

ME/CFS IN PRIMARY CARE

Guide to Assessment and Management

Myalgic Encephalomyelitis / Chronic Fatigue Syndrome

WHAT IS ME/CFS?

A long term multi-systemic illness, involving nervous, endocrine, autonomic, and immune systems.

Symptom severity ranges: *mild, moderate, severe.*

Triggers: viral or bacterial infections, toxic chemical exposure, physical or emotional trauma, anaesthesia, genetic predisposition.



DIAGNOSIS

Institute of Medicine Criteria:

Three primary symptoms must be present:

- **Post Exertional Malaise (PEM)**
- **Unexplained Fatigue**
- **Unrefreshing sleep**

Plus at least one of the following additional symptoms:

- **Orthostatic Intolerance**
- **Cognitive impairment**

Symptoms must be present for at least 6 months, moderate to severe, and present 50% of the time.

CO-MORBIDITIES

- Fibromyalgia (an overlapping condition)
- dysautonomia
- allergies
- irritable bowel syndrome (IBS)
- sleep disorders and
- multiple chemical sensitivities (MCS)

Symptoms of a number of diseases can mimic ME/CFS. Presence of PEM and symptom exacerbation increases likelihood of ME/CFS as the correct diagnosis.

SYMPTOM MANAGEMENT

A Personalised Patient-Centred Approach

Prioritise and tackle one symptom at a time.

- **Energy management** - Pacing: a self management technique to help support rehabilitation; balancing activity and rest to help reduce PEM.
- **Sleep** - sleep hygiene, medication, lifestyle changes.
- **Pain** - medication, lifestyle changes, referrals - pain clinics, physiotherapy, complementary therapies.
- **General health measures** - limit alcohol and caffeine, quit smoking, varied and balanced diet.
- **Regularly monitor and review symptoms.**
- **Stress management** - referrals - counselling, relaxation techniques (e.g. breathwork), and support groups.

CONTRAINDICATED

Graded exercise Therapy is no longer recommended for ME/CFS. Psychological intervention, such as CBT may be helpful for the psychological distress caused by having a long term chronic illness.

PACING

Pace, never push.

Everyone's available energy limits are unique and what one person with ME/CFS can do in a day may be very different from another person with ME/CFS.



ASSESSMENT

- Medical history, physical condition and lifestyle
- Ask the patient to describe their symptoms
- Consider physical, psychological and environmental factors
- Exclude other fatiguing illnesses - anaemia, autoimmune disease, cardiac disease, endocrine disorders, malignancy, rheumatological disorders, neurological disorders – (eg MS, Parkinsons), primary sleep disorder, depression etc.

EXAMINATION

Vital signs, Blood pressure, pain points, temperature, lymph node palpation, mobility (exclude hypermobility disorders). Cardiac, pulmonary, GI, and basic neurology, NASA Lean Test for dysautonomia, NMH, POTS.

INVESTIGATION

Bloods:

Full blood count, Liver function, Renal function, Electrolytes, Iron studies, Thyroid, B12, serum folate, calcium, CRP, ANA. Magnesium, and celiac antibodies (only if indicated by symptoms). Urinalysis.



CARE & SUPPORT PLANNING

- Educate patient on ME/CFS symptoms and prognosis.
- Assess individual circumstances and needs.
- Acknowledge the reality of living with ME/CFS to build an effective therapeutic relationship - recognise the patient may have experienced prejudice or disbelief.
- Provide written handouts of discussions/management plans.
- Provide work certificates, insurance support, and letters to employers, schools etc as required.
- Refer to local Health Pathways.
- Refer to specialists, physiotherapists, occupational therapists, counsellors etc. as required using a team centred approach.
- Refer to ANZMES for information & CME education.
- Refer to regional support groups.
- See current NICE guidelines & Clinicians Primer for additional information on best practice symptom management.



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