

Appendices

Appendix 1: Some important diagnoses to consider in the diagnosis of ME/CFS¹⁰

Autoimmune/Rheumatology: Polymyalgia rheumatica, Rheumatoid arthritis, SLE

Endocrine: Addison's disease, Hypo- or hyperthyroidism, vitamin deficiencies – b12, vit D

Gastrointestinal: Coeliac disease, Inflammatory bowel disease, IBS

Malignancy: Primary and secondary tumours

Infections: HIV, Hepatitis B and C, Lyme disease

Neurological: Multiple sclerosis, Myasthenia Gravis

Psychiatric: Generalised anxiety disorder, major depressive disorder, personality disorder

Sleep disorders: Obstructive sleep apnoea, central sleep apnoea, narcolepsy

Toxins: Lead poisoning, carbon monoxide poisoning, organophosphate pesticide poisoning, substance misuse

Appendix 2: Orthostatic intolerance in ME/CFS²⁴

Written instructions to perform the NASA lean test for orthostatic intolerance

- Lie still for at least 10 minutes, check baseline BP and heart rate
- Stand and lean against wall, heel should be 15cm distance from the wall with upper back leaning on wall
- Measure BP, heart rate and symptoms every 60sec for 10 minutes
- Patient may feel weak, dizzy or be noted to have mottled or bluish extremities
- If HR increases >30bpm, may have POTS. If BP falls >25mmHg, may have neurally mediated hypotension (NMH)
- Stop the test if the patient is about to faint

For further information on orthostatic intolerance and the NASA lean test see: [What is Orthostatic Intolerance? Part 1- Diagnostic Workup](#)

Appendix 3: Classification of severity of ME/CFS NICE 2021³

Mild ME/CFS People with mild ME/CFS care for themselves and do some light domestic tasks (sometimes needing support) but may have difficulties with mobility. Most are still working or in education, but to do this they have probably stopped all leisure and social pursuits. They often have reduced hours, take days off and use the weekend to cope with the rest of the week.

Moderate ME/CFS People with moderate ME/CFS have reduced mobility and are restricted in all activities of daily living, although they may have peaks and troughs in their level of symptoms and ability to do activities. They have usually stopped work or education, and need rest periods, often resting in the afternoon for 1 or 2 hours. Their sleep at night is generally poor quality and disturbed.

Severe ME/CFS People with severe ME/CFS are unable to do any activity for themselves or can carry out minimal daily tasks only (such as face washing or cleaning teeth). They have severe cognitive difficulties and may depend on a wheelchair for mobility. They are often unable to leave the house or have a severe and prolonged after-effect if they do so. They may also spend most of their time in bed and are often extremely sensitive to light and sound.

Very severe ME/CFS People with very severe ME/CFS are in bed all day and dependent on care. They need help with personal hygiene and eating and are very sensitive to sensory stimuli. Some people may not be able to swallow and may need to be tube fed.

Diet and fluids

Adequate fluids and a mixed diet are very important for affected patients. The 'Eat Well–NHS' website is a useful starting point. Consider referral to a dietitian, preferably one with an interest in CFS/ME, if further advice is needed. This may be appropriate for those with problems eating and swallowing, and also if affected by nausea. It is also valuable for those patients who are losing or gaining weight, or who report a restricted diet. This may be more apparent when talking to relatives and carers. Depending on the amount of exposure to natural sunlight, it is appropriate to discuss oral vitamin D supplements.

Medicines

No therapy has been shown to be an effective cure to CFS/ME and none should be offered for this purpose at present. If a patient has a co-morbidity such as type 2 diabetes, thyroid disease etc, then these conditions should be treated as normally patients living with CFS/ME may be more sensitive to the side effects of a range of medicines – suggest lower doses with slower dose increases and close follow up to look for side effects. Be prepared to drop the dose if needed.

