

Management of chronic fatigue syndrome myalgic encephalomyelitis

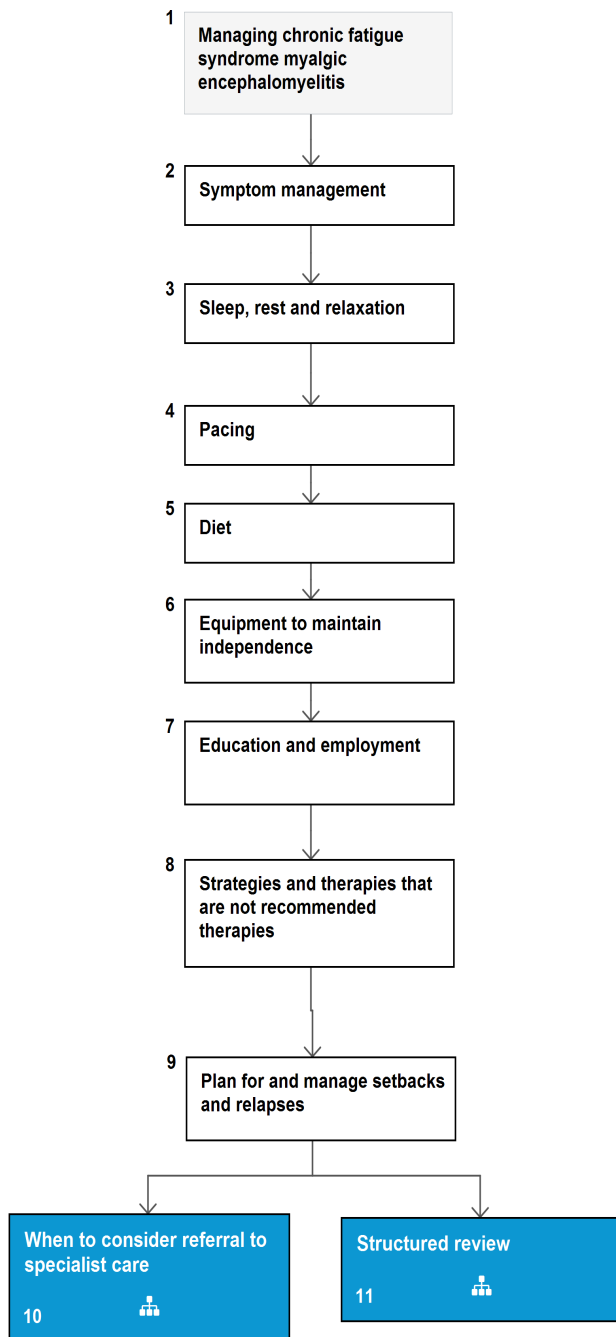
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To view the online version of this pathway visit:

<http://pathways.nice.org.uk/pathways/chronic-fatigue-syndrome-myalgic-encephalomyelitis>

Pathway last updated: 27 July 2015. To see details of any updates to this pathway since its launch, visit: [About this Pathway](#). For information on the NICE guidance used to create this path, see: [Sources](#).

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1 Managing chronic fatigue syndrome myalgic encephalomyelitis

No additional information

2 Symptom management

There is no known pharmacological treatment or cure for CFS/ME. However, manage symptoms of CFS/ME as in usual clinical practice.

No research evidence was found to support the experience of some people with CFS/ME that they are more intolerant of drug treatment and have more severe adverse/side effects. However, if people with CFS/ME have concerns, consider starting drug treatment for CFS/ME symptoms at a lower dose than in usual clinical practice. Increase the dose gradually, in agreement with the patient.

If a person experiences nausea as part of CFS/ME, manage this conventionally, including giving advice on eating little and often, snacking on dry starchy foods and sipping fluids. Consider the use of anti-emetic drugs only if the nausea is severe.

Although exclusion diets are not generally recommended for managing CFS/ME, many people find them helpful in managing symptoms, including bowel symptoms. If a person with CFS/ME undertakes an exclusion diet or dietary manipulation, seek advice from a dietitian because of the risk of malnutrition.

Specific drug treatment for children and young people with CFS/ME should be started by a paediatrician. However, prescribing may be continued in primary care, depending on the preferences of the patient and their carers, and local circumstances.

3 Sleep, rest and relaxation

Sleep management

Provide tailored sleep management advice that includes:

- Explaining the role and effect of disordered sleep or sleep dysfunction in CFS/ME.
- Identifying the common changes in sleep patterns seen in CFS/ME that may exacerbate fatigue symptoms (such as insomnia, hypersomnia, sleep reversal, altered sleep-wake cycle and non-refreshing sleep).

