 2018 7239 ACC review of access for prospective participant with chronic fatigue syndrome 20190530 LM0044	CFS, fibromyalgia, migraines	Access met. Information indicates that she has a permanent and deteriorating physical impairment that results in substantially reduced functional capacity across the domains of mobility and self-care. While it is considered that she will continue to require supports through the Health system, it is also likely that she will require supports within the scope of the NDIS for her lifetime
NED18/56452	ADV 2017 1862 ACC Chronic Fatigue Syndrome. Access not met 20180226 RH0022	CFS, depression	Based on the evidence provided XX is ineligibility access the NDIS as she does not meet the Disability or Early intervention access criteria as outlined in Section 24 or 25 of the NDIA Act for her conditions of depression and CFS.
NED18/26770	ADV ACC 2017 1893 Access for participant with chronic fatigue syndrome 20180124 TSA612	CFS	Access met. Based on the information provided 847F - personal meets the NDIS disability access eligibility criteria and should me made eligible. access eligibility should be reviewed at each plan review, if not before.
NED17/76765	ADV 2016 2505 ACC Access for prospective participant with Chronic Fatigue Syndrome 20170718 LM0044	CFS. Major depressive disorder, fibromyalgia, IBS	Based on the available evidence XX does not meet the following: In relation to Chronic Fatigue: Does not meet S24 1c, 1e or 2 or S25 1b, 1ci, cii, ciii or 3a

HPRM Record	Title	Diagnosis	Key passages of outcome / recommendation
			In relation to Major Depression: Does not meet S24 1b, 1c, 1e, 2 or S25 1a, 1b, 1ci, cii, ciii or 3a In relation to Fibromyalgia: Does not meet any of the S24 or S25 criteria In relation to Irritable bowel: Does not meet any of the S24 or S25 criteria.

Appendix C - Report on Complex regional pain syndrome

Double click on report front page to open the full PDF report.



21st June 2018

Mr Tony s47F - pe
Technical Advisory Team
National Disability Service

Dear Tony,

We are pleased to provide you with signed drafts of our advice to the NDIS regarding:

Chronic non-cancer pain;

Complex regional pain syndrome

With kind regards,

s47F - personal privacy

Dr s47F - personal D Clin Physio, M Manip Physio, Grad Dip Manip Ther, B App Sc (Physio)

s47F - personal privacy

Dr s47F - personal privacy MAPS B.A. Hons (psych) Doctor of Clinical Psychology

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Dr s47F - personal priv MBBS, Dip Med (pain management), FANZCA, FFPM(ANZCA)

Appendix D - Report on Chronic Fatigue Syndrome

Double click on report front page to open the full PDF report.

s47F - personal privacy

MD FRACP

Professor of Medicine

Consultant Infectious Diseases Physician

Provider No: s47F - persona

All Correspondence to Private Consulting Rooms:

s47F - personal privacy

Appointments:

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Email: s47F - personal privacy

s47F - personal privacy

Report in response to a request for information and advice regarding chronic fatigue syndrome.

Preamble: The request (31.1.2018) sought information and advice regarding chronic fatigue syndrome, however it should be noted firstly that this diagnosis is syndromal - that is it is a syndrome recognized via a characteristic set of symptoms and careful exclusion of alternative medical and psychiatric explanations for those symptoms (individually or as a whole) via medical and psychiatric history, physical examination and laboratory investigation)[1]. This sort of assessment contrasts with diagnoses made on the basis of a test, such as pneumonia recognized by chest Xray. Secondly, as a consequence of this syndromal diagnosis the label of chronic fatigue syndrome is recognized to overlap with other syndromal diagnoses, such as fibromyalgia (in which pain rather than fatigue is the dominant feature).[2] In practice, this means that individual patients may be given both diagnoses in relation to the same set of symptoms. Thirdly, a diagnosis of chronic fatigue syndrome may be replaced in some circumstances with an alternative label (for the same condition) when the prolonged illness follows from a well-characterised initiating event. This includes post viral fatigue syndrome or post-infective fatigue syndrome when the triggering event was an acute infection (such as glandular fever)[3]. The label chronic fatigue syndrome is referred to in the UK as myalgic encephalomyelitis (ME). The symptom set and diagnostic approach for chronic fatigue syndrome is closely analogous to the diagnosis of post cancer fatigue, which is applied when survivors of cancer have completed surgery and adjunctive treatments such as chemotherapy and radiotherapy, are free of cancer recurrence, but have a disabling chronic fatigue state[4]. Finally, there are various diagnostic criteria that have been proposed for the chronic fatigue syndrome, placing emphasis on slightly different elements of the illness, but the most widely accepted and recommended criteria[5], are those usually termed the 'international diagnostic criteria' which were formulated by an international expert group convened by the Centers for Disease Control in the USA[1].

1. *What is the aetiology of this condition?*

Chronic fatigue syndrome is a condition characterised by prolonged (greater than 6 months), unexplained and disabling fatigue, which is accompanied by neurocognitive difficulties, like impairments in short-term memory and concentration, as well as the complaint of unrefreshing sleep. In addition, constitutional symptoms are typical including muscle pain (myalgia), joint pain (arthralgia), recurrent sore throat, headache, and tender lymph nodes in the neck (i.e cervical lymph nodes)[1]. The fatigue state is characterised by a sustained worsening of symptoms after

Appendix E - Report on Fibromyalgia

Double click on report front page to open the full PDF report.

s47F - personal privacy

s47F - personal privacy
MB BS PhD (Medicine) FAFRM (RACP)
Consultant Physician in Rehabilitation Medicine

18 January 2018

Ms Wendy s47F - p
Acting Director
Technical Advisory Team- Operational Guidance
NDIA

Dear Ms s47F - pe

Request for expert information and advice - fibromyalgia

Thank you for your request, dated 22 December 2017, that I provide information and advice regarding fibromyalgia to the National Disability Insurance Agency (NDIA). This is a revised report that has been prepared after consideration of additional materials.

