

Understanding NICE guidance

Information for people who use NHS services

Chronic fatigue syndrome/ myalgic encephalomyelitis (or encephalopathy)

NICE 'clinical guidelines' advise the NHS on caring for people with specific conditions or diseases and the treatments they should receive.

This booklet is about the care of people with chronic fatigue syndrome, which is also called myalgic encephalomyelitis (or encephalopathy), in the NHS in England and Wales. Throughout this booklet we refer to the condition as CFS/ME for short. The booklet explains guidance (advice) from NICE (the National Institute for Health and Clinical Excellence). It is written for people with CFS/ME, and parents or carers of people with the condition. It may also be useful for other family members or for anyone with an interest in CFS/ME.

The booklet aims to help you understand the care and treatment options that should be available in the NHS.

It does not describe CFS/ME or the tests or treatments for it in detail. A member of your healthcare team should discuss these with you. There are examples of questions you could ask throughout this booklet to help you with this.

Some sources of further information and support are on page 18. Medical terms printed in **bold** type are explained on page 19. Information for people with severe CFS/ME is highlighted throughout the booklet.

Contents

What is CFS/ME?	3
How CFS/ME is diagnosed	4
General principles of care	6
Managing CFS/ME	9
Specialist CFS/ME care	12
Setbacks/relapses	16
Regular review of your care	17
More information about CFS/ME	18
Explanation of medical terms	19
About NICE	20

The advice in the NICE guideline covers:

- care for adults and children (5 years and older) with CFS/ME
- how CFS/ME should be diagnosed
- treatments and strategies that may be used
- information and support needs for people with CFS/ME.

It does not specifically look at:

- how to treat fatigue in people who have had a diagnosis of CFS/ME ruled out
- treating other illnesses or conditions the patient has as well as CFS/ME
- highly specialised treatments, or treatments that are under development.

What is CFS/ME?

CFS/ME is a long-term illness with a broad range of symptoms. The prominent symptom for most people is feeling extremely tired (fatigue) and generally unwell (malaise) after minimal effort, which can make it hard to do everyday tasks and activities. People with CFS/ME can also have headaches, sleep problems, muscle pain and problems concentrating. The pattern of a person's symptoms, and their severity, can vary from day to day, or even in the same day. Some people have relatively mild symptoms, while others have a serious illness that severely affects their everyday lives and their families. The illness may last a long time.

People with 'mild' CFS/ME are generally able to carry on everyday activities, such as their work or education, or housework, but with difficulty. To achieve this, they may have given up hobbies and social activities and need to rest in their spare time.

People with 'moderate' CFS/ME can't move around easily and have problems continuing normal levels of daily activities. They have usually had to give up their work or education, may need to sleep in the afternoon and rest frequently between activities, and have problems sleeping at night.

People with 'severe' CFS/ME are only able to do very basic daily tasks such as cleaning their teeth, or may need help even with these. They may be housebound or even bedbound most or all of the time and need a wheelchair to get around. They have problems with learning, memory and concentrating, and are usually very sensitive to noise and light. It may take them a long time to recover from an activity involving extra effort, such as leaving the house or talking for too long.

There is no one way of managing CFS/ME that helps everyone but there are several options to try (see pages 9–16).

Questions you might like to ask your healthcare team

- What is CFS/ME and how long will I have it?
- How will it affect my life and my family?
- Are there any support organisations in my local area?
- Where can I find self-help books and other information?
- Who can provide information for my family/carers?

The contact details of some national support organisations are listed on page 18.

How CFS/ME is diagnosed

Investigating the symptoms

The symptoms of CFS/ME are similar to the symptoms of some other illnesses, and to find out what is wrong (make a diagnosis), your doctor will need to do some tests. There is no specific test that can identify CFS/ME, so the diagnosis has to be based on ruling out other conditions that could be causing your symptoms.

Your doctor should consider CFS/ME if you have disabling tiredness (fatigue) that is new or started suddenly, lasts a long time or keeps coming back and cannot be explained by other causes. CFS/ME should be considered if the fatigue means you can't do the things you used to, if it gets worse after activity or gentle **exercise** such as a short walk, and if you also have some of the following symptoms:

There is no test to diagnose CFS/ME – doctors diagnose CFS/ME based on your symptoms.

- sleep problems
- pain in the muscles or joints
- headaches
- sore throat or sore glands that aren't swollen
- problems thinking, remembering, concentrating or planning
- flu-like symptoms
- feeling dizzy or sick or having palpitations (irregular or fast heartbeats), or
- exercising or concentrating on something makes your symptoms worse.

