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Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

This pathway uses the definition and diagnostic criteria for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) from the US National Academy of Medicine (NAM). Be aware other diagnostic criteria are in use. See also:

- Post-Covid-19 Long COVID
- Fibromyalgia
- Fatique

Background

About myalgic encephalomyelitis/chronic fatigue syndrome

About myalgic encephalomyelitis/chronic fatigue syndrome

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), is a chronic multi-system disease of variable and fluctuating severity and of uncertain aetiology. There is ample evidence of patho-physiological changes causing immunological, metabolic, neurologic, and autonomic dysfunction. There is no evidence the disorder is psychological, functional, or due to somatisation.

The cause of ME/CFS is not known. Recognised etiological factors or triggers include:

- Infection with viruses, bacteria, or protozoa (e.g., Epstein-Barr virus (EBV), influenza, COVID-19, giardia)
- Immunisation
- Physical trauma (e.g., surgery, motor vehicle accident)
- General anaesthesia
- Genetic susceptibility
- Major life stressors
- Environmental toxin exposure

The estimated prevalence of ME/CFS is 0.2 to 1% in Australia. It affects people of all ages. Peak incidence occurs in ages 11 to 19 years and 30 to 39 years. It is 3 times more common in girls or women. $\frac{4}{5}$

ME/CFS is a lifelong illness for the majority of patients, with no cure or specific treatment. Young people with ME/CFS have a more favourable prognosis than adults. $\frac{6}{3}$, $\frac{7}{3}$

Symptom severity can vary and fluctuate, and ranges from mild (50% reduction in premorbid functioning) to very severe (totally bedbound).

Patients often experience delayed or incorrect diagnosis for several years. Up to 90% of patients with symptoms meeting the diagnostic criteria remain undiagnosed.

The prevalence of anxiety and depression in ME/CFS is similar to that seen in any chronic illness.

ME/CFS is diagnosed based on clinical assessment criteria.

Common features are <u>post-exertional malaise (PEM)</u>, fatigue, sleep disturbances, cognitive difficulties, and orthostatic intolerance symptoms.

Post-exertional malaise (PEM)

- Significant worsening of fatigue and other symptoms after even minor physical, mental, or
 emotional exertion that is disproportionate to the activity, and would not have caused a problem
 before the illness.
- PEM onset can be immediate or delayed by hours or days following overexertion.
- PEM symptoms may last days or weeks after the activity, or sometimes even longer.
- PEM is not substantially relieved by normal amounts of rest.
- Sensory overload (light, sound, or touch), and orthostatic stress can induce PEM in some patients.

Other features can include muscle weakness, flu-like symptoms, temperature intolerance, pain, sensory sensitivities, neuroendocrine disturbances, immune system abnormalities, and cellular metabolism abnormalities.

Routine physical examination and investigations are frequently normal or non-specifically mildly abnormal (e.g., red throat, swollen lymph nodes), except for signs of orthostatic intolerance.

Cognitive behaviour therapy (CBT) and graded exercise therapy (GET) are not recommended treatments to treat the underlying ME/CFS but may be considered as adjunct therapies with caution, to address secondary sequelae of the condition.

Assessment

- 1. Ask about diagnostic features of ME/CFS:
 - post-exertional malaise (PEM). This is the hallmark symptom of ME/CFS.
 - the other diagnostic features of ME/CFS based on the US National Academy of Medicine
 (NAM) diagnostic criteria.
 ¹ Consider using the NAM Quick Reference Diagnostic Algorithm.

US National Academy of Medicine (NAM) diagnostic criteria

Diagnosis requires that the patient have the following 3 symptoms:

Fatigue and reduced functioning

Fatigue and reduced functioning

A substantial reduction or impairment in the ability to engage in pre-illness levels of activity (occupational, educational, social, or personal activities), that persists

for more than 6 months and is accompanied by fatigue, which is often profound, that is of new or definite onset (not life-long), is not the result of ongoing or unusual excessive exertion, and is not substantially alleviated by rest.

- Post-exertional malaise (PEM)*
- Unrefreshing sleep*

Plus at least one of the following two manifestations:

Cognitive impairment*

Cognitive impairment

Patients have problems with thinking, memory, executive function, and information processing, as well as attention deficit and impaired psychomotor functions. All can be exacerbated by exertion, effort, prolonged upright posture, stress, or time pressure, and may have serious consequences on a patient's ability to maintain a job or attend school full time.