I note the "issues to consider" that you outlined. These, and my responses, are shown below.

This report is based on a review of the scientific literature. I conducted a systematic review and meta-synthesis to update the systematic review of Clauw (2014). The database, Medline, was searched using the terms "fibromyalgia" and "meta-analysis" from 2014 to current. This was to bring the search strategy of Clauw (2014) up to date.

My responses are:

1. What is the aetiology of fibromyalgia?

Fibromyalgia is a condition of generalized body pain without a known cause or cure (Fitzcharles et al 2013). Its aetiology is therefore unknown. It is hypothesised that certain people are more likely to experience chronic widespread pain. This is due to a combination of environmental and genetic influences (Clauw et al 2014). It is definitely more prevalent in women and men in a ratio of 2:1 (Clauw 2014).

2. *What is the impairment, if any?*

You have advised that "impairment" has been interpreted in this context to mean a loss of, or damage to, a physical, sensory or mental function – see *Mulligan and NDIA* [2014] AATA 374. This decision states that the words "disability" and "impairment" are not defined in the NDIS Act or Rules. It then goes on to state "Impairment commonly refers to a loss of, or damage to, a physical, sensory or mental function".

The central component of fibromyalgia is generalised pain. Pain is a sensory function. This is supported by the International Association for the Study of Pain's definition of pain as "An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such

1

21st June 2018

Mr Tony [redacted]

Technical Advisory Team

National Disability Service

Dear Tony,

We are pleased to provide you with signed drafts of our advice to the NDIS regarding:

Chronic non-cancer pain;

Complex regional pain syndrome

With kind regards,

[redacted]

Dr [redacted] D Clin Physio, M Manip Physio, Grad Dip Manip Ther, B App Sc (Physio)

[redacted]

Dr [redacted] MAPS B.A. Hons (psych) Doctor of Clinical Psychology

[redacted]

Dr [redacted] MBBS, Dip Med (pain management), FANZCA, FFPM(ANZCA)

Complex Regional Pain Syndrome

1. What is the aetiology of this condition?

Complex Regional Pain Syndrome (CRPS) is a painful, disabling and distressing condition that predominantly affects the upper or lower limb. Clinically, CRPS is characterised by pain, abnormal regulation of blood flow and sudomotor activity (sweating), oedema (swelling), active and passive movement disorders and trophic changes of the skin, hair and nails and subcutaneous tissues[1]. CRPS usually follows trauma to the limb, such as a fracture, sprain, surgery or a penetrating injury[2]. Central nervous system lesions such as spinal cord injuries and cerebro-vascular accidents and cardiac ischaemia are less frequent precipitating events[1].

The effects of CRPS can range from mild to severe and may last from months to years[3]. CRPS-1 is thought to occur after 1-7 % of fractures, and 2-5% of peripheral nerve lesions[1,4]. Fracture appears to be the most frequent initiating event[3]. Females are more often affected than males, with a female to male ratio ranging from 2:1 to 4:1. CRPS occurs across all age groups with a mean peak in age of 37 to 50 years[1]. CRPS predominantly occurs in one limb, usually the upper limb, and is distributed evenly between the left and right side, with an incidence bilaterally of around 2%[1].

Terminology

The term CRPS was introduced in 1994[5]. Prior to this, terms such as Reflex Sympathetic Dystrophy (RSD) and Causalgia were applied. Under the 1994 terminology, RSD was re-labelled CRPS-1 and Causalgia as CRPS-2. However these terms have recently been abandoned and the single term CRPS is now preferred.

The authors note that the terms ***Chronic*** Regional Pain Syndrome and "Regional Pain Syndrome" are also frequently used to refer to persistent pain conditions. Neither of these labels refers to Complex Regional Pain Syndrome which utilises strict diagnostic criteria including signs and symptoms other than pain. In fact, there is no formal diagnostic category for either "Chronic Regional Pain Syndrome" or "Regional Pain Syndrome".

CRPS has been defined as:

"A syndrome that usually develops after an initiating noxious event, is not limited to the distribution of a single peripheral nerve and is apparently disproportionate to the inciting event. It is

associated at some point with evidence of oedema, changes in skin blood flow, abnormal sudomotor activity in the region of the pain, or allodynia or hyperalgesia[5]."

Diagnosis

Diagnosis of CRPS has evolved since 1994. Currently CRPS is diagnosed using the following criteria ("Budapest Criteria"[6]).

