

## Specialist care for chronic fatigue syndrome myalgic encephalomyelitis

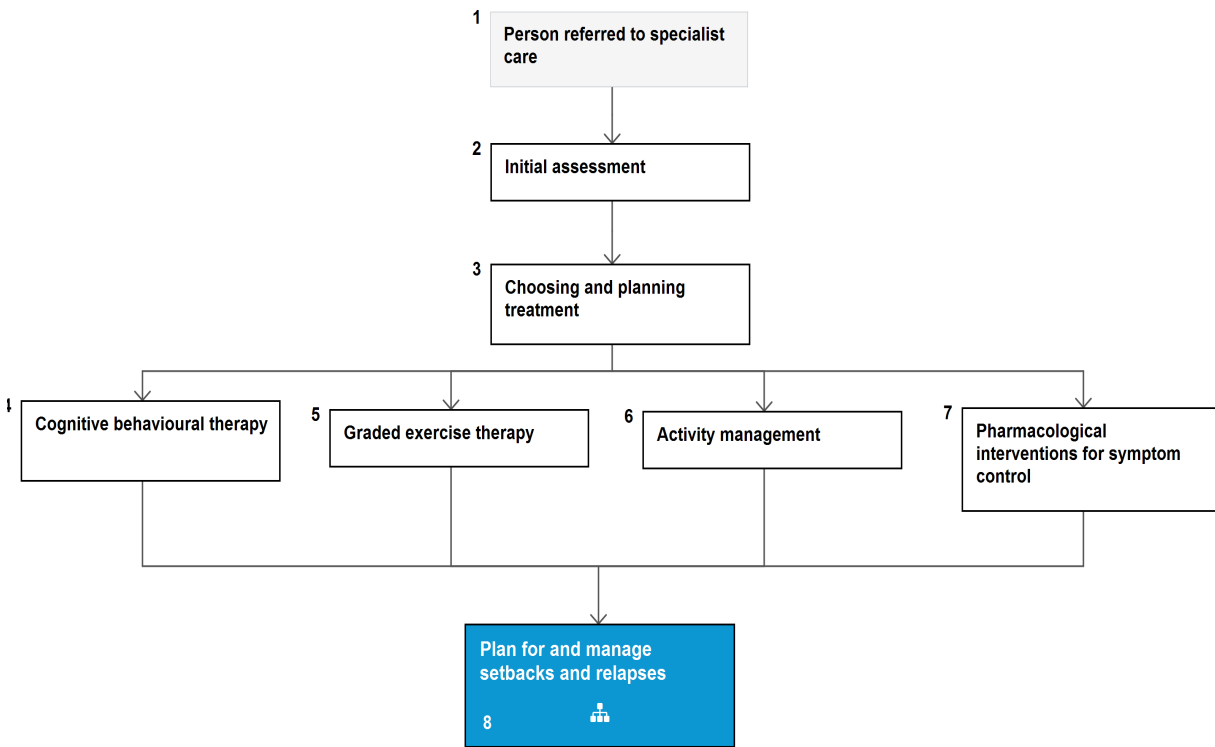
A NICE pathway brings together all NICE guidance, quality standards and materials to support implementation on a specific topic area. The pathways are interactive and designed to be used online. This pdf version gives you a single pathway diagram and uses numbering to link the boxes in the diagram to the associated recommendations.

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 Person referred to specialist care

No additional information

## 2 Initial assessment

After a patient is referred to specialist care, perform an initial assessment to confirm the diagnosis.

If general management strategies (see [management of CFS/ME](#) in this pathway) are helpful for a person with CFS/ME, continue these after referral to specialist CFS/ME care.

## 3 Choosing and planning treatment

Offer an individualised, person-centred programme to people with CFS/ME. The objectives of the programme are:

- to sustain or gradually extend, if possible, the person's physical, emotional and cognitive capacity
- to manage the physical and emotional impact of their symptoms.

Fully explain the rationale and content of the different programmes, including their potential benefits and risks, to the person with CFS/ME. Explain that no single strategy will be successful for all patients, or during all stages of the condition.

Recognise that the person with CFS/ME is in charge of the aims of the programme. Mutually agree the choice of the programme, its components, and progression throughout the programme based on:

- the person's age, preferences and needs
- the person's skills and abilities in managing their condition, and their goals (such as improvement or treatment of deterioration of symptoms, prevention of relapse or maintenance)
- the severity and complexity of symptoms

physical and cognitive functioning.

