

**Principles of Management of ME-CFS following diagnosis** – adapted from the [Scottish Good Practice Statement on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome \(ME-CFS\) Feb 2023](#).

**Key approaches include:**

- Understanding symptoms and concerns, aiming for shared decision making and collaborative treatment;
- Considering support and wellbeing, using the principles of good chronic disease management;
- Giving a clear diagnosis, with information about the implications of the condition and why the diagnosis has been reached;
- Recognising that there is no single treatment shown to be consistently effective but various approaches can be helpful: give honest information and suggestions for symptom management and “*encourage cautious optimism*”;
- Outlining and understanding that the course / prognosis of the condition is very variable; and that patient responses to interventions also vary so exploring a range of management options helps;
- Giving support round an even approach to activity, avoiding ‘boom and bust’ tactics;
- Signposting for occupational and benefits support where indicated;
- Considering emotional and social support, including the needs of family and carers;
- NICE 2021 recommends simple approaches to maintaining mobility including: bed mobility, moving from lying to sitting to standing, transfers between furniture, correct use of mobility aids, joint mobility, muscle strength and stretching, balance & mobilising around the house including stairs.

**Pharmacological interventions:**

- Use low doses and titrate slowly: patients may be very sensitive to drug effects, including between different drugs in the same class. B-blockers and anti-depressants can be especially problematic. Stop treatments / polypharmacy not bringing benefit.
- Pain is often problematic – the standard analgesia ladder can be used, with the usual caveats round long-term opioids. Medication for neuropathic pain can be tried: low dose sedating tricyclics (slow upward titration if necessary), gabapentin and other drugs licenced for this indication. These include carbamazepine, duloxetine and pregabalin (the latter two may be particularly helpful if fibromyalgia is present and have level 1+ evidence for this). Some advocate baclofen or benzodiazepines for muscle cramps / spasms but there is evidence of harm outweighing benefit. Consider non-pharmacological approaches to pain, including local heat, massage, use of TENS machines and acupuncture. Please also see RefHelp’s [Chronic Pain](#) pages.
- Sleep disturbance is common – hypersomnia is well recognised, especially early on; low dose trazodone may help insomnia as can standard non-pharmacological approaches.
- Headache, IBS-like abdominal pain and balance disorders can be treated with the usual approaches.

**Dietary approaches:**

- A healthy diet should be recommended, and there are no clear evidence-based recommendations, other than awareness that those with restricted diets, or not getting sun exposure, may suffer complications as a result, including of low Vitamin D.

In such situations NICE 2021 advises adequate fluids, small frequent meals, referral to dietetics or advice about Vitamin D where indicated.

### **Rehabilitation and Re-enablement:**

- This is usually the aim of management, keeping awareness of the need for adjustment due to relapse or fluctuations in the condition. Cognitive, emotional, social and physical aspects can be considered, and rehabilitation does not necessarily mean exercise – but any activity;
- *“Any rehabilitation or increase in activity should start from an agreed, stable and possibly very low baseline and should be gradual. Keep goals small and achievable.*
- A structured programme can help – please see details of [Lothian’s ME-CFS Rehabilitation Service](#).

### **Physical Functioning - Managing Exercise and Energy:**

- There are benefits to maintaining mobility for multiple areas of health including joint mobility, muscle flexibility, balance, muscle function, bone and cardiovascular health.
- Consider that those with severe ME may suffer the complications of long-term profound immobility (pressure ulcers, DVT, risk of contractures etc)
- Graded Exercise Therapy (GET) is no longer recommended by NICE, though it may benefit some. Instead, the approach is to manage the ‘energy envelope’, aiming for sustainable activity levels by pacing and taking account of all the activities that use a person’s reserves. ME-CFS patient surveys have indicated this to be the most useful approach.

Please see the [NHS Lothian patient leaflet on managing fatigue](#) – applicable to ME-CFS as well as post-viral recovery.

**CBT:** can help as with any long-term condition but is not seen as ‘curative’. Counselling may help, again as with any chronic condition but there is no specific evidence base for benefit.

### **Managing Flare Ups and Relapses in Symptoms:**

NICE 2021 outlines that:

- *“A flare up is defined as experiencing a worsening of their symptoms that is beyond their normal day-to-day fluctuations that can last a few days.*
- *A relapse is defined as sustained and marked exacerbation of symptoms lasting longer than a flare-up that needs substantial and sustained adjustment of energy management.”*

And suggests a care plan, allowing the person to self-manage:

#### **Flare-ups:**

- Identify possible triggers e.g. exercise, illness
- Temporarily adjust activity levels
- Monitor symptoms in case they develop into a relapse
- Only return to normal activity levels once flare up has fully resolved.

#### **Relapses:**

- Identify possible causes
- Reduce or even stop some activities
- Increase frequency or duration of rest periods
- Reassess energy limits to stabilise symptoms.