

## essentials of CFS/ME management



there is little evidence to suggest that any treatment has a substantive impact on CFS/ME. However, clinical experience and patient reports suggest that individuals can be greatly helped by a flexible, regularly reviewed management plan that includes:

- offering advice on energy management to help the person find the correct balance between rest and activity
- applying generic clinical skills to provide symptomatic relief and manage comorbid conditions
- in particular, problems with sleep, pain and mood should be addressed as each compounds the other
- CFS/ME patients are often relatively intolerant of medication so it is wise to start with lower doses and to make use of agents that are less likely to have adverse effects



### prognosis

- prognosis is extremely variable
- most patients will improve by varying degrees with time but health and functioning rarely return completely to the individual's previous healthy levels



### when to refer

- GPs should usually be able to manage patients with CFS/ME. If referral is necessary then expertise and understanding of CFS/ME are more important than the speciality of the referral

## special issues



### severely affected individuals

- around 25% of all patients are severely affected and may have substantial neurological impairments including feeding difficulties, muscle spasm and involuntary muscle movement
- they may be bed or house bound and clinicians should ensure that appropriate provision is made for the delivery of home care

### children and young people



- children as young as five do get and can be profoundly affected by CFS/ME
- ideally diagnosis and management should be overseen by a community or hospital specialist
- for severely affected young people, GPs can access consultants' domiciliary visiting service
- prognosis is generally better for children with many recovering even after long illnesses
- some children will require home tuition and those too severely affected to study at all need encouragement to set a level of sustainable activity with regular review

### child protection



- neither the fact of a child having unexplained symptoms nor the exercising of selective choice about treatment or education for such a child constitutes evidence of abuse
- clear evidence of harm should be obtained before convening child protection procedures
- social services should be made aware that medical opinion in this area is divided and expert clinical opinion should be sought

### welfare benefits



- CFS/ME patients often face considerable problems accessing state benefits, private insurance or ill-health retirement. Hence support is needed from clinicians to provide medical reports that give a clear diagnosis, stress the incapacity experienced by patients and likely prognosis

## specific therapeutic strategies

### energy management (pacing)

- the aim is to establish a consistent and sustainable level of daily activity that:
  - avoids relapses through over exertion
  - avoids deconditioning caused by too much rest (although rest is important in the early stages of the illness)
  - as the patient improves a carefully monitored increase in activity can be explored

### cognitive behavioural therapy & graded exercise

- there is some evidence to suggest that Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET) can improve the functional capacity of some ambulant adult patients when applied flexibly by experienced practitioners. However, caution is required as many patients have reported a deterioration in their health following these interventions

### sleep

- establishment of a sufficient and regular sleep pattern is an important goal
- reducing daytime sleeping may improve nocturnal sleep quality but some patients will need to have a 'siesta' or other period of daytime rest
- low doses of tricyclic agents, if tolerated, are often effective in restoring sleep quality and rhythm, and are preferable to hypnotic agents

### pain

- if simple analgesics are not effective then agents such as low dose tricyclics, or the anticonvulsants carbamazepine, sodium valproate and gabapentin, can be especially useful for pain with neuropathic quality
- muscle relaxants, such as baclofen, may help muscle pain associated with twitching and cramps
- headaches sometimes have a migrainous character and where migraines are less frequent or severe, triptans may help
- frequent headaches may merit a trial of migraine prophylaxis, such as low dose tricyclics, pizotifen or sodium valproate (beta-blockers are often poorly tolerated in CFS/ME)
- severe unremitting chronic pain may merit referral to a specialist pain team

### mood

- it is important to note that antidepressants have been shown to be ineffective in the treatment of CFS/ME *per se*; however, both children and adults with CFS/ME can suffer from mood disorders and treating these improves prognosis
- choice of therapeutic agent should take account of:
  - the particular sensitivity of CFS/ME patients to psychotropic medication (agents with less anti-muscarinic activity may be better tolerated)
  - the sleeping pattern of the individual
- CFS/ME patients with depression are often well suited by citalopram or sertraline; they are often poorly tolerant of more activating agents such as fluoxetine, paroxetine and venlafaxine

### diet

- exclusion diets, particularly avoidance of wheat and dairy products, may help with bowel problems or refractory headaches