Table 1 Budapest Diagnostic Criteria for CRPS[6]

	Interpretation for making a clinical diagnosis:			
	1+ symptoms from each symptom category & 1+ signs at time of evaluation from 2+ sign categories.			
i.	**Continuing pain,** which is disproportionate to any inciting event			
	Symptom categories:			
ii.	**Sensory:** reports of hyperaesthesia +/or allodynia	**Vasomotor:** reports of temperature asymmetry +/or skin colour changes +/or skin colour asymmetry	**Sudomotor / oedema:** reports of oedema +/or sweating changes +/or sweating asymmetry	**Motor/Trophic:** reports of decreased range of motion +/or motor dysfunction (weakness, tremor, dystonia) +/or trophic changes (hair, nail, skin)
	Sign categories:			
iii	**Sensory:** evidence of hyperalgesia (to pinprick) +/or allodynia (to light touch) +/or temperature sensation +/or deep somatic pressure +/or joint movement	**Vasomotor:** evidence of temperature asymmetry (>1 degree Celsius) +/or skin colour changes +/or asymmetry	**Sudomotor / oedema:** evidence of oedema +/or sweating changes +/or sweating asymmetry	**Motor/Trophic:** evidence of decreased range of motion +/or motor dysfunction (weakness, tremor, dystonia) +/or trophic changes (hair, nail, skin)
iv	There is **no other diagnosis** that better explains the signs and symptoms			

Despite advances in the refinement of the diagnostic criteria, there remains limited capacity to discriminate between CRPS and the presence of other conditions with overlapping symptoms. This makes it difficult to distinguish CRPS from other neuropathic, medical and psychiatric conditions[7]. Figure 1 lists differential diagnoses that should be considered when making the diagnosis of CRPS.

Figure 1 Differential diagnoses for CRPS[7]

☐ Entrapment syndromes e.g. carpal tunnel	☐ Costo-clavicular compression syndrome
☐ Compartment syndrome	☐ Lymphoedema
☐ Thrombosis	☐ Infection
☐ Disuse or nonuse of a limb	☐ Conversion disorder
	☐ Self harm

The difficulties with diagnosing CRPS have resulted in many radiological and laboratory investigations for patients. While these tests may assist in differential diagnosis, none of these tests has been found to offer any additional value in confirming the diagnosis of CRPS over clinical or 'bed-side' diagnosis alone[7]. This creates a burden of cost to the individual and the health system along with the risk of complications and side effects that may occur when 'red herrings' are treated following these investigations.

Clinical Presentation

Pain in CRPS is usually experienced in one limb, and is often described as burning. The pain may appear to be out of proportion to the precipitating event. Allodynia (pain from a stimulus that is not usually painful) and hyperalgesia (excessive pain from a stimulus that is painful) are often present throughout the limb, but do not reflect the distribution of a peripheral nerve or spinal nerve root[5].

Movement disorders include loss of voluntary control of movements of the affected limb, slowing of movement, dystonia (long lasting muscle spasm that can cause the limb to twist), myoclonus (brief involuntary muscle twitches) and tremor (involuntary rhythmic muscle contraction and relaxation)[8]. Weakness of the distal muscles of the affected limb, especially in the hand and foot, can occur[2].

The hand or foot may be swollen, sweaty or dry, warmer or cooler, and may vary in colour from the non-affected side by being pink, red or purplish or white or bluish in colour[9]. These signs are not constant and may be triggered by sensory stimuli, environmental changes and psychological stressors.

Nails can grow thickened and ridged. Hair growth can be thick and dark, or absent. Skin can eventually become thin, glossy and fibrotic. Focal osteoporosis (areas of reduced bone density) may occur. At joints restrictions in range of motion may develop[1].

2. What is the impairment, if any?

***Note**: The term "impairment" has been interpreted in this context to mean a loss of, or damage to, a physical, sensory or mental function – see Mulligan and NDIA [2014] AATA 374 at [19]*

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 and tone, involuntary movements, balance and co-ordination
- functions of skin & related structures e.g. skin temperature, sweating, nail & hair growth

3. What medical and allied health specialties are involved in:

a) Diagnosis

CRPS is often suspected by a medical doctor, occupational therapist or physiotherapist. However, the diagnosis should only be confirmed when the client's presentation meets the Budapest diagnostic criteria[6]. The authors caution against the inappropriate use of the diagnostic label "CRPS" as it can create fear and stress in clients (who then undertake misguided internet-based research on the condition) or can lead to a lack of appropriate treatment for the true underlying condition e.g infection, nerve compression or conversion disorder.

b) Treatment of this condition

Treatment is optimally provided in a multidisciplinary environment where medical specialists, occupational therapists, physiotherapists, psychologists, and others work together in a fluid and interactive manner[10]. In order to minimise chronicity, treatment of acute CRPS should be immediate and directed toward restoration of function in the affected extremity[1]. Because use of the affected part is painful, flexible pain reduction strategies to make the treatment tolerable to the patient must underpin the functional restoration[10]. In chronic CRPS, the treatment paradigm becomes more reflective of the chronic non cancer pain (CNCP) model and the reader is invited to refer to that document for a full discussion. In chronic CRPS where there is dystonia, myoclonus and/or limb deformity, neurologists, orthotists, and podiatrists may also play an ongoing role in treating the condition and assisting the client to adapt to their impairment.

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.**

The International Association for the Study of Pain (IASP) has recommended early multidisciplinary management of individuals with CRPS, which includes the provision of physiotherapy, psychology and medical interventions[10]. The outcome of the early management of CRPS is difficult to predict, which creates additional uncertainty and distress to those with CRPS, although there is a reasonable likelihood that the acute form of this condition will resolve or almost completely resolve in the first six to twelve months.

In its chronic stages, CRPS should be managed in a similar manner to other chronic pain diagnoses[7]. Unfortunately, a percentage of people will continue to have CRPS and some of these will be severely affected by the condition. These people are a small minority of cases, but as NDIS clients they will require long term support including physical rehabilitation, psychological treatment, pain management training via a multidisciplinary team (refer to the CNCP document), and pain reduction therapies (medications, interventions and implanted devices). In clients experiencing dystonia, botulinum toxin injections may be appropriate. In addition there may be a need for the provision of orthotics, braces, splints and other aids, modifications to homes, cars and workplaces.

