Chronic fatigue syndrome and myalgic encephalopathy (CFS/ME) - suspected

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1 Background information

Quick info:

Scope:
- diagnosis and management of chronic fatigue syndrome and myalgic encephalopathy (CFS/ME)

Out of scope:
- this pathway does not cover fibromyalgia

Definition:
- this is a condition where there are a great many conflicting opinions. This even extends to the name of the condition. For the purpose of this pathway it is referred to as Chronic fatigue syndrome/myalgic encephalopathy although it is acknowledged that fatigue is only part of the symptom complex and some researchers regard the term encephalopathy as inaccurate. In the development of this pathway the best available evidence has been drawn upon although there are apparent contradictions within the literature
- CFS/ME is clinically unexplained, persistent or relapsing fatigue lasting more than 4 months in adults and 3 months in children and young people.

The stages in the course of CFS/ME are:
- acute illness
- maintenance or stabilisation
- recovery or remission

Incidence and prevalence:
- prevalence of 0.2-0.4% in UK population
- prevalence of 0.07-1% in school children in UK
- primarily occurs in young to middle aged adults
- twice as common in female patients
- it has been less commonly recognised in children and the elderly. It can affect both sexes at any age from any ethnic group.

Prognosis:
- most CFS/ME symptoms improve gradually:
  - some people will recover and others will continue to experience symptoms
  - CFS/ME duration may be shorter in primary care and in children
  - degree of functional disability and the presence of psychiatric disorder (rather than severity or number of symptoms) may predict poor outcome
  - patients who do not show rapid improvement tend to have prolonged CFS/ME
- most favourable prognostic features are:
  - younger age, especially under age 20 years
  - less severe symptoms
  - shorter duration of untreated symptoms

References:
2 Information resources for patients and carers

Quick info:
Useful websites:

- NHS Clinical knowledge summaries : chronic fatigue syndrome patient information leaflet
- NHS Direct Wales patient information on chronic fatigue syndrome/myalgic encephalopathy
- ME Association
- Action for ME

4 Clinical features

Quick info:
Features are non-specific.
Consider the possibility of CFS/ME if a person has the key symptoms:

• fatigue with all of the following features:
  • new or had a specific onset (that is it is not lifelong)
  • 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:
  • unrefreshing or disturbed sleep
  • muscular or joint pain without evidence of inflammation
  • headache
  • painful lymph nodes without pathological enlargement
  • recurrent sore throat
  • cognitive dysfunction such as difficulty word finding, planning/organising thoughts and information processing, impaired short-term memory and concentration span
  • 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

May be associated with:

• generalised muscle weakness
• altered bowel habit and irritable bowel syndrome (IBS)
• chemical sensitivities
• intolerances – including alcohol and caffeine
• pins and needles
• subjective peripheral pain and numbness
• photophobia
• excess sweats, feverish
• rash

NB: Any associated features that suggest other serious conditions should be investigated as appropriate.

CFS/ME severity can be divided into:
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- severe, where people:
  - are unable to do activity for themselves or can only do small tasks, eg cleaning teeth
  - have severe cognitive difficulties
  - are often unable to leave the house or have severe and prolonged effects if they do
  - may spend most of their time in bed
  - often depend on wheelchair for motility
  - are often extremely sensitive to light and noise
  - referral to a specialist should be offered immediately for adults or children

- moderate, where people:
  - have reduced mobility and restricted ability to perform daily tasks (with peaks and troughs)
  - usually have stopped work or education
  - need rest periods
  - have poor sleep
  - adults should be referred to a specialist after 3 months

- mild, where people can:
  - care for themselves
  - do light domestic tasks with difficulty
  - mostly continue in work or education but often take days off; and
  - leisure and social pursuits have probably stopped
  - adults should be offered referral to a specialist after 6 months

- a child or young person who has symptoms suggestive of CFS/ME should be referred to a paediatrician for assessment to exclude other diagnoses within 6 weeks of presentation (see special considerations in young patients)

References:

5 History

Quick info:
History:
  - ask about both physical and mental activity (tasks involving concentration, planning, memory, sustained or switching of attention) and the effect of activity on fatigue
  - distinguish fatigue from somnolence and muscle weakness
  - assess for symptoms of psychological disorder, eg depression, anxiety, eating disorders
  - assess quality of personal, social and occupational functioning
  - assess for sleep disorders such as sleep apnoea
  - establish if sleep improves symptoms
  - assess appetite and diet
  - ask about weight loss
  - exacerbations and relieving factors
  - ask about fluctuation of symptoms
  - establish drug history, including over the counter medicines, supplements, alternative and herbal medicines
  - establish for current or prior substance abuse
  - establish if the patient has a history of polio
  - a person's understanding of and response to their illness

References:
6 Health professional-patient relationship

Quick info:
The health professional-patient relationship is important to help patients cope and facilitate access to help. Shared decision making between the person with CFS/ME and health professionals should take place during diagnosis and all phases of care.