- Providing general advice on good sleep hygiene. (For general advice on sleep hygiene, see the [NHS Choices website](#).)
- Introducing changes to sleep patterns gradually.
- Regular review.

If sleep management strategies do not improve the person's sleep and rest, consider the possibility of an underlying sleep disorder or dysfunction, and provide interventions if needed.

Sleep management strategies should not include encouraging daytime sleeping and naps. Advise people with CFS/ME that excessive sleep does not generally improve physical or mental functioning, and excessive periods of daytime sleep or frequent napping may further disrupt the sleep-wake cycle.

Rest periods

Rest periods are a component of all management strategies for CFS/ME. Advise people with CFS/ME on the role of rest, how to introduce rest periods into their daily routine, and the frequency and length appropriate for each person. This may include:

- Limiting the length of rest periods to 30 minutes at a time.
- Introducing 'low level' physical and cognitive activities (depending on the severity of symptoms).
- Using relaxation techniques.

Review the use of rest periods regularly as part of the patient's management plan.

Relaxation

Offer relaxation techniques appropriate to the person with CFS/ME for the management of pain, sleep problems and comorbid stress or anxiety. There are a number of different relaxation techniques (such as guided visualisation or breathing techniques) that can be incorporated into rest periods.

People with severe CFS/ME

When making decisions about prolonged bed rest, seek advice from a specialist experienced in the care of people with severe CFS/ME. The significant physical and psychological risks associated with prolonged bed rest should be taken into account.

When working with people with severe CFS/ME who are in bed most (or all) of the time, explain the associated risks (such as postural hypotension, deep venous thrombosis, osteoporosis, pressure sores and deconditioning) and monitor these.

4 Pacing

People with CFS/ME have reported pacing to be helpful in self-managing CFS/ME. However, advise people with CFS/ME that, at present, there is insufficient research evidence on the benefits or harm of pacing.

5 Diet

Emphasise the importance of a well-balanced diet in line with 'The balance of good health'¹. Work with the person with CFS/ME to develop strategies to minimise complications that may be caused by nausea, swallowing problems, sore throat or difficulties with buying, preparing and eating food.

Emphasise the importance of eating regularly, and including slow-release starchy foods in meals and snacks. Explain the physiological consequences of not doing so to the person with CFS/ME.

There is insufficient evidence for the use of supplements – such as vitamin B12, vitamin C, co enzyme Q10, magnesium, NADH (nicotinamide adenine dinucleotide) or multivitamins and minerals – for people with CFS/ME, and therefore they should not be prescribed for treating the symptoms of the condition. However, some people with CFS/ME have reported finding these helpful as a part of a self-management strategy for their symptoms.

Advise people with CFS/ME who are using supplements not to exceed the safe levels recommended by the [Food Standards Agency](#).

Some people with CFS/ME need supplements because of a restricted dietary intake or nutritional deficiencies. Seek advice from a dietitian about any concerns.

¹ Food Standards Agency (2006) '[The balance of good health](#)'. London: Foods Standards Agency.

6 Equipment to maintain independence

For people with moderate or severe CFS/ME, consider providing or recommending equipment and adaptations (such as a wheelchair, blue badge or stairlift) as part of an overall management plan, taking into account the risks and benefits for the individual patient. This may help them to maintain their independence and improve their quality of life.

7 Education and employment

Having to stop their work or education is generally detrimental to people's health and well-being. Therefore, address the ability of a person with CFS/ME to continue in education or work early and review regularly.

Proactively advise about fitness for work and education, and recommend flexible adjustments or adaptations to work or studies to help people with CFS/ME to return to them when they are ready and fit enough. This may include, with the informed consent of the person with CFS/ME, liaising with employers, education providers and support services, such as:

- occupational health services
- disability services through Jobcentre Plus
- schools, home education services and local education authorities
- disability advisers in universities and colleges.

For people with CFS/ME who are able to continue in or return to education or employment, ensure, with the person's informed consent, that employers, occupational health or education institutions have information on the condition and the agreed management plan.

Education

Follow the guidance from the [Department for Children, Schools and Families](#) on education for children and young people with medical needs, or equivalent statutory guidance.

Work closely with social care and education services to ensure a common understanding of the goals of the person with CFS/ME. The use of a flexible approach should be discussed, including home tuition and use of equipment that allows a gradual reintegration into education.

Time in education should not be used as a sole marker of progress of CFS/ME, and education should not be the only activity a person undertakes. There should be a balance between time

spent attending school or college and doing homework, and time spent on home and social activities.

