**1. The key characteristic – Post exertional exacerbation of symptoms**

There are many different diagnostic criteria, but all agree that post-exertional exacerbation of symptoms is a defining characteristic of ME-CFS.

It can be known by a number of different names:

* Post-exertional malaise [SGPS](http://www.scot.nhs.uk/scottish-good-practice-statement-on-me-cfs/), [NICE](http://www.rcpch.ac.uk/sites/default/files/asset_library/Research/Clinical%20Effectiveness/Endorsed%20guidelines/Chronic%20Fatigue%20Syndrome%20%28NICE%29/CFS%20NICEGuideline.pdf), [MEA](http://www.meassociation.org.uk/2016/04/the-me-associations-purple-booklet-apologies-for-late-delivery-18-april-2016/)
* Post-exertional neuro-immune exhaustion [MEICP](http://www.hetalternatief.org/ICC%20primer%202012.pdf)
* Systemic exercise intolerance [IoM](http://www.nationalacademies.org/hmd/~/media/Files/Report%20Files/2015/MECFS/MECFS_ReportBrief.pdf) (USA)

Delayed onset post exertional fatigue - DOPE [Whiting](http://wames.org.uk/cms-english/tag/dope/)

* Delayed post activity relapse – DPAR [Ezelius](http://wames.org.uk/cms-english/2016/03/post-activity-relapse-par-or-pem/)

**2. Fatigue – not always the major symptom**

While fatigue is a major part of the condition, patients may find other symptoms more debilitating some, or all of the time e.g.

* flu-like malaise, or just ‘feeling really ill’
* sleep disturbance e.g. insomnia, hypersomnia, unrefreshing sleep, a disturbed
sleep–wake cycle
* pain – not experienced by everyone
* balance problems e.g. POTS is present in a significant sub-group
* muscle problems & mobility e.g. weakness, spasms, ataxia, gait dysfunction
* neurocognitive impairments e.g. difficulty processing information, impaired concentration, short-term memory loss, overload phenomena, brain-fog
* gastro-intestinal symptoms

**3. Diagnostic criteria**

Changing perceptions of ME-CFS and publication of new research findings lead to new criteria and guidelines being produced somewhere in the world every year. They join a wide range of documents with different understandings of the nature and severity of the condition. Two major guidelines for health professionals illustrate different approaches:

[**NICE**](http://www.rcpch.ac.uk/sites/default/files/asset_library/Research/Clinical%20Effectiveness/Endorsed%20guidelines/Chronic%20Fatigue%20Syndrome%20%28NICE%29/CFS%20NICEGuideline.pdf) - To diagnose CFS/ME NICE requires fatigue to be present, plus one other symptom. The fatigue must have 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 activitylevel
* characterised by post-exertional malaise and/or fatigue (typically delayed, for example by at least 24 hours, with slow recovery over
several days)

[**MEICP**](http://www.hetalternatief.org/ICC%20primer%202012.pdf) - the International guidelines diagnose a more severely affected group of patients with a wide range of dysfunction. Diagnosis of ME requires:

* Post-Exertional Neuroimmune Exhaustion ( PENE)
* 3 Neurological Impairments : at least 1 symptom from 3 symptom categories
* 3 Immune/gastro-intestinal/genitourinary Impairments: at least 1 symptom from 3 symptom categories
* 1 Energy metabolism/ion Transport Impairments: 1 symptom

**4. The name of the illness – CFS or ME?**

The term ‘Chronic Fatigue Syndrome’ (CFS) is common in the UK. Many patients however are uncomfortable with a name which focuses on just one symptom and may prefer to have a diagnosis of ME (Myalgic encephalomyelitis or Myalgic Encephalopathy)

The term CFS is also often considered to refer to a group of patients with fewer, less serious symptoms, or even a different patient group, therefore it is important to clarify terminology with the patient and carer.

**5. Everyone is different**

There is currently no diagnostic test, nor a treatment which is consistently effective in alleviating the underlying disease process, though some medication and management approaches can be helpful in reducing symptoms and aiding recovery.

What works for one patient may not work for another. There is a need to tailor interventions to the needs and circumstances of the individual patient.

Some therapies may not be accepted by or practical for some patients. NICE emphasises that people with ME-CFS have the right to refuse or withdraw from any component of their care plan without this affecting the provision of other aspects of their care or future choices about care.

**6. Important to understand the pattern of symptoms – diary**

Consider asking your patient to use a diary to record the nature and frequency of their symptoms. This will be key to developing a successful management approach, and sometimes can also help in reaching a diagnosis.

The diary will help to identify the ebb and flow of symptoms and which activities trigger them. There are a range of template diaries available. The simpler the better. Download a template diary can be downloaded from [CFIDSSelfhelp](http://www.cfidsselfhelp.org/files/activity_log.pdf) or [Southern Health NHS](http://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=6&cad=rja&uact=8&ved=0ahUKEwjrzfi2jsPMAhVqIsAKHeHyDxgQFghCMAU&url=http%3A%2F%2Fwww.southernhealth.nhs.uk%2Feasysiteweb%2Fgatewaylink.aspx%3Falid%3D26093&usg=AFQjCNG_d3i-rZHBqJIKQcxx6oKmy3AGGg) Trust

**7. Activity management**

This could be the most controversial topic in the management of ME-CFS! Opinions differ about the validity of the research underlying the effectiveness of rehabilitative therapies, with eminent clinicians and researchers on both sides of the fence. In a person-centred approach to management it is important to acknowledge the patient’s views on the matter and accept some may not wish to undergo CBT or GET.

NICE recommends **CBT & GET**: ([Quick ref guide](http://www.rcpch.ac.uk/sites/default/files/asset_library/Research/Clinical%20Effectiveness/Endorsed%20guidelines/Chronic%20Fatigue%20Syndrome%20%28NICE%29/CFS%20NICEGuideline.pdf) p17)

Offer cognitive behavioural therapy (CBT) and/or graded exercise therapy(GET) to people with mild or moderate CFS/ME, and provide them for those who choose them, because these are the interventions for which there is the clearest research evidence of benefit.

If a full CBT or GET programme is inappropriate or not available, offer components of CBT or GET, either individually or (more effectively) together with:
– activity management strategies
– sleep management and relaxation techniques.

**Pacing: the energy envelope approach** [CFIDSselfhelp](http://www.cfidsselfhelp.org/library/finding-your-energy-envelope-part-1) [Phoenix rising](http://phoenixrising.me/living-i-the-basics/energy-envelope-in-chronic-fatigue-syndrome-by-cort-johnson)

The energy envelope relies on four central concepts:

* ME-CFS patients have a certain (very limited) amount of energy that they can use safely
* Using up your safe stores of energy triggers a reaction in the body that results in a deterioration of symptoms
* Not using up your ‘available’ energy may help your body to heal at least to some extent
* You can affect your energy stores by adjusting the amount and type of mental, physical and emotional exertion you engage in