The following may help to maintain and improve the relationship:

- listening carefully and showing understanding of the patient's symptom complex
- engaging with the family and teachers for children and young people, and for those with severe CFS/ME
- for children and adolescents consider specialist referral to a paediatrician within 6 weeks of presentation
- acknowledging and advising:
  - symptom complex is real and debilitating
  - severity is variable, often incapacitating
  - normal tests are expected but do not invalidate the reality of disease
  - CFS/ME is a well defined syndrome but psychological factors are important
- attendance at surgery may be difficult if symptoms are severe so it may be necessary to provide domiciliary services (including specialist assessment) or use methods such as telephone or email
- psychological factors:
  - such as depression can be a consequence of developing CFS/ME (or the physical or social consequences such as loss of independence, job)
  - may affect how the patient copes with CFS/ME

Consider education and reassurance:

- education brochures and self help books
- information on patient support groups
- time and space for discussion

Develop individualised management plan with the patient and include:

- relevant symptoms and history
- plans for care and treatment
- information and support needs
- education, training or employment support needs
- details of the healthcare professionals involved in care
- it may be useful to offer a summary record of every consultation to people with CFS/ME

References:

7 Special considerations in young patients

Quick info:
Specific considerations in young patients include:

- effects of disorder and management on psychological development:
  - self perception and body image
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• socialisation
• family life
• schooling
• effects on physical development:
  • chronic fatigue syndrome and myalgic encephalopathy (CFS/ME) may lead to poor diet and dietary deficiencies
• urgent referral if severe symptoms present

For children and adolescents consider specialist referral – NICE guidance recommends referral to a paediatrician within 6 weeks of presentation.

Consider managing children and adolescents within a community based multidisciplinary team coordinated by a paediatrician or relevant specialist that includes:

• GP
• paediatric nurse
• physiotherapist
• occupational therapist
• social worker
• child psychiatrist or psychologist
• educational psychologist
• CAMHS (child and adolescent mental health services)
• dietician
• school nurse
• school counsellor
• special education needs coordinators

References:

8 Examination

Quick info:
Full physical examination including:
• general appearance
• weight
• height and head circumference (in children)
• developmental and growth history (in children)
• mental state examination
• temperature
• lymphadenopathy
• spleen and liver enlargement (in children)
• signs of cardiac or respiratory disease
• signs of abnormal thyroid status
• neurological assessment – assess also muscle bulk, tone and strength

References:
9 Consider differential diagnoses

Quick info:
Many conditions may present with symptoms similar to chronic fatigue syndrome and myalgic encephalopathy (CFS/ME) which may also co-exist with other chronic disorders.

The following are common but not exhaustive differentials:

- anaemia
- autoimmune disorders:
  - lupus
  - rheumatoid arthritis (RA; see 'Rheumatoid arthritis' pathway)
- cardiopulmonary:
  - chronic cardiac failure
  - chronic pulmonary disease
  - obstructive sleep apnoea (see 'Obstructive sleep apnoea' pathway)
- drug use:
  - antihypertensive agents, especially beta blockers
  - hypnotics
  - antidepressants
  - thyroxine
  - alcohol or drug abuse
  - alcoholism
- endocrine and metabolic disorders:
  - hypothyroidism (see 'Hypothyroidism' pathway)
  - apathetic hyperthyroidism
  - pituitary insufficiency
  - adrenal insufficiency
  - renal and liver decompensation
  - diabetes mellitus (see 'Diabetes' pathway)
  - hypercalcaemia (see 'Hypercalcaemia' pathway)
- gastrointestinal disorders:
  - inflammatory bowel disease (IBD)
  - coeliac disease (see 'Coeliac disease' pathway)
- immunodeficiencies
- infections:
  - infectious mononucleosis
  - viral hepatitis
  - cytomegalovirus (CMV)
  - infective endocarditis (see 'Infective endocarditis' pathway)
  - tuberculosis
  - HIV infection (see 'HIV' pathway)
- inflammatory arthritis or connective tissue disease
- neurological and neuromuscular disorders:
  - multiple sclerosis (MS; see 'Multiple sclerosis' pathway)
  - muscular dystrophy (see 'Muscular dystrophy' pathway)
  - post-polio syndrome (PPS; see 'Post-polio syndrome' pathway)
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- occult malignancy
- psychiatric and psychological disorders:
  - anxiety
  - depression
  - somatisation disorders
  - bipolar disorders
  - eating disorders
  - organic brain disease
  - sleep deprivation

Reference:

10 Seek advice on possible diagnosis

Quick info:
If CFS/ME is suspected as a possible diagnosis it may be appropriate to seek advice from a specialist. This may be by telephone rather than a formal referral.