The following provides some insights into current treatment strategies for CRPS for which there is some evidence. The evidence for most therapies is low: amongst reasons for this are: the challenge of providing a suitable control group in studies; the variability and fluctuating course of the clinical manifestations of CRPS; and the difficulty in measuring changes in variables with clinical significance.

Physical therapies

Physiotherapy and occupational therapy are of the utmost importance in achieving functional recovery in CRPS[1]. It has been recommended that physiotherapy aimed at restoring function be started as soon as possible after the onset of CRPS[7]. An algorithm of treatment has been published which promotes a stepwise progression commencing with reduction of pain and oedema, followed by improving range of motion, then improving muscle strength, function of the whole limb, and finally function of the whole person[10]. Graded exposure delivered in a psychologically informed manner by a physical therapist offers an appropriate approach[11,12]. Graded motor imagery and mirror therapies have shown utility in certain groups of research subjects with CRPS[13].

Psychological therapies

Psychological therapies for people with CRPS are generally the same as those used in other pain conditions. However there are some distinctive features of the presentation that require specific responses. It is particularly important in CRPS to teach strategies such as relaxation, mindfulness, and breathing techniques that assist the person to cope with stress and decrease sympathetic nervous system arousal. Pacing, graduated exposure and desensitsation are likely to be necessary to overcome fear of movement and avoidance of activity. Cognitive reframing (used in Cognitive Behavioural Therapy) will be vital if a client has developed "dysmorphobia" (a pre-occupation with the appearance of the affected body part leading to avoidance including socializing or exposing the affected part). In rare cases, clients develop problems with "body integrity"[14], so the person has a sense that the affected body part does not belong to them or has changed in shape or size. Cognitive reframing, desensitization and graduated exposure and de-arousal/relaxation techniques would all be appropriate in these cases. It is essential to address coexisting psychopathology such as anxiety, post traumatic stress disorder and depression, and to be aware of the impact of any personality factors.

Medications

Initially, the principal role of medication should be to assist improving function including participation in occupational therapy and physical therapy; however for clients whose symptoms remain a year or more after intensive rehabilitation, the role of medication may be largely palliation of pain. Medications may potentially be used for decades in patients with CRPS[15].

No particular class of medications is specifically indicated for the treatment of CRPS, and the response to each class varies from patient to patient. Medications used are those used in other pain conditions. As always, use of a medication should balance actual benefit from side effects. Medications commonly used may be from these therapeutic classes: tricyclic antidepressants, selective noradrenergic reuptake inhibitors, gabapentinoids, opioids, paracetamol/non-steroidal anti-inflammatories/COX-2 inhibitors. Other types of medications including creams and gels may be used. Often, more than one class is used. Despite this, many patients with chronic CRPS will have incomplete pain relief.

Interventional Therapies

Sympathetic ganglion blockade has historically been considered an important procedure in both the diagnosis and treatment of CRPS[16]. It would appear that only a subgroup of CRPS patients – perhaps

30% - respond favourably to sympathetic ganglion blockade and this subgroup of patients is considered to exhibit a feature called sympathetically maintained pain[17]. There are several methods of achieving sympathetic ganglion blockade:

- Sympathetic ganglion blocks use local anaesthetic to temporarily stop the sympathetic outflow to a limb[1,18].
- Intravenous regional sympatholysis has fallen out of favour due to concerns over its safety[19] and effectiveness.
- Surgical sympathectomy is rarely utilised because of its irreversible nature and the risk of patients developing adaptive supersensitivity and therefore more pain[1].

Implanted therapies

Implanted therapies for CRPS include forms of neurostimulation such as spinal cord stimulation and peripheral nerve stimulation, as well as intrathecal drug delivery. Implanted therapies in current clinical use with patients with CRPS include:

- Spinal cord stimulation (SCS) arises from electrodes being placed in the epidural space (the space surrounding the spinal cord) and connected to an impulse generator which sends rapid pulses of electrical energy into the spinal cord causing inhibition of pain signalling, and sometimes changing the neural control of blood flow to parts of the body[20].
- Peripheral nerve stimulation is indicated in the patient with pain predominating in the distribution of a peripheral nerve, such as the median or ulnar nerve. The technology is similar to SCS.
- Other forms of stimulation such as trans-cranial magnetic stimulation and deep brain stimulation have been found to be effective in selected cases, but remain mostly utilised in research rather than being clinically applicable at present[1].
- Implantable pumps deliver certain drugs intrathecally, i.e. to the fluid around the spinal cord and onto the spinal cord and brain, straight to the drug's target receptors. The result is higher concentrations at the target receptors and less side effects from delivery of the drug to other parts of the body[21]. For example, this can be particularly useful when using baclofen to treat dystonia.

5. If this condition results from an impairment, what is the likelihood that this impairment will be permanent?

   Note: *An impairment is, or is likely to be, permanent only if there are no known, available and appropriate evidence based treatments that would be likely to remedy (i.e. cure or substantially relieve) the impairment – see Rule 5.4 of the Rules*

There is enormous variation in the prognosis for 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 (a stiffening of the 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.

6. Are individuals suffering this condition likely to require lifelong support? If so, what types of supports are likely to be required?

Individuals suffering the severe form of CRPS are likely to require life long support, although the nature of this will vary between individuals. As stated in section 4, this support may include pain reduction and management, physical rehabilitation, psychological assistance with coping and acceptance of their changed body, pain management training via a multidisciplinary team (refer to the CNCP document) and pain reduction therapies (medications, interventions and potentially implanted devices). In clients experiencing dystonia, botulinum toxin injections may be appropriate. In addition, there will be a need for the provision of orthotics, braces, splints and other aids, modifications to homes, cars and workplaces. In the cohort of severely affected clients, these treatments may need to be provided regularly, but not frequently, e.g. botulinum toxin every 3 to 6 months, accompanied by 2 physiotherapy sessions, ketamine infusion every 3 to 6 months, an occupational therapy review every 2 years.