Orthostatic intolerance

Orthostatic intolerance

Patients develop a worsening of symptoms upon assuming and maintaining upright posture as measured by objective heart rate and blood pressure abnormalities during standing, bedside orthostatic vital signs, or head-up tilt testing. Orthostatic symptoms including light headedness, fainting, increased fatigue, cognitive worsening, headaches, or nausea are worsened with quiet upright posture (either standing or sitting) during day-to-day life and are improved (though not necessarily fully resolved) with lying down. Orthostatic intolerance is often the most bothersome manifestation of ME/CFS among adolescents.

Symptoms must be present for ≥ 6 months.

* Frequency and severity of these symptoms should be assessed. The diagnosis of ME/CFS should be questioned if patients do not have these symptoms at least half of the time with moderate, substantial, or severe intensity.

Source: CDC – <u>Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: IOM 2015 Diagnostic Criteria</u>.

- 2. If a paediatric patient, consider also using the <u>clinical diagnostic worksheet</u>.
- 3. Ask about other common symptoms associated with ME/CFS.

Other common symptoms

- Nausea, altered appetite, irritable bowel syndrome (IBS) symptoms, abdominal pain
- Palpitations with or without cardiac arrhythmia
- Sensitivity to sound, light, touch, smell
- New sensitivities to food, medications, or chemicals
- Myalgia, joint pain, headaches, abdominal pain

- Urinary frequency
- Exertional dyspnoea
- Ataxia, muscle weakness, twitching and jerks
- Neuroendocrine symptoms:
 - Intolerance to heat and cold
 - Sweating, chills, hot flushes
 - Cold extremities
 - Low body temperature or low-grade fever
- Immune symptoms:
 - Swollen or tender lymph nodes
 - Recurrent sore throat
 - Recurrent flu-like symptoms
- 4. Assess severity of ME/CFS. Be aware severity sometimes fluctuates for unclear reasons.

Severity of ME/CFS

- Mild 50% reduction in pre-illness activity. May still work or study by reducing other activities, mobile and independent in activities of daily living (ADLS).
- Moderate mostly housebound, not working or studying, mobility and ADLs restricted, frequent rest periods required.
- Severe mostly bedridden, may be wheelchair dependent, minimal capacity for ADLs, significant cognitive difficulties.
- Very severe totally bedridden, dependent for all or most ADLs, extreme sensory sensitivities, severe pain, may need tube feeding, continence aids, or catheter.
- 5. Ask about <u>possible triggers</u> keep in mind symptoms may develop immediately after trigger, or appear gradually over the following weeks or months.

Possible triggers

- Infection with viruses, bacteria, or protozoa (e.g. Epstein-Barr virus (EBV), influenza, COVID-19, giardia)
- Immunisation
- Physical trauma (e.g. surgery, motor vehicle accident)
- General anaesthesia
- Genetic susceptibility
- Major life stressors
- Environmental toxin exposure
- 6. Take a further medical and social history. Pay particular attention to current support networks.

Support networks

Be aware that the quality of existing supports is a significant factor in a patient's ability to manage their condition. Ask about:

- family and friends, and other close relationships.
- social networks, religious communities, and work or school supports.
- any health professionals who are involved.

Medical and social history

- Work and school performance
- Diet, physical activity
- Sleep patterns
- Alcohol and drug use
- Relationships, social functioning
- · Headaches, generalised pain
- Anxiety, depression, other psychiatric history
- Family history of ME/CFS (genetic predisposition exists),
- Fibromyalgia, irritable bowel syndrome (IBS), and conditions that may cause fatigue e.g., auto-immune and thyroid disorders
- Medications including over-the-counter products
- 7. Consider differential diagnoses and common co-morbidities.

Common co-morbidities

 Orthostatic intolerance, including <u>postural orthostatic tachycardia syndrome (POTS)</u>, and <u>neurally mediated hypotension (NMH)</u> (very common in adolescents)

Neurally mediated hypotension (NMH)

Autonomic dysregulation of postural tone, with a drop in blood pressure and heart rate on assuming upright posture, causing lightheadedness or fainting, often associated with nausea, sweating and pallor.

Postural orthostatic tachycardia syndrome (POTS)

Abnormal increase in heart rate in the absence of orthostatic hypotension:

- heart rate increase of:
 - 30 beats per minute (bpm) or more in adults
 - 40 bpm or more in children and adolescents
- or heart rate over 120 bpm within the first 10 minutes of standing.
- often with associated dizziness, fainting.