Employment

If possible, and with the informed consent of the person with CFS/ME, discuss employment issues with occupational health professionals, who will communicate with the person's manager or human resources representative. If there is no access to occupational health services, the responsible clinician should liaise with the employer directly.

[NHS Plus](#) has produced guidance on the occupational aspects of the management of CFS/ME.

8 Strategies and therapies that are not recommended therapies

Strategies that should not be used for CFS/ME

Do not use the following drugs for the treatment of CFS/ME:

- monoamine oxidase inhibitors
- glucocorticoids (such as hydrocortisone)
- mineralocorticoids (such as fludrocortisone)
- dexamphetamine
- methylphenidate
- thyroxine
- antiviral agents.

Do not offer the following strategies to people with CFS/ME:

- Advice to undertake unsupervised, or unstructured, vigorous exercise (such as simply 'go to the gym' or 'exercise more') because this may worsen symptoms.
- Specialist management programmes (see [specialist CFS/ME care \[See page 7\]](#) in this pathway) delivered by practitioners with no experience in the condition.

Although there is considerable support from patients (particularly people with severe CFS/ME) for the following strategies, be aware that there is no controlled trial evidence of benefit:

- Encouraging maintenance of activity levels at substantially less than full capacity to reserve energy for the body to heal itself (sometimes known as the envelope theory).
- Encouraging complete rest (cognitive, physical and emotional) during a setback/relapse.

Strategies for managing CFS/ME should not include:

- Prolonged or complete rest or extended periods of daytime rest in response to a slight increase in symptoms.
- An imposed rigid schedule of activity and rest.

Complementary therapies

There is insufficient evidence that complementary therapies are effective treatments for CFS/ME and therefore their use is not recommended. However, some people with CFS/ME choose to use some of these therapies for symptom control, and find them helpful.

9 Plan for and manage setbacks and relapses

Preparing for a setback/relapse

Advise people with CFS/ME that setbacks/relapses are to be expected as part of CFS/ME.

Develop a plan for managing setbacks/relapses, so that skills, strategies, resources and support are readily available and accessible when needed. This plan may be shared with the person's carers, if they agree.

During a setback/relapse

Setbacks/relapses may be triggered by factors such as unexpected/unplanned activities, poor sleep, infection or stress. In discussion with the person with CFS/ME, try to identify the cause(s) of a setback/relapse, but recognise that this may not always be possible.

Review the management plan when managing a setback/relapse. Discuss and agree an appropriate course of action with the person with CFS/ME, taking into account:

- the person's experience
- possible causes of the setback/relapse, if known
- the nature of the symptoms
- the severity and duration of the setback/relapse
- the current management plan.

When managing setbacks, put strategies in place that:

- Include relaxation and breathing techniques.

- Maintain activity and exercise levels if possible, by alternating activities with breaks and pacing activities, as appropriate.
- Involve talking to families and carers, if appropriate.
- Recognise distressing thoughts about setbacks/relapses such as 'this means I'll never get better', but encourage optimism.
- Involve reconsidering and revising the levels and types of symptom control.

In some setbacks/relapses, it may be necessary to reduce, or even stop some activities and increase the frequency and/or duration of rest periods to stabilise symptoms and re-establish a baseline activity level. This should be discussed and agreed with the person with CFS/ME.

Advise people with CFS/ME to minimise daytime sleep periods. However, recognise that this is not always possible, depending on the severity of a person's symptoms and the setback.

After a setback/relapse

After a setback/relapse, review the person's activity levels to re-establish a baseline and review the management plan. Encourage a gradual return, when possible, to previous exercise and functional routines. Increase activity gradually.

Advise:

- Slowly decreasing the frequency and duration of rest periods.
- Continuing the use of relaxation techniques, even when the person with CFS/ME is beginning to feel better.

After a setback, review the experience to determine, if possible, whether triggers can be managed in the future, and put strategies in place to do this.

10 When to consider referral to specialist care

[See Chronic fatigue syndrome myalgic encephalomyelitis / Assessment and diagnosis of chronic fatigue syndrome myalgic encephalomyelitis / When to consider referral to specialist care](#)

11 Structured review

[See Chronic fatigue syndrome myalgic encephalomyelitis / Chronic fatigue syndrome myalgic encephalomyelitis overview / Structured review](#)

Glossary

Activity

Any task or series of tasks that a person performs. A task may have physical, emotional, cognitive and social components.

Activity management

A person-centred approach to managing a person's symptoms by using activity. It is goal-directed and uses activity analysis and graded activity to enable people to improve, evaluate, restore and/or maintain their function and well-being in self-care, work and leisure.

Age

- Adult: aged 18 years and older.
- Young person: aged between 12 and 17 years.
- Child: aged between 5 and 11 years.