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?

Yes: symptom management specifically aims to reduce the functional impact of the diagnosis and associated disability. However, for some people with a severe form of CRPS, pain reduction alone can be an appropriate aim, whether it reduces the functional impact or not. The following interventions aim to reduce the functional impact and associated disability:

- Reduction of dystonia through botulinum toxin injections and the use of splinting to prevent contractures.
- Medication management.
- Multidisciplinary pain management (refer to the CNCP document).

- Exercise programs designed and supervised by a physiotherapist over a period of 8 to 12 weeks in gymnasiums or hydrotherapy pools.
- Hydrotherapy pools also allow for the whole person to exercise while the affected limb is gently supported by the buoyancy of the water, the water temperature and pressure on the limb can exert a therapeutic advantage greater than that of gym-based exercise.
- The general principle should be that clients are instructed in land-based and water-based exercises in the expectation that they continue them without supervision but having reviews at intervals of say 6 months to 2 years to confirm that the exercises are being continued appropriately or so that minor changes can be made.

8. How prevalent is the incidence of CRPS being diagnosed as a stand-alone condition as opposed to being diagnosed as part of comorbidity?

By definition CRPS "usually develops after an initiating noxious event"[5], such as a fracture, a soft tissue injury, or some form of surgery. If diagnosis is made promptly then the inciting event is often clear and the CRPS can be seen to have occurred in relation to this. However, when diagnosis occurs late in the presentation, the inciting event may no longer be contributing to the presentation, for example a fracture or soft tissue injury may have healed.

9. Any other comments?

A small subset of people with CRPS develop an extremely disabling and painful condition, so severe that they may ask for the limb to be amputated. These requests can be misinterpreted as a sign of mental illness. It is essential that people making these requests are taken seriously and are given access to a multidisciplinary service skilled in the management of CRPS and able to offer assessment by an entire team including a Pain Specialist (Fellow of the Faculty of Pain Medicine) and a Psychiatrist where deemed necessary.

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Appendix A: Disability and Early Intervention sections of the NDIS Act 2013

Section 24: Disability requirements

(1) A person meets the disability requirements if:

(a) the person has a disability that is attributable to one or more intellectual, cognitive, neurological, sensory or physical impairments or to one or more impairments attributable to a psychiatric condition; and

(b) the impairment or impairments are, or are likely to be, permanent; and

(c) the impairment or impairments result in substantially reduced functional capacity to undertake, or psychosocial functioning in undertaking, one or more of the following activities:

(i) communication;

(ii) social interaction;

(iii) learning;

(iv) mobility;

(v) self care;

(vi) self management; and

(d) the impairment or impairments affect the person's capacity for social and economic participation; and

(e) the person is likely to require support under the National Disability Insurance Scheme for the person's lifetime.

(2) For the purposes of subsection (1), an impairment or impairments that vary in intensity may be permanent, and the person is likely to require support under the National Disability Insurance Scheme for the person's lifetime, despite the variation.

Section 25. Early intervention requirements

(1) A person meets the early intervention requirements if:

(a) the person:

(i) has one or more identified intellectual, cognitive, neurological, sensory or physical impairments that are, or are likely to be, permanent; or

(ii) has one or more identified impairments that are attributable to a psychiatric condition and are, or are likely to be, permanent; or

(iii) is a child who has developmental delay; and

(b) the CEO is satisfied that provision of early intervention supports for the person is likely to benefit the person by reducing the person's future needs for supports in relation to disability; and

(c) the CEO is satisfied that provision of early intervention supports for the person is likely to benefit the person by:

(i) mitigating or alleviating the impact of the person's impairment upon the functional capacity of the person to undertake communication, social interaction, learning, mobility, self care or self management; or

(ii) preventing the deterioration of such functional capacity; or

(iii) improving such functional capacity; or

(iv) strengthening the sustainability of informal supports available to the person, including through building the capacity of the person's carer.

Note: In certain circumstances, a person with a degenerative condition could meet the early intervention requirements and therefore become a participant.

(2) The CEO is taken to be satisfied as mentioned in paragraphs (1)(b) and (c) if one or more of the person's impairments are prescribed by the National Disability Insurance Scheme rules for the purposes of this subsection.

(3) Despite subsections (1) and (2), the person does not meet the early intervention requirements if the CEO is satisfied that early intervention support for the person is not most appropriately funded or provided through the National Disability Insurance Scheme, and is more appropriately funded or provided through other general systems of service delivery or support services offered by a person, agency or body, or through systems of service delivery or support services offered:

(a) as part of a universal service obligation; or

(b) in accordance with reasonable adjustments required under a law dealing with discrimination on the basis of disability.