- Gynaecological issues e.g., pelvic congestion syndrome, <u>dysmenorrhoea</u>, PMS
- Gastrointestinal issues e.g., <u>irritable bowel syndrome (IBS)</u>
- Food intolerances, aphthous ulcers, nausea
- Allergies commoner than in the general population e.g., mast cell activation syndrome
- Oral and dental issues e.g., dry mouth, caries, bruxism, temporomandibular joint (TMJ) dysfunction
- Hypermobility connective disorders e.g., Ehlers-Danlos syndrome (roughly 60% of ME/CFS patients versus 20% in the general population)
- Fibromyalgia
- <u>Depression</u> and <u>anxiety</u> common in chronic illness

Differential diagnoses

- Fibromyalgia
- Obstructive sleep apnoea (OSA)
- Long COVID
- Multiple sclerosis
- Iron deficiency
- Anaemia
- Thyroid disorders
- Diabetes mellitus
- Cardiopulmonary disease
- Primary adrenal insufficiency (Addison's disease)
- Coeliac disease, food allergy
- Eating disorder
- Depression
- Orthostatic intolerance, including <u>postural orthostatic tachycardia syndrome (POTS)</u>, and <u>neurally mediated hypotension (NMH)</u>
- Autoimmune disorders e.g., <u>systemic lupus erythematosus (SLE)</u>, <u>inflammatory arthritis</u>, <u>polymyalgia rheumatica (PMR)</u>

8. Examination:

- Keep in mind that the patient may not look unwell, and examination may be normal once any triggering illness has resolved.
- Check height, weight, and BMI.
- Check <u>vital signs</u>.

Vital signs

- Temperature relative hypothermia, low-grade fever
- Lying or sitting and standing heart rate and blood pressure resting or orthostatic tachycardia, hypotension

Consider further assessment of <u>orthostatic intolerance</u> using the <u>NASA 10 Minute Lean Test</u>.

Orthostatic intolerance

Inability to tolerate upright position due to symptoms such as dizziness, fainting, nausea, sweating. Includes:

- Neurally mediated hypotension (NMH)
- Postural orthostatic tachycardia syndrome (POTS)
- Check for:
 - Cold extremities, dependent rubor, pallor, suborbital dark shadows.
 - Tender palpable cervical lymph nodes, non-exudative pharyngitis with "crimson crescents".
- Look for signs of <u>alternative diagnoses</u>.
- Perform a neurological examination.
- Assess cognitive function.

Cognitive function

Ask about brain fog, word-finding difficulties, difficulty multitasking, reduced concentration and memory. Consider using clinical tools. See:

- General Practitioner Assessment of Cognition (GPCOG).
- The Cognitive Failures Questionnaire.
- Consider formal mental state assessment.

Mental state assessment

- Aim to distinguish between:
 - normal emotional reactions to chronic illness (grief, anger, apprehension, frustration),
 - depression or anxiety secondary to ME/CFS
 - primary psychiatric illness as a differential diagnosis e.g., major depressive disorder (MDD), school refusal
- Be aware that a patient with depression or anxiety will often feel better after increased activity, while a patient with ME/CFS will have <u>post-exertional malaise</u> (<u>PEM</u>).
 - ME/CFS patients are usually motivated but unable to be more active socially or physically, while patients with depression usually lack motivation and interest.

- Anhedonia, feeling worthless, and low self-esteem are features of depression but not ME/CFS.
- 9. Consider baseline <u>investigations</u> as indicated by history and examination.

Investigations

- FBE
- ESR, CRP
- Fasting glucose or HbA1c
- Urea and electrolytes
- Liver function tests
- Calcium, phosphate
- Iron studies
- TSH
- B12. folate
- Urinalysis
- Coeliac antibodies
- Keep in mind ME/CFS is a clinical diagnosis and tests are often normal. Use clinical judgement to arrange other possible investigations.

Other possible investigations

- Antinuclear antibodies (ANA)
- Rheumatoid factor, anti-cyclic citrullinated peptide (anti-CCP)
- Creatinine kinase (CK),
- 9 am cortisol (suspected Addison's disease)
- Vitamin D
- Specific infection serology if indicated clinically e.g., HIV, Epstein-Barr virus (EBV)
- ECG, holter monitor, echocardiogram, tilt table test (orthostatic intolerance symptoms)
- Sleep studies (suspected <u>obstructive sleep apnoea (OSA)</u> or other sleep disorders)
- Avoid performing multiple serological investigations. 8

Management

Practice point

Be cautious with exercise programs

Be aware there is currently is a lack of consensus on the place of exercise in ME/CFS, due to concerns it has the potential to cause unintended harm. $\frac{4}{}$

Individualised exercise programs can play a role in improving functional capacity for some patients. Any guided exercise program should be conducted within the patient's existing energy capacity, be carefully monitored and include discussion of possible risks.

