

NICE ME/CFS 2021: Q&A summary for GPs

What is ME/CFS?

ME/CFS is a chronic, complex, multi-system biological illness with often devastating consequences. It can affect different aspects of the life for both people with ME/CFS and their families and carers, including activities of daily living, family life, social life, emotional well-being, work and education. It has a worse [quality of life score](#) than many other serious illnesses including cancer, stroke, rheumatoid arthritis and MS. ME/CFS is not psychosomatic, and psychological therapies will not cure the disease.

What are the symptoms of ME/CFS?

The most important symptom of ME/CFS is Post Exertional Malaise ([PEM](#)). This is the exacerbation of illness that results when a patient's energy limit is exceeded. Other symptoms are:

- Debilitating fatigue that is worsened by activity, is not caused by excessive cognitive, physical, emotional or social exertion, and is not significantly relieved by rest.
- Unrefreshing sleep or sleep disturbance.
- Cognitive difficulties or 'brain fog'.

The following associated symptoms can also be present.

- Orthostatic intolerance, autonomic dysfunction, dizziness, palpitations, fainting, nausea on standing or sitting upright from a reclining position.
- Temperature hypersensitivity resulting in profuse sweating, chills, hot flushes, or feeling very cold.
- Neuromuscular symptoms, including twitching and myoclonic jerks.
- Flu-like symptoms, including sore throat, tender glands, nausea, chills or muscle aches.
- Intolerance to alcohol, or to certain foods and chemicals.
- Heightened sensory sensitivities, including to light, sound, touch, taste and smell.
- Pain, including pain on touch, myalgia, headaches, eye pain, abdominal pain or joint pain without acute redness, swelling or effusion.

How is ME/CFS diagnosed?

ME/CFS should be suspected when the four main symptoms have been present for six weeks in adults or four weeks in children. Perform a thorough workup to rule out other causes. If no other causes are found and symptoms are still present after 3 months, ME/CFS can be confirmed.

How do we treat ME/CFS?

There is no cure for ME/CFS. The most important aspect of management is to learn to [manage activities](#) to stay within the individual's energy limit and avoid triggering Post Exertional Malaise. Advise patients to rest and pace as soon as the diagnosis is suspected. An occupational therapist who understands ME/CFS can be invaluable in teaching [pacing](#) techniques and providing aids and adaptations that help conserve energy.

What about exercise and CBT?

Given that PEM is the hallmark symptom of ME/CFS, exercise can be [very harmful](#). NICE's [comprehensive review](#) of all studies of Graded Exercise Therapy (GET) and CBT found them to be universally of low to very low quality. NICE states, "Do not offer people with ME/CFS:

- Any therapy based on physical activity or exercise as a cure for ME/CFS.
- Generalised physical activity or exercise programmes – this includes programmes developed for healthy people or people with other illnesses.
- Any programme that uses fixed incremental increases in physical activity or exercise, for example Graded Exercise Therapy.
- Physical activity programmes that are based on deconditioning and exercise avoidance theories as perpetuating ME/CFS.
- The Lightning Process, or therapies based on it."

[CBT](#) can at best provide psychological support and at worst contribute to [harm](#) by consuming precious energy or misinforming patients. It is not a cure and NICE states that it must not assume people have abnormal illness beliefs and behaviours as an underlying cause of their ME/CFS.

There is nothing we can do for patients. Why diagnose ME/CFS at all?

There is a lot we can do for patients, as compassionate care can make a huge difference to

the patient experience. NICE recommends a patient centred approach whereby patients are given full control of their treatment goals and therapeutic choices. It is important to make the diagnosis of ME/CFS as:

- Not doing so would be discriminatory and unlawful.
- Patients deserve a diagnosis and to be validated.
- It protects from inappropriate psychological or psychiatric labels.
- Diagnosis allows access to available support (financial, social, accommodations at the place of work or education).
- Diagnosis is necessary for research.
- Treatments may become available in the future.

So what DO we do, other than just energy management?

1. Believe your patients

2. Learn about ME/CFS

Join [Doctors with M.E.](#) and make use of the educational opportunities on offer. Learn about the many symptoms of ME/CFS, how you may help with them, and the common comorbidities that can be present, which should be treated in their own right.

3. Provide symptomatic treatment

Do what you can to make your patients' lives a little easier. Target the most troublesome symptoms first. When prescribing medications, start low and go slow as ME/CFS patients are more susceptible to side effects.

4. Be accessible

Provide telephone or video consultations and home visits for patients who are unable to attend appointments. Respect patients' hypersensitivities and allergies as this can otherwise trigger Post Exertional Malaise. Provide a named contact so that patients know how to get help when needed.

5. Support applications for financial support and social care

ME/CFS has been shown to be [more debilitating](#) than many other serious illnesses. Only a minority are able to [work](#) and most of these work part-time and have to sacrifice social and other activities to sustain the energy requirements of their work. Therefore,

access to any help to which patients are entitled is very important. The severely and very severely affected patients may need much practical help and social care.

6. Support accommodations at work and in education

ME/CFS is a recognised disability with rights to reasonable adjustments. Accommodations can include modifications to the work environment, rest facilities, shorter working hours, working from home and transport or parking arrangements. In many circumstances patients may be entitled to assistance via the [Access to Work](#) scheme to enable them to continue doing their jobs.

For children and young people, consider education at home where required, making use of online resources, communication tools, home schooling and flexible or hybrid arrangements, to provide equal access to education as much as is possible. ME/CFS is the single greatest cause of [long-term sickness absence](#) in UK schools, therefore solutions must be found to minimise the impact of this disease on educational attainment and long-term outcomes.

7. Arrange nutritional support where required

Severely ill ME/CFS patients can struggle to maintain their [nutrition](#) for a variety of reasons, including muscle weakness or paralysis, difficulty swallowing, nausea or abdominal pain, food intolerances or allergies and Mast Cell Activation Syndrome. Screen for undiagnosed gastrointestinal disorders, such as Coeliac disease. Some patients need tube feeding. Be alert to this possibility and refer early for nutritional assessment and support to prevent deterioration from preventable malnutrition.

8. Review regularly

At least annually, 6 monthly for children. Evaluate and investigate new symptoms and change in symptoms to determine if they are due to ME/CFS or to another condition.

9. Refer for specialist care

ME/CFS specialist teams should include medically trained physicians, GPs or Paediatricians, as well as allied health care professionals specialising in ME/CFS.

For the full GP update see

<https://doctorswith.me/nice-gp-update/>