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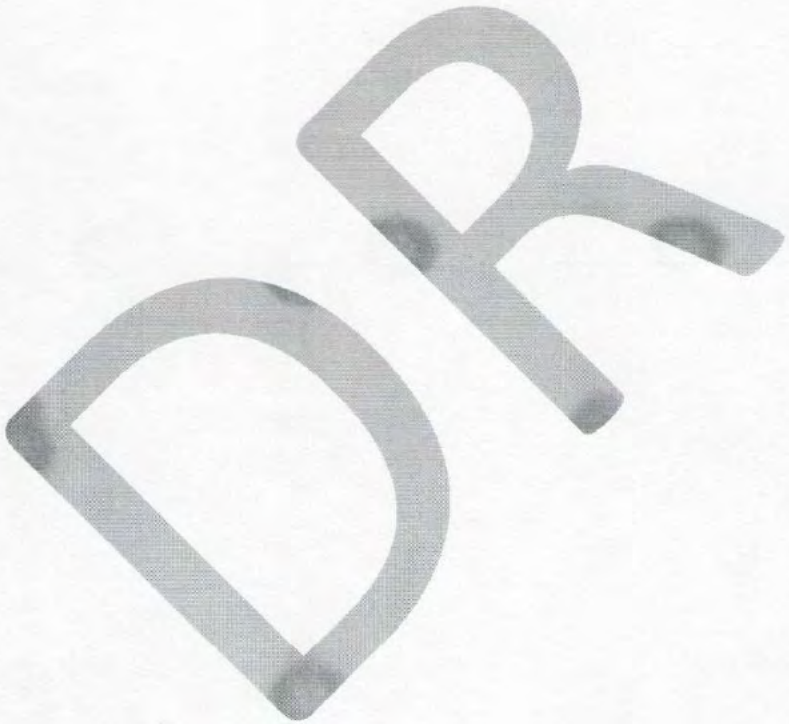

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Report in response to a request for information and advice regarding chronic fatigue syndrome.

Preamble: The request (31.1.2018) sought information and advice regarding chronic fatigue syndrome, however it should be noted firstly that this diagnosis is syndromal - that is it is a syndrome recognized via a characteristic set of symptoms and careful exclusion of alternative medical and psychiatric explanations for those symptoms (individually or as a whole) via medical and psychiatric history, physical examination and laboratory investigation)[1]. This sort of assessment contrasts with diagnoses made on the basis of a test, such as pneumonia recognized by chest Xray. Secondly, as a consequence of this syndromal diagnosis the label of chronic fatigue syndrome is recognized to overlap with other syndromal diagnoses, such as fibromyalgia (in which pain rather than fatigue is the dominant feature).[2] In practice, this means that individual patients may be given both diagnoses in relation to the same set of symptoms. Thirdly, a diagnosis of chronic fatigue syndrome may be replaced in some circumstances with an alternative label (for the same condition) when the prolonged illness follows from a well-characterised initiating event. This includes post viral fatigue syndrome or post-infective fatigue syndrome when the triggering event was an acute infection (such as glandular fever)[3]. The label chronic fatigue syndrome is referred to in the UK as myalgic encephalomyelitis (ME). The symptom set and diagnostic approach for chronic fatigue syndrome is closely analogous to the diagnosis of post cancer fatigue, which is applied when survivors of cancer have completed surgery and adjunctive treatments such as chemotherapy and radiotherapy, are free of cancer recurrence, but have a disabling chronic fatigue state[4]. Finally, there are various diagnostic criteria that have been proposed for the chronic fatigue syndrome, placing emphasis on slightly different elements of the illness, but the most widely accepted and recommended criteria[5], are those usually termed the 'international diagnostic criteria' which were formulated by an international expert group convened by the Centers for Disease Control in the USA[1].

1. What is the aetiology of this condition?

Chronic fatigue syndrome is a condition characterised by prolonged (greater than 6 months), unexplained and disabling fatigue, which is accompanied by neurocognitive difficulties, like impairments in short-term memory and concentration, as well as the complaint of unrefreshing sleep. In addition, constitutional symptoms are typical including muscle pain (myalgia), joint pain (arthralgia), recurrent sore throat, headache, and tender lymph nodes in the neck (i.e cervical lymph nodes)[1]. The fatigue state is characterised by a sustained worsening of symptoms after

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relatively minor physical or cognitive tasks – often termed 'post-exertional malaise' (after physical activity) or 'brain fog' (after cognitive activity). The diagnostic criteria also require careful exclusion of alternative medical and psychiatric explanations for the symptoms by a full history, complete physical examination, and laboratory investigations. The minimum requirement for the investigations include: a full blood count, markers of inflammation (ESR or CRP), renal, liver and thyroid function tests, as well as a random blood sugar, and a urinalysis.

In terms of aetiology, the only scientifically-recognised trigger for the onset of a chronic fatigue syndrome is an acute infection[3, 6]. The mechanism of disease remains unknown.

2. *What is the impairment, if any?* ***Note:*** *The term "impairment" has been interpreted in this context to mean a loss of, or damage to, a physical, sensory or mental function – see Mulligan and NDIA [2014] AATA 374 at [19]*

I have noted "impairment" has been interpreted in this context to mean a loss of, or damage to, a physical, sensory or mental function, and that the words "disability" and "impairment" are not defined in the NDIS Act or Rules, but that "impairment commonly refers to a loss of, or damage to, a physical, sensory or mental function".

Given this background, I would suggest that loss of, or reduction in, normal physical or mental capacity as a result of a diagnosed illness meets the criteria for impairment. Consider by comparison another syndromal diagnosis – schizophrenia, which when chronic and unresponsive to treatment may result in a major reduction in mental function (and presumably support from the NDIS).

If this approach is accepted, then it is clear that patients with chronic fatigue syndrome are impaired in both physical and mental (cognitive) domains of functioning.