- 1. Consider non-acute general medicine referral, or non-acute paediatric medicine referral if:
 - there is uncertainty about the diagnosis
 - chronic fatigue is associated with:
 - weight loss or faltering growth.
 - fevers.
 - abnormal tests including anaemia.
 - the patient is housebound or bedbound.
 - there is inadequate response to management.
- 2. If significant orthostatic intolerance, consider <u>non-acute cardiology referral</u> or <u>non-acute paediatric</u> medicine referral.
- 3. Discuss the diagnosis and provide education about ME/CFS.

Education

ME/CFS is a chronic illness with no cure or specific treatment available at this time.

- For most adults, it is a lifelong illness. A small percentage fully recover.
- Recovery is more likely in children and young people, but often takes years.
- Fluctuations in severity and relapses are common.
- No effective treatment options have been shown to alter the course of ME/CFS.
- Initial management with enforced rest improves prognosis the most.

Provide educational resources for patients:

- Emerge Australia <u>Homepage</u>
- Centers for Disease Control and Prevention (CDC) <u>Myalgic Encephalomyelitis/Chronic Fatique Syndrome</u>
- 4. Develop an individualised management plan based on general principles of ME/CFS management.

General principles

- Acknowledge and validate the patient's symptoms and lived experience.
- Take time to develop a strong therapeutic relationship by reviewing regularly.
- Involve family and support people where appropriate and if desired by the patient.
- Be clear that the goals of treatment are:
 - prevention or minimisation of <u>PEM</u>.
 - symptom relief.
 - improved quality of life.
- Tailor management by prioritising symptoms that are most troubling for the patient. Ask the patient to consider using an <u>activity diary</u>.

- Offer telehealth appointments and keep in mind home visits may be necessary for a severely affected patient.
- Provide written notes after consults to counter cognitive difficulties.
- Consider referral to Emerge Australia's <u>patient support team</u> or their <u>Telehealth nurse</u> <u>service</u> for further management strategies and support.

Emerge Australia's patient support team

- Phone 1800-865-321
- Email information@emerge.org.au
- 5. Be proactive in arranging supports:
 - <u>Taxi program application</u>, <u>community transport</u>
 - Accessible parking permit
 - Centrelink medical certificates/disability support pension application. Consider using the WHO Disability Assessment Schedule 2.0 (WHODAS 2.0) as supporting documentation.
 - NDIS application (general practitioner documentation such as WHODAS 2.0, FACIT-Fatigue functional assessment, and a patient-recorded activity diary can help with this)
 - Medical cooling concession
 - Advance care planning

With permission, educate workplace or school personnel about ME/CFS and liaise to develop an educational attendance or workplace capacity plan.

- 6. Consider specific management strategies:
 - Pacing, rest, and energy management

Pacing, rest, and energy management

- See Emerge Australia <u>Pacing</u>.
- Help the patient to:
 - identify the relationship between specific activities (physical and cognitive) and symptoms, rather than following a strict activity schedule.
 - balance energy spent on social, physical, cognitive, and academic or work
 activities with adequate rest, to minimise or avoid <u>post-exertional malaise</u>
 (<u>PEM</u>). In young people especially, recognise the importance of balancing
 social, physical and academic activities, rather than prioritising only
 education.
- Discuss strategies with the patient that are useful for managing activity levels:
 - Keeping activity or symptom diaries, pacing apps.
 - Using tools to monitor or save energy e.g., step counters, heart rate monitors, shower chairs, disabled parking permits, electric scooters.
 - Dividing activities into smaller tasks with rest breaks in between.

- Alternating between cognitive and physical tasks.
- Observing the body for signs that more rest is needed e.g., muscles becoming fatigued, higher resting heart rate.

