



# MANAGEMENT FILE

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This leaflet is based on an article which first appeared in the ME Association's quarterly *ME Essential* magazine .  
MEA membership costs £18 a year for people living in the UK/BFPO.  
For contact details, see foot of this page.

the ME association



May 2016

# The importance of early and accurate diagnosis

## INTRODUCTION

ME/CFS is a complex multisystem disease that has a population prevalence of at least 0.2% to 0.4% (ie it affects up to 2 to 4 per 1,000 of the population and up to 250,000 people in the UK).

Many people in the UK experience a long delay in obtaining a diagnosis. A 2016 MEA website survey found that only 18 % were diagnosed within six months of onset of symptoms; 62% waited a year or more.

Chronic fatigue is common and some people are being misdiagnosed with ME/CFS when they have another, sometimes perfectly treatable, explanation.

## WHY IT IS SO IMPORTANT

- To lessen the chance of ME/CFS taking a more prolonged and severe course.
- To exclude other conditions that present with similar symptoms.
- To prevent harmful approaches to management such as 'working through fatigue' and inappropriate exercise programmes
- To organise a comprehensive management plan involving activity management; symptom relief; information and support relating to education, employment and sickness benefits.

## TAKING A HISTORY

The commonest age of onset is in the early 20s to mid 40s.

The illness is often triggered by an acute infection, followed by a 'failure to recover' and development of characteristic ME/CFS symptoms.

Other immune system stressors – eg vaccinations – occasionally trigger ME/CFS.

Gradual onset in a minority with no clear precipitating event.

Allow adequate time for taking a detailed history – medical, drug (plus alternative and recreational drugs), social, family and overseas travel – and performing a full clinical examination.

A doctor should also ask about impact on education or employment.

Where symptoms are atypical, or more pronounced than normal in ME/CFS, a more thorough clinical assessment is essential.

Assess psychological well-being and mental health.

## CHARACTERISTIC SYMPTOMS

There is no agreed diagnostic criteria for ME/CFS. Diagnosis is based on a cluster of characteristic symptoms along with exclusion of other possible explanations.

- Activity-induced muscle fatigue.
- Post-exertional malaise/symptom

exacerbation whereby symptoms are amplified by physical and/or mental exertion with a delayed impact – later the same day, the next day, or even later. The amount of activity that provokes symptom exacerbation can be very minimal.

- Cognitive dysfunction involving short-term working memory, concentration and attention span, information processing, and word-finding ability
- Pain can affect muscles (myalgia), joints (arthralgia) and nerves (neuropathic) but is not always present. Pain is often difficult to alleviate with simple analgesics and may be accompanied by sensory disturbances/paraesthesiae.
- Unrefreshing sleep pattern may include hypersomnia in the early post-infection stage, fragmented sleep and restless legs syndrome later on. In more severe cases, there may be a reversal of normal sleep rhythm (ie being awake at night but sleeping during the day).
- Autonomic nervous system dysfunction involving orthostatic intolerance, orthostatic hypotension – resulting in dizziness or feeling faint – and in some cases postural orthostatic tachycardia syndrome.
- Poor temperature control including increased sensitivity to hot and cold, sweating, feeling feverish.

- On-going flu like symptoms including sore throats and tender glands.
- Intolerance to alcohol and medications - especially psychotropic (antidepressant) drugs.
- Headaches of a new type or severity that may have a migrainous quality.
- Sensory disturbances including paraesthesiae ('pins and needles') and increased sensitivity to noise and bright light.
- Digestive disturbances consistent with irritable bowel syndrome (ie abdominal pain, bloating, change in bowel habit) may develop following the onset of ME/CFS and be exacerbated by certain foods (e.g wheat or dairy products).
- Severely affected patients may have substantial neurological impairments, including atypical seizures (fits), unwanted muscle activity, and swallowing difficulties that may require nasogastric (tube) feeding.

Symptoms fluctuate in severity, throughout the day, day to day, week to week. The pattern may change over time.

There is a substantial and sustained reduction in both physical and mental activity. This has a major effect on all aspects of daily living.

Exacerbations and relapses are caused by infections, trauma and other stressors, including menstrual exacerbation.

## EXAMINATION

In addition to a full clinical examination:

- Check for anaemia, thyroid and liver disease, lymphadenopathy
- Where there are orthostatic symptoms, check pulse and blood pressure lying and standing
- Hypermobility syndromes should be checked for in younger patients
- In children, check and monitor height and weight.

## BASELINE INVESTIGATIONS

There is no diagnostic blood test for ME/CFS.

Baseline investigations are essential in order to exclude common conditions that can cause chronic fatigue:

- Full blood count and differential
- Serum ferritin
- ESR and C-reactive protein
- Metabolic screen for calcium, phosphorous, urea and electrolytes, total protein, albumin and globulin, blood sugar
- Coeliac disease screening test – IgA anti-tissue transglutaminase
- Creatine kinase
- Serum creatinine
- Liver function tests
- Thyroid function tests
- Urinalysis for protein, blood and glucose

Results should be within normal limits. Where abnormalities occur, consideration must be given to other diagnostic explanations.