3. *What medical and allied health specialties are involved in:*
   a. *diagnosis; and*
   b. *treatment?*

The diagnosis of chronic fatigue syndrome is made either in general practice, or in specialty practice. For the latter, the most common sub-specialties include: infectious diseases, immunology, rheumatology, and psychiatry. As the diagnostic process requires confident positive recognition of the key symptoms of fatigue, neurocognitive disturbance, and unrefreshing sleep, as well as reliable exclusion of alternative medical and psychiatric possibilities, many general

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practitioners are not confident in making the diagnosis – despite the expert recommendations that they should be able to do so[5]. In my opinion, in cases being considered by the NDIS, it may be reasonable to enforce an expectation that the diagnoses be affirmed by both a specialist physician and psychiatrist.

Despite more than 100 randomised controlled trials having been completed, there is no evidence-based curative treatment for chronic fatigue syndrome[3, 6, 7]. There are a myriad of proposed cures found on the internet, which have no credible evidence-base.

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.*

The only evidence-based management approaches which reduce symptom severity and impairment, include cognitive behavioural therapy (CBT) [8, 9], graded exercise therapy (GET)[10] and cognitive remediation[11, 12]. There are Australian data from an integrated service providing these interventions which support their effectiveness, but recognize that the benefits are incomplete (that is not everyone gains improvement), the magnitude is relatively modest, and may not be sustained[13].

5. *If this condition results from an impairment, what is the likelihood that this impairment will be permanent?* ***Note:*** *An impairment is, or is likely to be, permanent only if there are no known, available and appropriate evidence based treatments that would be likely to remedy (i.e. cure or substantially relieve) the impairment – see Rule 5.4 of the Rules.*

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[14]. 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.[5]

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

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of disability associated with chronic fatigue syndrome is commonly comparable to or greater than conditions such as rheumatoid arthritis [15]. 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.

6. *Are individuals suffering this condition likely to require lifelong support? If so, what types of supports are likely to be required?*

If the above criteria are met (i.e prolonged and severe disability attributable to chronic fatigue syndrome), the 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. The support may include items for practical support such as computers adapted for bed-based use.

7. Would symptom management through interventions such as medication, pain management, exercise programs etc. reduce the functional impact of the diagnosis and associated disability?

All simple interventions such as symptom-relieving medication for pain relief or sleep-promotion should already be in place as part of standard management. I have referred to the evidence base for graded exercise therapy above.

8. *How prevalent is the being diagnosed as a stand-alone condition as opposed to being diagnosed as part of co-morbidity?*

At least 50% of all patients with a chronic fatigue syndrome will develop co-morbid mood disorder (major depression, anxiety) during the course of the illness. This should be recognized and managed on its merits (if present) and the mood disorder will respond to interventions such as anti-depressant medication comparable to 'stand alone' major depression. It should be noted that there are multiple studies demonstrating the lack of efficacy of anti-depressant medication in patients with 'stand alone' chronic fatigue syndrome.

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18 January 2018

Ms Wendy s47F - pers
Acting Director
Technical Advisory Team- Operational Guidance
NDIA

Dear Ms s47F - perso

Request for expert information and advice - fibromyalgia

Thank you for your request, dated 22 December 2017, that I provide information and advice regarding fibromyalgia to the National Disability Insurance Agency (NDIA). This is a revised report that has been prepared after consideration of additional materials.

I note the "issues to consider" that you outlined. These, and my responses, are shown below.

This report is based on a review of the scientific literature. I conducted a systematic review and meta-synthesis to update the systematic review of Clauw (2014). The database, Medline, was searched using the terms "fibromyalgia" and "meta-analysis" from 2014 to current. This was to bring the search strategy of Clauw (2014) up to date.

My responses are:

1. What is the aetiology of fibromyalgia?

Fibromyalgia is a condition of generalized body pain without a known cause or cure (Fitzcharles et al 2013). Its aetiology is therefore unknown. It is hypothesised that certain people are more likely to experience chronic widespread pain. This is due to a combination of environmental and genetic influences (Clauw et al 2014). It is definitely more prevalent in women and men in a ratio of 2:1 (Clauw 2014).

2. *What is the impairment, if any?*

You have advised that "impairment" has been interpreted in this context to mean a loss of, or damage to, a physical, sensory or mental function – see *Mulligan and NDIA* [2014] AATA 374. This decision states that the words "disability" and "impairment" are not defined in the NDIS Act or Rules. It then goes on to state "Impairment commonly refers to a loss of, or damage to, a physical, sensory or mental function".

The central component of fibromyalgia is generalised pain. Pain is a sensory function. This is supported by the International Association for the Study of Pain's definition of pain as "An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such

damage (IASP 2017). The World Health Organisation's International Classification of Functioning, Disability and Health (ICF) defines generalized pain in similar terms "b2800 Generalized pain - Sensation of unpleasant feeling indicating potential or actual damage to some body structure felt all over, or throughout the body." (WHO 2017) .

Whether long standing generalized pain is seen as an impairment is open to conjecture. Taking the definition of impairment listed in the Mulligan decision there needs to be a loss or damage to a sensory function. It is not possible to detect damage to the body in people with fibromyalgia (Fitzcharles et al 2013). On this basis there is not loss or damage and thus there is no impairment.

The IASP and ICF definitions emphasise pain as a subjective experience that is associated with potential or actual tissue damage. Pain is classified as an abnormality of body function in the ICF (and thus is an impairment in the terms of that classification) but, in the context of the NDIS, it cannot be seen as an impairment given the requirement for actual tissue damage because this is not present in fibromyalgia.

While pain is the most important symptom in fibromyalgia, others "such as fatigue, nonrefreshed sleep, mood disturbance and cognitive impairment are common, but not universal" (Macfarlane et al 2017). These are also symptoms and are not associated with actual tissue damage.