• Cognitive difficulties

Cognitive difficulties

- Use lists or devices for daily tasks and planning
- Plan cognitive activities and allow for rests
- Use caution with stimulants e.g., caffeine

Sleep disturbance

Sleep disturbance

Advise the patient:

- on sleep hygiene principles. Keep in mind this alone is usually not adequate.
- to minimise or avoid caffeine, energy drinks, alcohol, and smoking.
- if hypersomnia, to ensure adequate hydration and nutrition during waking hours.
- to avoid electronic screens (TV, devices) before and after bedtime.
- to pace daytime activities to avoid <u>PEM</u>, as PEM can interfere with sleep
- on sleep medication options

Sleep medication

Trial medication using the principle of start low, go slow:

- melatonin
- low-dose tricyclic antidepressant (TCA) e.g., amitriptyline (can worsen orthostatic intolerance)
- benzodiazepines e.g., temazepam, clonazepam (low doses only at night are unlikely to lead to psychological dependence in ME/CFS)

If pain interferes with sleep, consider a trial of simple analgesics at bedtime. For specific paediatric advice on pain management, see Frontiers in Pediatrics – ME/CFS in Young People Primer: Management and Treatment.

• Orthostatic symptoms

Orthostatic symptoms

Advise the patient to:

- Avoid:
- standing in hot or humid environments (e.g., hot showers use shower chair).
- sudden rising from lying down or sitting.

- prolonged sitting or standing.
- large meals, too much alcohol.
- rapid weight loss regimens.

Advise:

- drinking 2 to 3 litres of water daily, at regular intervals throughout the day.
- adequate sodium in diet e.g., salting meals, using electrolyte drinks, salt tablets (suggested target 10 g per day for an adult).
- eating regularly with 3 meals and snacks.
- raising feet when seated.
- raising head of bed.
- physical counter manoeuvres when sitting or standing e.g., squatting, muscle tensing, leg crossing.
- wearing medical compression stockings and garments.

Be aware medications such as fludrocortisone (with potassium supplementation), beta blockers, and ivabradine can be used. Specialist advice is recommended before prescribing.

Pain management

Pain management

- · Pain management strategies can include:
 - simple analgesics, stretching, heat packs (caution with heat in orthostatic intolerance).
 - physiotherapy, massage (home-based if needed, and with caution as touch can trigger <u>PEM</u> in some patients).
 - cognitive behavioural therapy (CBT), particularly if stress or mood disturbance present, meditation, mindfulness exercises.

Be aware low dose naltrexone is currently being evaluated and used off-label as a treatment for ME/CFS pain.

- If pain is inadequately managed despite several strategies, consider:
 - chronic or persistent pain referral
 - non-acute paediatric medicine referral.

Keep in mind this often requires long and/or regular attendances so may not be achievable for a patient with ME/CFS.

- 7. Consider referring for <u>psychological therapy</u> to help manage impact of chronic illness and/or associated anxiety and depression. Psychological therapy can be helpful in coping with chronic illness, fatigue, pain and sleep difficulties, and associated mental health issues.
- 8. Tailored exercise should be considered with caution and be implemented within the patient's energy capacity with ongoing evaluation.
 - Exercise can cause <u>PEM</u> and may worsen symptoms.

Do not give generic exercise advice e.g., join a gym, go for a daily walk.

Only if patient consents and is already successfully pacing and minimising or avoiding <u>PEM</u>, consider referral to an <u>exercise physiologist</u> or <u>physiotherapist</u> with experience in ME/CFS for an individualised activity program. Inappropriate exercise advice may lead to significant harm by worsening of symptoms long term.

- If patient reports worsening symptoms and increased episodes of <u>PEM</u> following commencement of a tailored exercise program, reconsider the appropriateness of this intervention or if still indicated, amend the program and/or refer to a more experienced exercise therapist.
- Regular evaluation of this intervention is recommended to avoid symptom and functional deterioration.
- 9. Consider home-based <u>physiotherapy assessment</u> or <u>occupational therapy assessment</u>:
 - for bed-bound patients to manage risk of pressure sores and maintaining range of motion.
 - if concerned about the patient's level of independence in daily living.
 - if in need of advice about managing symptoms.

Keep in mind that simple treatment can trigger <u>PEM</u> in this group.

10. Provide advice about diets and supplements. Request dietitian assessment if:

Diets and supplements

Discuss patient-initiated diets and supplements. Many patients with ME/CFS try elimination diets, which can be restrictive, expensive, and have no evidence base. Some patients report improvement following low FODMAPs or gluten-free diets.

There is no evidence that supplements are useful for patients with healthy nutrition, however those commonly taken include:

- magnesium for nocturnal cramps
- co-enzyme Q10 for muscle fatigue
- B12 injections
- vitamin D and C
- probiotics.
- the patient has unintentional weight loss.
- concerned about the patient's nutritional intake.
- 11. Provide immunisation advice.

