Presentation, diagnosis and pathway of care

CFS/ME is recognised on clinical grounds alone. Primary healthcare professionals should be able to identify the characteristic features of CFS/ME.

Person presents with symptoms that may indicate CFS/ME (see box 1)

Do an initial assessment
- Take a full history (including exacerbating and alleviating factors, sleep disturbance, intercurrent stressors).
- Examine the person.
- Assess their psychological wellbeing.

Reassess and seek advice
- If symptoms of an apparently self-limiting condition do not resolve, listen to the concerns of the person and their family and/or carers and reassess.
- If CFS/ME or another serious condition is possible, discuss with a specialist any uncertainty about the interpretation of signs and symptoms, and the need for referral.

Arrange investigations
- Investigate symptoms listed in box 2 before attributing them to CFS/ME.
- Consider other investigations according to symptoms (see box 3, page 8).

Manage symptoms
- Give tailored advice on managing symptoms, aiming to minimise their impact on daily life.
- Do not delay advice until diagnosis.

Refer
- Refer a child or young person to a paediatrician for assessment (as in boxes 2 and 3) within 6 weeks of presentation.

Offer referral to specialist CFS/ME care
- If the person has severe CFS/ME symptoms, offer referral immediately.

Make the diagnosis
- In adults: if symptoms have lasted 4 months and other diagnoses have been excluded.
- In children and young people: if symptoms have lasted 3 months and other diagnoses have been excluded; diagnosis is made or confirmed by a paediatrician.
- Reconsider if none of the features in box 4 (page 8) are present.

Follow general principles of care (see page 9)

Start general management (see page 11)

Plan for and manage setbacks/relapses (see page 15)

Arrange regular review (see page 16)

Consider referral to specialist CFS/ME care
- Offer referral:
  - within 6 months of presentation to people with mild CFS/ME
  - within 3–4 months of presentation to people with moderate CFS/ME symptoms.
- Make any decision to refer jointly with the person, depending on their symptoms and any comorbidities.
- Continue primary care involvement after referral.

Specialist CFS/ME care (see pages 17–20)

● Work in partnership with the patient ● Mutually agree all treatments and changes to them

Box 1 Symptoms that may indicate CFS/ME

Consider the possibility of CFS/ME if a person has:

- fatigue with all of the following features:
  - new or had a specific onset (that is, it is not life long)
  - persistent and/or recurrent
  - unexplained by other conditions
  - has resulted in a substantial reduction in **activity** level characterised by post-exertional malaise and/or fatigue (typically delayed, for example by at least 24 hours, with slow recovery over several days)

and

- one or more of the following symptoms:
  - difficulty with sleeping, such as insomnia, hypersomnia, unrefreshing sleep, a disturbed sleep–wake cycle
  - muscle and/or joint pain that is multi-site and without evidence of inflammation
  - headaches
  - painful lymph nodes without pathological enlargement
  - sore throat
  - cognitive dysfunction, such as difficulty thinking, inability to concentrate, impairment of short-term memory, and difficulties with word-finding, planning/organising thoughts and information processing
  - physical or mental exertion makes symptoms worse
  - general malaise or 'flu-like' symptoms
  - dizziness and/or nausea
  - palpitations in the absence of identified cardiac pathology.

The symptoms of CFS/ME fluctuate in severity and may change in nature over time.

Box 2 Consider other diagnoses or comorbidities before attributing clinical features to CFS/ME

In particular, investigate these 'red flag' features:

- localising/focal neurological signs
- signs and symptoms of inflammatory arthritis or connective tissue disease
- signs and symptoms of cardiorespiratory disease
- significant weight loss
- sleep apnoea
- clinically significant lymphadenopathy.

Follow 'Referral guidelines for suspected cancer' (NICE clinical guideline 27) or other NICE guidelines as the symptoms indicate. See www.nice.org.uk for details.

Box 3 Investigations

These tests should usually be done:

- urinalysis for protein, blood and glucose
- full blood count
- urea and electrolytes
- liver function
- thyroid function
- erythrocyte sedimentation rate or plasma viscosity
- C-reactive protein
- random blood glucose
- serum creatinine
- screening blood tests for gluten sensitivity
- serum calcium
- creatine kinase
- assessment of serum ferritin levels (children and young people only).

Use clinical judgement to decide on additional tests to exclude other diagnoses.

Do not do:

- tests for serum ferritin in adults, unless other tests suggest iron deficiency
- tests for vitamin B_{12} deficiency or folate levels, unless a full blood count and mean cell volume show a macrocytosis
- serological testing, unless there is an indicative history of an infection; if so, consider tests for:
  - chronic bacterial infections, such as borreliosis
  - chronic viral infections, such as HIV or hepatitis B or C
  - acute viral infections, such as infectious mononucleosis (heterophile antibody tests)
  - latent infections, such as toxoplasmosis, Epstein–Barr virus or cytomegalovirus.

Do not do the following tests routinely:

- the head-up tilt test
- auditory brainstem responses
- electrodermal conductivity.

Box 4 Reconsider the diagnosis of CFS/ME

- Reconsider the diagnosis if the person has none of the following symptoms:
  - post-exertional fatigue or malaise
  - cognitive difficulties
  - sleep disturbance
  - chronic pain.