11 Investigations to rule out other conditions

Quick info:
CFS/ME cannot be diagnosed by any test currently available.

To rule out possibility of other conditions do the following:
First-line testing:
- urinalysis:
  - protein
  - blood
  - glucose
- full blood count (FBC) with differential count
- erythrocyte sedimentation rate (ESR)
- plasma viscosity (PV)
- C-reactive protein (CRP)
- blood biochemistry:
  - blood glucose
  - sodium and potassium
  - serum calcium and phosphate levels
  - serum creatinine
  - creatine kinase (raised in some myopathies)
- anti-endomysial antibodies to exclude coeliac disease
- urea and electrolytes
- thyroid function tests (T4 and TSH) thyroid peroxidase antibodies
- liver function tests (LFTs)
- serum ferritin levels (children and young people only)
- Epworth sleepiness scale

If symptoms or signs raise suspicion, consider from the following:
- test for infectious mononucleosis
- serum ferritin levels in adults if tests suggest iron deficiency
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• vitamin B12 and folate if macrocytosis identified
• Lyme disease serology
• immunoglobulins and serum electrophoresis
• serological tests for:
  • hepatitis B and C, HIV, cytomegalovirus, tuberculosis, borreliosis
• currently no indication for routine brain CT scan, magnetic resonance image (MRI) or single photon emission computed tomography (SPECT) scanning

Reference:

12 Negative or insignificant results for conditions other than CFS/ME

Quick info:
If clinical features are present and no other abnormalities detected then assume diagnosis for chronic fatigue syndrome/ME

14 Manage accordingly

Quick info:
See relevant pathway according to results.

15 Diagnosis of CFS/ME confirmed

Quick info:
Confirm diagnosis of chronic fatigue syndrome and myalgia encephalopathy (CFS/ME) if the patient has the following for more than 4 months in an adult or 3 months in a child or young person:
• fatigue with all of the following features:
  • new or had a specific onset (ie not lifelong)
  • 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 that is typically delayed, eg at least 24 hours, with slow recovery over several days
  • and one or more of the following symptoms:
    • sleeping, eg insomnia, hypersomnia, unrefreshing sleep, a disturbed sleep–wake cycle
    • muscle and/or joint pain that is multi-site but no evidence of inflammation
    • headaches
    • painful lymph nodes without pathological enlargement
    • sore throat
    • cognitive dysfunction, eg:
      • difficulty thinking
      • inability to concentrate
      • impairment of short-term memory
      • 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
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CFS/ME symptoms will fluctuate in severity and may change over time.

References:

16 Review symptoms

Quick info:
- reassess symptoms
- do not delay advice on symptom management until diagnosis is established

17 Management of symptoms

Quick info:
- do not delay advice on symptom management until diagnosis is established
- if there are concerns about adverse/side effects of drug treatment, consider starting at the lower dose and increase gradually

18 Discharge if symptoms are resolved

Quick info:
If all symptoms are resolved discharge. However, if chronic fatigue syndrome/myalgic encephalopathy (CFS/ME) is still suspected continue to consider differential diagnoses. Also consider:
- urgent referral to a specialist if severe CFS/ME
- referral to a specialist after 3 months if moderate CFS/ME
- referral to a specialist after 6 months if mild CFS/ME
- a child or young person who has symptoms suggestive of CFS/ME should be referred to a paediatrician for assessment to exclude other diagnoses within 6 weeks of presentation

In addition consider the following further investigations:
- electrocardiogram (ECG)
- chest X-ray
- head-up tilt test
- auditory brainstorm responses
- electrodermal conductivity
- brain CT scan
- magnetic resonance image (MRI) or single photon emission computed tomography (SPECT) scanning

20 Supported self management

Quick info:
Where symptoms are mild and do not interfere with daily functioning to a significant extent ongoing management in conjunction with the GP may be appropriate. If however symptoms deteriorate then referral to specialist teams should be considered.