Immunisations

There is a lack of high quality research in the area of immunisation and ME/CFS. Most patients with ME/CFS tolerate standard immunisations. A small number experience worsening of symptoms.

- Consider timing recommended immunisations when the patient is relatively well, followed by 2 to 3 days of rest.
- Weigh up the risks and benefits for the patient based on severity of ME/CFS and risks to health of catching vaccine-preventable diseases (e.g., influenza infection can trigger serious relapses, HPV and hepatitis B immunisation are important for long term health).

- After the COVID-19 vaccination, some patients have reported worsening symptoms and a small number have reported improvement to their health. Be aware there are significant numbers of reported adverse effects in placebo arms of COVID-19 vaccine trials.
- Consider vaccinating family members to help protect the patient.
- 12. Identify and treat <u>common co-morbidities</u> this can significantly improve the patients quality of life and overall wellbeing.
- 13. Arrange <u>regular follow-up appointments</u> to provide ongoing support, to monitor progress, and to provide <u>opportunistic recommended healthcare and screening</u>.

Opportunistic recommended health care and screening

Use regular follow-up appointments to ensure regular health care is not neglected:

- Cervical screening
- Sexual health screening
- Breast cancer screening
- Bowel cancer screening
- Cardiovascular risk assessment
- 45 to 49 year old health check
- Skin check

Arrange regular follow-up appointments

- Review adult patients at least once a year after initial investigation and supports are in place.
- Review children at least every 6 months for review of current symptoms, to monitor symptom severity, and ensure approaches to education and social development remain optimal.
- Consider 3-monthly follow-up to detect:
 - new symptoms. Advise the patient to report any worsening or new symptoms. The range of symptoms and fluctuations typical of ME/CFS can make identifying differential diagnoses and co-morbidities difficult.
 - deteriorating social or psychological health.
- Consider using tools such as <u>WHODAS 2.0</u>, a patient-recorded <u>activity diary</u>, and <u>FACIT-Fatigue</u> to monitor symptom severity and to maintain supporting documentation for applications such as NDIS and pensions.
- Be aware patients may not be able to attend the clinic due to illness severity, or may suffer from <u>PEM</u> following appointments.
- Use telehealth, consider home visits, or arrange for the patient to lie down if waiting in the clinic.

Referral

- Consider non-acute general medicine referral, or non-acute paediatric medicine referral if:
 - there is uncertainty about the diagnosis.
 - chronic fatigue is associated with:
 - weight loss or faltering growth.
 - fevers.
 - · abnormal tests including anaemia.
 - the patient is housebound or bed-bound.
 - there is inadequate response to management.
- Consider <u>non-acute cardiology referral</u> or <u>non-acute paediatric medicine referral</u> if significant orthostatic intolerance.
- Consider <u>chronic or persistent pain referral</u> or <u>non-acute paediatric medicine referral</u> if pain symptoms are prominent.
- Refer to Emerge Australia's <u>patient support team</u> or their <u>Telehealth nurse service</u> for management strategies and support.
- Consider referring for <u>psychological therapy</u> to help manage impact of chronic illness and/or associated anxiety and depression.
- Consider home-based <u>physiotherapy assessment</u> or <u>occupational therapy</u>:
 - for bed-bound patients to manage risk of pressure sores and maintain range of motion.
 - as part of pain management.
 - if concerned about the patient's level of independence in daily living.
 - if in need of advice about managing symptoms.
- Request dietitian assessment if:
 - the patient has unintentional weight loss.
 - concerned about the patient's nutritional intake.
- If the patient wishes to improve their physical activity, arrange an <u>exercise</u> <u>physiology</u> or <u>physiotherapy assessment</u>, with a practitioner experienced in ME/CFS.

Information

For health professionals

Education

Emerge Australia and ThinkGP – <u>GP Education Program – Module 1: Busting the Myths and Redefining Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)</u>

Further information

- Centers for Disease Control and Prevention (CDC) <u>Myalgic Encephalomyelitis/Chronic Fatigue Syndrome</u>: Information for Healthcare Providers
- Frontiers in Paediatrics <u>Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Diagnosis</u> and Management in Young People: A Primer
- FACIT-Fatigue Functional Assessment of Chronic Illness Therapy: Fatigue Scale

- Mayo Clinic <u>Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Essentials of Diagnosis and Management</u>
- National Academies of Medicine <u>Beyond Myalgic Encephalomyelitis/Chronic Fatigue</u> <u>Syndrome</u> [book, 2015]
- World Health Organization WHO Disability Assessment Schedule 2.0 (WHODAS 2.0)