# Chief Medical Officer's Working Group Report on CFS/ME

a summary of the key clinical issues endorsed by Professor Allen Hutchinson, Chair of the Working Group

## introduction

- chronic fatigue syndrome (CFS) / myalgic encephalomyelitis (ME) is now generally accepted as being a discrete disorder or spectrum of disorders sometimes known as postviral fatigue syndrome
- it is a quite common, very heterogeneous condition of both adults and children that lacks specific disease markers but is clinically recognisable
- the broader impact of the disease can be extensive even in its milder forms and may be under recognised
- although the aetiology and pathogenesis are not known, reported abnormalities include down regulated HPA axis, abnormal autonomic responses and immunological changes
- triggers include certain infections such as glandular fever, viral meningitis and viral hepatitis

## characteristic symptoms

- severe and persistent fatigue of a type entirely distinct from everyday tiredness
- chronic pain - may be muscular, joint, neuropathic, headache (often migrainous)
- post exertional malaise sometimes with a flu-like character
- cognitive impairment
- sleep disturbance
- IBS like symptoms
- postural hypotension or rotational dizziness
- increased sensitivity to sensory stimuli such as light or sound
- recurrent sore throat - with or without lymphadenopathy

## differential diagnoses

- |   |   |
|---|---|
| <input type="checkbox"/> Addison's disease                      | <input type="checkbox"/> mood disorders         |
| <input type="checkbox"/> anaemia                                | <input type="checkbox"/> multiple sclerosis     |
| <input type="checkbox"/> chronic infections (e.g. Lyme disease) | <input type="checkbox"/> myasthenia gravis      |
| <input type="checkbox"/> chronic somatisation disorder          | <input type="checkbox"/> primary sleep disorder |
| <input type="checkbox"/> coeliac disease                        | <input type="checkbox"/> rheumatic diseases     |
| <input type="checkbox"/> immunodeficiency                       | <input type="checkbox"/> thyroid disease        |
| <input type="checkbox"/> malignancy                             |   |

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charity number 1083992

ME North East  
Bullion Hall  
South Approach  
Chester le Street  
County Durham DH2 2DW



0191 388 4228  
tel/fax 0191 389 2222

info@menortheast.org  
www.menortheast.org

## diagnostic process

### background information



- four-six weeks after the onset of abnormal fatigue CFS/ME should be considered as one of the differential diagnoses
- although there is no validated diagnostic test it is still possible to make a positive diagnosis by recognising the presence of a characteristic set of symptoms together with the exclusion of alternative diagnoses
- perhaps the prime indicator of the condition is that physical or mental exertion beyond the individual's tolerance prompts worsening of symptoms with a characteristic delayed impact, which may be felt after several hours, the next day or later still
- in some instances the person can sustain a level of activity for several weeks, but a cumulative impact is seen causing relapse
- given the complex nature of the assessment, several consultations may be necessary before the diagnosis is finally confirmed however a provisional diagnosis is valuable as it allows active management to begin

### clinical evaluation



- the crucial diagnostic procedure for CFS/ME is the clinical history, including a detailed drug history so it is important that sufficient time is allowed for patients to give a full narrative account of their illness
- mental health and psychosocial assessment should be carried out at an early stage so any problems can be either dealt with or excluded
- primary sleep disorders should be excluded in all people with unexplained fatigue
- physical examination is essential, and should be repeated as indicated by symptoms and clinical course. Findings are frequently normal in CFS/ME but the examination may be helpful in ruling out other conditions

### basic screening tests



- several screening tests should be undertaken to exclude a range of common conditions that can cause chronic fatigue and identify any comorbid conditions
- full blood count
- concentration of C-reactive protein (CRP)
- blood biochemistry tests for creatinine, urea, electrolytes, calcium, phosphate, glucose, liver enzymes and markers of thyroid function
- simple urine analysis

### specialised screening tests



- these may be required within the differential diagnostic process so as to exclude particular conditions that are suggested by specific types or mixtures of symptoms or abnormal findings on physical examination or investigation
- e.g. rheumatoid factor and ANA where there are prominent joint or skin features or antibodies to gliadin and endomysium when coeliac disease is part of the differential diagnosis