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

If a full CBT or graded exercise therapy programme is inappropriate or not available, components of CBT or graded exercise therapy, either individually or more effectively in combination with:

- activity management strategies
- sleep management
- relaxation techniques

(See activity management in this path and [sleep, rest and relaxation](#) in the management of CFS/ME path.)

Regularly review the choice of programme, its components and progression through it, taking into account the goals and abilities of the person with CFS/ME, and other approaches agreed as necessary.

Advise people with CFS/ME to contact a healthcare professional if they experience an increase in symptoms that lasts for longer than a few days after starting the specialist programme, or if symptoms are severe or distressing.

## 4 Cognitive behavioural therapy

A course of CBT should be delivered only by a therapist with appropriate training in CBT and experience in CFS/ME, under clinical supervision. The therapist should adhere closely to empirically grounded therapy protocols.

Offer CBT on a one-to-one basis if possible.

Plan CBT for a person with CFS/ME according to the usual principles of CBT, and include:

- Acknowledging and validating the person's symptoms and condition.
- Explaining the CBT approach in CFS/ME, such as the relationship between thoughts, feelings, behaviours and symptoms, and the distinction between causal and perpetuating factors.
- Discussing the person's attitudes and expectations.
- Developing a supportive and collaborative therapeutic relationship.

- Developing a shared formulation and understanding of factors that affect CFS/ME symptoms.
- Agreeing therapeutic goals.
- Tailoring treatment to the person's needs and level of functioning.
- Recording and analysing patterns of activity and rest, and thoughts, feelings and behaviours (self-monitoring).
- Establishing a stable and maintainable activity level (baseline) followed by a gradual and mutually agreed increase in activity.
- Challenging thoughts and expectations that may affect symptom improvement and outcomes.
- Addressing complex adjustment to diagnosis and acceptance of current functional limitations.
- Developing awareness of thoughts, expectations or beliefs and defining fatigue-related cognitions and behaviour.
- Identifying perpetuating factors that may maintain or exacerbate CFS/ME symptoms to increase the person's self-efficacy (sense of control over symptoms).
- Addressing any over-vigilance to symptoms and related checking or reassurance-seeking behaviours by providing physiological explanations of symptoms and using refocusing/distractioin techniques.
- Problem solving using activity management and homework tasks to test out alternative thoughts or beliefs, such as undertaking pleasure and mastery tasks (tasks that are enjoyable and give a sense of accomplishment).
- Building on existing assertion and communication skills to set appropriate limits on activity.
- Managing sleep problems, for example by addressing any unhelpful beliefs about sleep, behavioural approaches to sleep disturbance, stress management, and/or relaxation training (see [sleep, rest and relaxation](#) in this pathway).
- Treating any associated or comorbid anxiety, depression or mood disorder according to NICE clinical guidelines on these conditions (see the NICE pathway on [generalised anxiety disorder](#)).
- Offering information on managing setbacks/relapses (see [plan for and manage setbacks and relapses](#) in this pathway).

## 5 Graded exercise therapy

Graded exercise therapy should be delivered only by a suitably trained therapist with experience in CFS/ME, under appropriate clinical supervision.

Offer graded exercise therapy on a one-to-one basis if possible.

Offer graded exercise therapy that includes planned increases in the duration of physical activity to people with mild or moderate CFS/ME. Increase the intensity when appropriate, leading to aerobic exercise (that is, exercise that increases the pulse rate).

Base graded exercise therapy on the person's current level of activities (such as physical activity, daily routines, sleep patterns and frequency of setbacks/relapses) and emotional factors, vocational or educational factors and individual goals (details of these may be obtained from an activity diary). The programme should also include sleep and relaxation strategies (see [sleep, rest and relaxation](#) in this pathway).

When planning graded exercise therapy:

- Undertake an activity analysis to ensure that the person with CFS/ME is not in a 'boom and bust' cycle before they increase the time spent in exercise.
- Discuss with the person the ultimate goals that are important and relevant to them. This might be, for example, a twice-daily short walk to the shops, a return to a previous active hobby such as cycling or gardening, or, for people with severe CFS/ME, sitting up in bed to eat a meal.
- Recognise that it can take weeks, months or even years to achieve goals, and ensure that this is taken into account in the therapy structure (for example, by setting short- and medium-term goals).
- Explain symptoms and the benefits of exercise in a physiological context.