3. *What medical and allied health specialties are involved in: a) Diagnosis; and b) Treatment of this condition?*

The recent clinical guidelines (Macfarlane et al 2017, Fitzcharles et al 2013) suggest that a definitive diagnosis of fibromyalgia, based on standardized criteria (Clauw 2014) should be made in primary medical care with a minimum of investigations. The most effective treatment is exercise, and health professionals involved with provision of exercise programs can be involved. Other allied health specialties may be involved in treatment, particularly psychologists if there are associated mental health conditions (Macfarlane et al 2017).

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.*

There are a variety of treatment options that are available. None of the Guidelines provide a measure of "likelihood of success of treatment" because this will be highly dependent on the group of people with fibromyalgia who are treated. Some groups of people with fibromyalgia, for example those assessed in primary medical care, will have substantially better responses to treatment than others, for example people assessed and treated by medical specialists or in specific settings, for example pain clinics.

The strength of evidence of effectiveness (GRADE) is the best approach to assessing the effectiveness of treatment. Using this method the recommendations are:

There is strong evidence of effectiveness for aerobic or strengthening exercise in the treatment of fibromyalgia. Weak evidence supports the use of non pharmacological treatments which are cognitive behavioural therapy, multicomponent therapies, defined physical therapies (hydrotherapy and acupuncture), meditative movement therapies (qigong, yoga, tai chi) and mindfulness-based stress

reduction. Weak evidence also supports the use of pharmacological treatments which are amitriptyline (in low dose), duloxetine, tramadol and pregabalin (MacFarlane et al 2017).

5. *If this condition results from an impairment, what is the likelihood that this impairment will be permanent?*

It is noted that impairment is, or is likely to be, permanent only if there are no known, available and appropriate evidence based treatments that would be likely to remedy (i.e. cure or substantially relieve) the impairment – as shown in Rule 5.4 of the Rules.

Fibromyalgia cannot be regarded as permanent because it is responsive to treatment (see above) and is likely to vary in intensity at different times due to a variety of factors.

A well conducted study has shown that most people continue to experience symptoms over a long period but approximately 25% improved in the long term (Walitt et al 2011). However, severity worsened in about 40%. Thus there is considerable variability in prognosis and responses to treatment. It should be noted that this study was conducted in patients of American rheumatologists and may represent a cohort of people with more severe fibromyalgia than those treated in primary healthcare settings.

Fibromyalgia cannot be considered permanent in the same way as many health conditions, because the underlying impairment is pain and this varies considerably over time and in response to treatments and life situations.

6. *Are individuals suffering this condition likely to require lifelong support? If so, what types of supports are likely to be required?*

Fibromyalgia is a form of chronic pain (that is pain that is present for more than three months of the previous six months). Chronic pain affects about 20% of the Australian population (Blyth et al 2001). Clearly almost all people with chronic pain do not require lifelong support.

Specifically, people with fibromyalgia do not require lifelong support and, indeed provision of this support is likely to be harmful to them. Fitzcharles et al (2013) summarise a fundamental component of assisting people with fibromyalgia as "the requirement that the health community focus toward maintaining and improving function of patients, with a call to temper the culture of disablement and medicalization that has become evident in recent years". While pain may interfere with daily activities to some extent the presence of pain is not a reason to avoid specific activities.

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?*

These are all treatments that have some evidence of effectiveness. Therefore they are likely to reduce the functional impact of fibromyalgia.

Contemporary clinical guidelines (Macfarlane et al 2017) recommend an approach of assessment and diagnosis in the setting of primary healthcare. If the diagnosis is established, patient education and provision of an information sheet is recommended. If that is insufficient, physical therapy with "individualized graded physical exercise" is the next step. If further treatment is required, the

recommendation is for further assessment and treatment. If psychological symptoms are prominent psychological therapies are recommended. If there is severe pain or sleep disturbance pharmacological therapy is recommended. If there is severe disability, a "multimodal rehabilitation program" is recommended (Macfarlane et al 2017). Thus there is a well established treatment guideline that is applicable in the condition and is likely to be effective in a significant proportion of people with fibromyalgia.

8. *How prevalent is the incidence of fibromyalgia being diagnosis as a stand-alone condition as opposed to being diagnosed as part of comorbidity?*

Fibromyalgia is frequently associated with other health conditions and adverse social circumstances and past adverse life events. Ten to 30% of people with fibromyalgia will have other rheumatological conditions and people with fibromyalgia more likely have psychiatric disorders, including depression, anxiety, obsessive-compulsive disorder, and posttraumatic stress disorder (Clauw et al 2014). These data suggest that about 20% to 40% of people with fibromyalgia will have another health condition that is relevant for how the fibromyalgia will be approached.

9. *Other comments*

There are clear risks for people with fibromyalgia in becoming involved in processes that involving proving that their disability is sufficiently severe to meet requirements for disability eligibility (Hadler 1996). Hadler discusses the "vortex of disability determination", which in his opinion, is clearly detrimental to the person with fibromyalgia, or chronic pain, more broadly.

Schweiger et al (2017) provide a worldwide review of trends in disability claims in fibromyalgia. They include Australia and note that Australian ICD-10- AM code for FMS is M79.7. They note that fibromyalgia "is not fully recognised worldwide, and patients often do not receive the treatment and disability benefits planned for other chronic diseases" (Schweiger et al 2017). However, their review concentrates on work disability claims and does not deal specifically with schemes such as the Australian National Disability Insurance Scheme.

I have noted Appendix A which sets out the disability requirements.

Yours sincerely,

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