The age at which care is transferred between child and adult health services varies between 16 and 19 years, depending on the young person and their family's preferences and local circumstances.

'Boom and bust' cycles

Cycles of fluctuating activity levels and symptoms, which are a common feature of CFS/ME. Boom and bust cycles can happen when a person with CFS/ME is overactive when they are feeling better, which may lead to an increase in symptoms and a decrease in function.

Cognitive behavioural therapy (CBT)

An evidence-based psychological therapy that is used in many health settings, including cardiac rehabilitation and diabetes management. It is a collaborative treatment approach. When it is used for CFS/ME, the aim is to reduce the levels of symptoms, disability and distress associated with the condition. A course of CBT is usually 12–16 sessions. The use of CBT does not assume or imply that symptoms are psychological or 'made up'.

Deconditioning

Loss of physical fitness as the general physiological response to, for example, a prolonged period of inactivity.

Graded exercise therapy (GET)

An evidence-based approach to CFS/ME that involves physical assessment, mutually negotiated goal-setting and education. The first step is to set a sustainable baseline of physical activity, then the duration of the activity is gradually increased in a planned way that is tailored to the person. This is followed by an increase in intensity, when the person is able, taking into account their preferences and objectives, current activity and sleep patterns, setbacks/relapses and emotional factors. The objective is to improve the person's CFS/ME symptoms and functioning, aiming towards recovery.

Pacing

The report of the Chief Medical Officer's working group defined the principles of pacing, and these are supported by people with CFS/ME and patient groups. Many of the principles are included in this guideline's recommendations on CBT, GET and activity management. Examples include spreading activities over the week, breaking tasks down into small manageable parts, interspersing activity with rest and setting appropriate, realistic goals for increasing activity.

In this guideline, pacing is defined as energy management, with the aim of maximising cognitive and physical activity, while avoiding setbacks/relapses due to overexertion. The keys to pacing are knowing when to stop and rest by listening to and understanding one's own body, taking a flexible approach and staying within one's limits; different people use different techniques to do this.

However, in practice, the term pacing is used differently by different groups of people. One understanding of its meaning is as adaptive pacing therapy, which is facilitated by healthcare professionals, in which people with CFS/ME use an energy management strategy to monitor and plan their activity, with the aim of balancing rest and activity to avoid exacerbations of fatigue and other symptoms.

Another understanding is that pacing is a self-management strategy, without specific intervention from a healthcare professional. People with CFS/ME generally support this approach.

Rest periods

Short periods when a person is neither sleeping nor engaged in physical or mental activity. Rest periods are a core component of all management approaches for CFS/ME.

Setback/relapse

An increase in symptoms above the usual daily fluctuations, which may result in a reduction in function for a time.

Severity

The degree to which CFS/ME affects a person's functioning and daily life.

- People with mild CFS/ME are mobile, can care for themselves and can do light domestic tasks with difficulty. Most are still working or in education, but to do this they have probably stopped all leisure and social pursuits. They often take days off, or use the weekend to cope with the rest of the week.
- People with moderate CFS/ME 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, school or college and need rest periods, often sleeping in the afternoon for 1 or 2 hours. Their sleep at night is generally poor quality and disturbed.
- People with severe CFS/ME are unable to do any activity for themselves, or can carry out minimal daily tasks only (such as face washing, cleaning teeth). They have severe cognitive difficulties and 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 noise.

Specialist CFS/ME care

A service providing expertise in assessing, diagnosing and advising on the clinical management of CFS/ME, including symptom control and specific interventions. Ideally this is provided by a multidisciplinary team, which may include GPs with a special interest in the condition, neurologists, immunologists, specialists in infectious disease, paediatricians, nurses, clinical psychologists, liaison psychiatrists, dietitians, physiotherapists and occupational therapists.

Stage

There are different stages in the natural course of CFS/ME: acute illness, maintenance or stabilisation, and recovery.

Sources

Chronic fatigue syndrome / myalgic encephalomyelitis (2007) NICE guideline CG53

Your responsibility

The guidance in this pathway represents the view of NICE, which was arrived at after careful consideration of the evidence available. Those working in the NHS, local authorities, the wider public, voluntary and community sectors and the private sector should take it into account when carrying out their professional, managerial or voluntary duties. Implementation of this guidance is the responsibility of local commissioners and/or providers. Commissioners and providers are reminded that it is their responsibility to implement the guidance, in their local context, in light of their duties to avoid unlawful discrimination and to have regard to promoting equality of opportunity. Nothing in this guidance should be interpreted in a way which would be inconsistent with compliance with those duties.

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