When starting graded exercise therapy:

- Assess the person's current daily activities to determine their baseline.
- Agree with them a level of additional low-intensity exercise that is sustainable, independent of daily fluctuations in symptoms, and does not lead to 'Boom and bust' cycles. This may be sitting up in bed or brushing hair, for example, for people with severe CFS/ME, or gentle stretches or a slow walk.
- Encourage them to undertake this exercise for at least 5 days out of 7, or build up to this level if and when possible.
- Advise them that this level of exercise may mildly increase symptoms for a few days (for example, a mild to moderate increase in stiffness and fatigue), explain why this may occur and discuss strategies to mitigate it.
- Offer information on the management of setbacks/relapses (see [plan for and manage setbacks and relapses](#) in this pathway).

### Progressing with graded exercise therapy

When the low-intensity exercise can be sustained for 5 days out of 7 (usually accompanied by a reduction in perceived exertion), review and increase the duration, if appropriate, by up to 20%.

For example, a 5-minute walk becomes 6 minutes, or a person with severe CFS/ME sits up in bed for a longer period, or walks to another room more often. The aim is to reach 30 minutes of low-intensity exercise.

When the duration of low-intensity exercise has reached 30 minutes, increase the intensity of the exercise gradually up to an aerobic heart rate zone, as assessed individually. A rate of 50-70% maximum heart rate is recommended.

Measure exercise intensity using a heart rate monitor, so that the person knows they are within their target heart rate zone.

If agreed graded exercise therapy goals are met, increase exercise duration and intensity further if appropriate, if other daily activities can also be sustained, and in agreement with the person with CFS/ME.

### **Maintaining exercise**

After completing a graded exercise therapy programme, continue working together to develop and build on strategies to maintain exercise. Provide support, if needed, to enable the person to reinforce the learning and lifestyle changes made and continue graded exercise therapy beyond discharge.

## **6 Activity management**

Activity management is a goal-oriented and person-centred approach tailored to the needs of the person with CFS/ME. It should include:

- Understanding that activities have physical, emotional and cognitive components, and identifying these components.
- Keeping a diary that records cognitive and physical activity, daytime rest and sleep. This will help to set baseline levels of activity (a stable and sustainable range of functioning), identify patterns of over- and underactivity, and develop an activity/exercise strategy.
- Establishing a baseline; specific activities may need to be increased or decreased while this is happening.
- Gradually increasing activity above the baseline in agreement with the person.
- Planning daily activities to allow for a balance and variety of different types of activity, rest and sleep. This may include making a weekly activity schedule.
- Spreading out difficult or demanding tasks over the day or week.

- Splitting activities into small achievable tasks according to the person's level of ability/functioning, followed by gradual increases in the complexity of the tasks.
- Monitoring, regulating and planning activities to avoid a 'boom and bust' cycle.
- Goal setting, planning and prioritising activities.
- Explaining the role of rest in CFS/ME and helping the person work out how to build in rest periods and achieve a productive day (see [sleep, rest and relaxation](#) in this pathway).
- Regularly reviewing activity levels and goals.
- Offering information on the management of setbacks/relapses (see [plan for and manage setbacks and relapses](#) in this pathway).

### People with severe CFS/ME

Offer people with severe CFS/ME an individually tailored activity management programme as the core therapeutic strategy, which may:

- be delivered at home, or using telephone or email if appropriate
- incorporate the elements above and draw on the principles of CBT and GET (see cognitive behavioural therapy and graded exercise therapy in this path).

Review an activity management programme regularly and frequently.

## 7 Pharmacological interventions for symptom control

If chronic pain is a predominant feature, consider referral to a pain management clinic.

Prescribing of low-dose tricyclic antidepressants, specifically amitriptyline, should be considered for people with CFS/ME who have poor sleep or pain. Do not offer tricyclic antidepressants to people who are already taking selective serotonin reuptake inhibitors (SSRIs) because of the potential for serious adverse interactions.

Melatonin may be considered for children and young people with CFS/ME who have sleep difficulties, but only under specialist supervision because it is not licensed in the UK.

## 8 Plan for and manage setbacks and relapses

[See Chronic fatigue syndrome myalgic encephalomyelitis / Management of chronic fatigue syndrome myalgic encephalomyelitis / Plan for and manage setbacks and relapses](#)



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## 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.

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## 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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## Contact NICE

National Institute for Health and Care Excellence  
Level 1A, City Tower  
Piccadilly Plaza  
Manchester  
M1 4BT

[www.nice.org.uk](http://www.nice.org.uk)

[nice@nice.org.uk](mailto:nice@nice.org.uk)

0845 003 7781