## FURTHER INVESTIGATIONS

Indications:

- Atypical symptoms (e.g joint pain accompanied by swelling)
- Red flag symptoms or signs (e.g weight loss, significant lymphadenopathy, fever)
- Symptoms not normally associated with ME/CFS (e.g breathlessness, chest pain)
- History or examination suggest other diagnostic explanations or co-existent problems

Examples:

- Autoantibody screen – where a rheumatological or autoimmune condition is possible
- Screening for infectious diseases – hepatitis B/C, HIV, Lyme disease, Q fever, toxoplasmosis

- Synacthen test – where Addison's disease is a possibility
- Serum hydroxyvitamin D – in housebound patients
- Tilt-table testing where there is significant autonomic system dysfunction
- Polysomnography where sleep disturbance suggests a primary sleep disorder such as sleep apnoea.

## TIMESCALE

Most ME/CFS research criteria stipulate that a diagnosis should only be made after six months of symptoms. In clinical practice this should normally be regarded as the endpoint of the diagnostic process.

A working or interim diagnosis is better than none and allows active management to begin.

The diagnosis often needs to be pieced together through a series of consultations.

**At six weeks:** A working diagnosis of post-viral fatigue syndrome can be made where appropriate. Where a child has missed around four weeks of school, action must be taken to speed up the diagnostic process.

**At three months:** A provisional diagnosis of ME/CFS can be made if symptoms persist and no other explanation is found. Diagnosis should normally have been confirmed in children and adolescents.

**By four months:** The provisional diagnosis should have normally been confirmed in adults. A management plan should now be in place.

Where there is continuing uncertainty about the diagnosis, or symptoms are severe, patients should be referred to a hospital-based ME/CFS referral service.

## CHILDREN AND ADOLESCENTS

- ME/CFS has been reported in children as young as five. There appears to be a peak onset of symptoms around 13 to 15.
- ME/CFS can be misdiagnosed as a behaviour problem or school phobia.
- Children often present differently to adults. Symptoms that are more common or prominent include stomach pain, nausea, headache and loss of appetite.
- ME/CFS is reported to be the commonest cause of long-term sickness absence from school.
- Children should be known to community paediatric services and under consultant care if away from school.

## SPECIALIST REFERRAL

Where there is continuing uncertainty

about the diagnosis, or symptoms are severe, patients should be referred to a hospital-based ME/CFS referral service.

If there is not a suitable ME/CFS referral service nearby, the Countess of Mar has established through a House of Lords parliamentary question that people can be referred elsewhere to an NHS service/consultant of their choice: <http://tinyurl.com/zj3h8k8>

The MEA website has details of all the multidisciplinary hospital-based referral services for adults and children: <http://tinyurl.com/h4ugdhs>

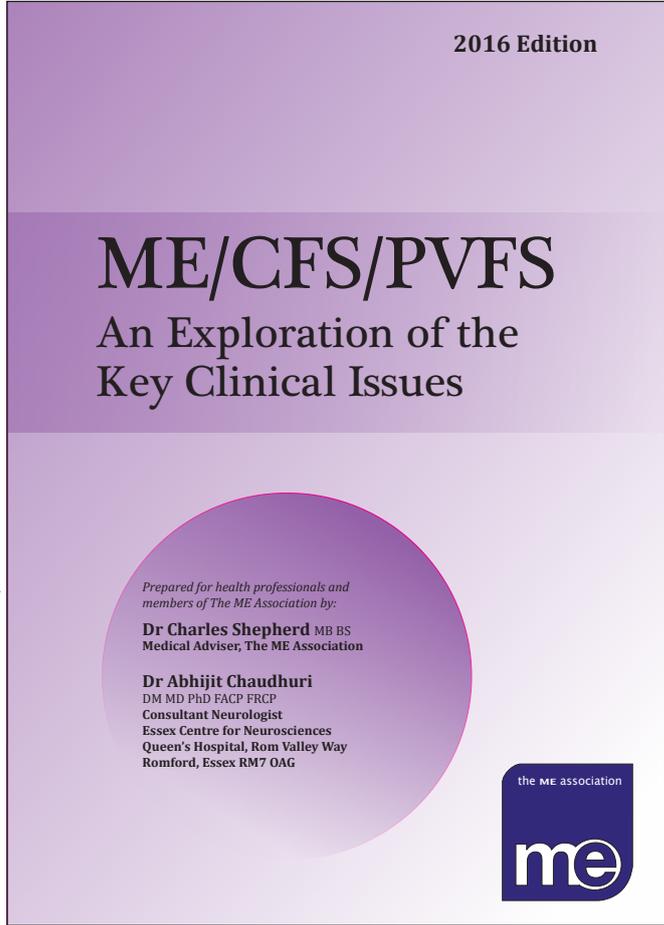
The MEA has an information leaflet covering Specialist Referrals in more detail.

## FURTHER INFORMATION

- ◆ An MEA booklet *ME/CFS/PVFS: An Exploration of the Key Clinical Issues* summarises and references key information on research, clinical assessment and management.

- The MEA has information leaflets covering all aspects of management: symptoms, benefits, employment, etc.
- The Chief Medical Officer's Report on ME/CFS, NICE guideline on ME/CFS, Canadian diagnostic criteria, and Institute of Medicine Report can be downloaded from the MEA website document archive (see *About The MEA > Policies and Documents*).

***Medical information contained in this leaflet is not intended to be a substitute for medical advice or treatment from your doctor. The ME Association recommends that you always consult your doctor or healthcare professional about any specific problem. We also recommend that any medical information provided by The MEA is, where appropriate, shown to and discussed with your doctor.***



2016 Edition

# ME/CFS/PVFS

## An Exploration of the Key Clinical Issues

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