Fatigue and Energy Management

It is important for patients, their carers and health care providers to establish what are the normal energy levels for individual patients and make sure that this boundary is not exceeded. Overuse of energy may result in a period of rebound fatigue and this may result in a flare up of symptoms or of a relapse. Energy may also be used up by cognitive and emotional functions as well as in a physical sense. Flare ups of the disease are generally considered to last a few days, whereas relapses are usually longer. It is possible that a flare-up may last longer and result in disease relapse.

It is important to identify potential triggers for flare-ups and to avoid these, if possible, in the future. Usually, energy levels will be reduced during a flare-up, and patients may need to restrict their activities for a period.

Fatigue may manifest as a variety of symptoms:

- general malaise with flu like symptoms (often in the early days of illness or during a flare up or relapse)
- restlessness and feeling tired
- low energy with sensations of being physically drained
- cognitive fatigue which worsens existing difficulties.

Physical functioning and mobility

Review should be aimed at improving functioning and mobility when possible. Patients may benefit from the specialist input of occupational therapists and physiotherapists in addition to dietitians. Increasing patient's independence is a goal for most practitioners and gentle physical activity should support muscle, bone and joint health as well as balance and postural control. Some patients may need referral for aids that will benefit activities of daily living such as hoists, transport aids and a blue badge. Close liaison with a specialist team that includes occupational therapists, physiotherapists and social workers may be required depending on the needs and functioning of individual patients.

Care requirements

It is good practice that the patient's care plan has details of who is involved in their regular care needs and how they might be contacted. What is provided by each individual carer (family, friends, and professional carers) will help the assessment of individual patients and work out what is sustainable in the future. If a person living with ME/CFS has worsening of their condition it is important to offer referral to a local specialist team for their intervention, should the patient choose this.

Rest and Sleep

Rest and sleep are important components in the management of ME/CFS. Patients may have trouble falling asleep and find that sleep is not refreshing. Relaxation strategies may help patients to fall asleep or feel more rested between activities and these could be incorporated prior to sleep or rest periods. Changes to rest and sleep should be introduced gradually and observing what happens to night-time sleep.

Mental health

Living with a debilitating chronic disease is associated with increased risks of poor mental health and depression. This can have a big impact on quality of life and should be actively screened for in ME/CFS as in other chronic diseases. Interventions such as Cognitive Behaviour Therapy can be beneficial.²¹

Appendix 5: Details of regional CFS/ME Services

The ME Association have a UK wide search facility by postcode for NHS specialist ME/CFS services which can be found at: <https://meassociation.org.uk/nhs-me-cfs-and-long-covid-services/>

Many health boards do not have a specialist service available. It may be possible to refer patients out with their local area. Specialist treatment services for ME/CFS in Scotland include:

NHS Greater Glasgow and Clyde:

The Holistic Chronic Fatigue Syndrome/ME service. 1053 Great Western Road, Glasgow. G12 0NR. Tel 01412111616. This is a therapeutic service for those already diagnosed with ME/CFS. On the sci gateway referral service this clinic is found under, West Glasgow, Homeopathy.

NHS Lothian:

There is a rehabilitation service for those who have received and accepted a diagnosis of ME/CFS and where investigations have been completed. It is based at the Astley Ainslie Hospital, 133 Grange Loan, Edinburgh, EH9 2HL
Telephone: 0131 537 9139 (open Thursday and Friday).

The referral form can be found at:

<https://apps.nhsllothian.scot/refhelp/guidelines/rehabilitation/chronicfatiguesyndromeme/me-cfs-chronic-fatigue-rehabilitation-service/>

Completed referral forms should be emailed to ME.CFSrehabreferral@nhsllothian.scot.nhs.uk. Within NHS Lothian, the Regional Infectious Diseases Unit (RIDU) can provide specific email advice regarding the management of ME/CFS. Referrals can also be made to the RIDU via sci gateway – found at Infectious diseases under Western General hospital – if a case is atypical and an infective cause is suspected.

NHS Western Isles, Stornoway:

There is an occupational therapy lead service available at Comhairle nan Eilean Siar, Sandwich Road, Stornoway, Isle of Lewis HS1 2XF
Telephone: 01851 822846