Because CFS/ME has symptoms similar to many common illnesses that get better on their own, doctors should consider whether a person has CFS/ME if they do not get better as quickly as expected. On the other hand, some other serious illnesses may also have the same symptoms as CFS/ME. So your doctor should take special care to rule these out, particularly if you have any of the following:

- symptoms such as double vision or blackouts that suggest a problem with your nervous system
- painful, swollen joints
- chest or heart problems
- weight loss
- signs of stopping breathing for short periods while asleep (called sleep apnoea)
- persistently swollen glands.

Before making a diagnosis of CFS/ME your doctor should ask you questions about your medical history, do a thorough physical examination, and assess your mental health. They should carry out tests to rule out other causes of your symptoms. These will depend on your symptoms but will include urine and blood tests. Your doctor should consult a specialist if they are unsure about the diagnosis, or if you have severe symptoms.

While you are waiting for a diagnosis or a referral, you should be given advice and help to deal with (or manage) your symptoms so that your everyday life and activities are affected as little as possible.

If a child or young person under 18 years old has symptoms of possible CFS/ME they should be referred to a paediatrician (a specialist children's doctor) within 6 weeks of first seeing their doctor about the symptoms.

If you have new and/or distressing symptoms at any time, you should talk to your doctor about them.

Your doctor should consult a specialist if they are unsure about the diagnosis, or if you have severe symptoms.

Questions about diagnosis

- What are the tests you are offering and why am I having them?
- What do these tests involve? Please give me details.
- Where will these tests be carried out? Can I have them at home?
- How long will I have to wait until I have the tests?
- How long will it take to get the results, and how will I be told about them?

Reaching a diagnosis of CFS/ME

Your doctor should diagnose CFS/ME if your symptoms can not be explained by another cause and have lasted for:

- 4 months in an adult
- 3 months in a child or young person (the diagnosis should be made in consultation with a paediatrician).

Your doctor should reassure you that most people's condition improves with time, and many people recover and are able to go back to work and do their normal activities. But you also need to know that some people's symptoms do not improve. For children, the outlook is generally better than for adults.

General principles of care

All healthcare professionals should treat you with respect, sensitivity and understanding. They should explain CFS/ME and the different managements and treatments for its symptoms simply and clearly.

Your treatment and care, and the information you are given about it, should take account of any religious or cultural needs you may have. It should also take into account any additional factors, such as physical or learning disabilities, sight or hearing problems, or difficulties with reading or speaking English. Your healthcare team should be able to arrange an interpreter or an advocate (someone who supports you in putting across your views) if needed.

People involved in your care

You may see a number of different healthcare professionals, depending on your symptoms and circumstances. These may include:

- your GP (family doctor) and nurses at your GP practice
- specialist doctors working in a hospital
- physiotherapists, clinical psychologists, nurses and occupational therapists with experience of caring for people with CFS/ME.

There should be one named healthcare professional who is responsible for coordinating your care.

Making decisions

Your treatment and care should take into account your personal needs and preferences, and you have the right to be fully informed and to make decisions jointly with your healthcare team.

Your healthcare professional should:

- recognise that your condition is real and how the symptoms are affecting you
- give you information about CFS/ME, the treatments and care described in this booklet, and going back to work or education
- give you information about self-help and support groups for you and your family or carers
- take account of your wishes, your age, how severe your CFS/ME is, and any previous experience that is relevant to your current care.

You should be given information in a way you can understand and that is relevant to your circumstances, such as a leaflet or a tape to listen to.

The information should include details of the possible benefits and risks of particular treatments or therapies. You can ask any questions you want to and can always change your mind as your treatment progresses or your condition or circumstances change. You can choose to refuse, change or withdraw from a particular treatment at any time, without this affecting other aspects of your care or choices about your care in the future.

If you have severe CFS/ME, you should be offered a summary of every discussion so that you can refer to it afterwards.

If you have severe CFS/ME, you should be offered a summary of all discussions.

Involving family and carers

If you agree, your family and carers should have the chance to be involved in decisions about your care. Involving your family is particularly important if you are a child, or if you have severe CFS/ME. Family and carers also have the right to the information and support they need in their roles as carers.

If people are unable to understand a particular issue or are not able to make decisions for themselves, healthcare professionals should follow the advice that the Department of Health has produced about this. You can find this by going to the Department of Health website (www.dh.gov.uk) and searching for information on 'consent' and 'capacity'. Your healthcare professional should also follow the code of practice for the new Mental Capacity Act. For more information about this, visit www.direct.gov.uk and search for 'capacity'.

Questions for carers, family members or friends to ask

- What is CFS/ME?
- How will it affect the person with CFS/ME and our lives?
- What can I/we do to help and support the person with CFS/ME?
- Is there any additional support that I as a carer might benefit from or be entitled to?

Children and young people

A child or young person's right to make decisions about their care will depend on their age and their ability to fully understand the information and the risks and benefits of the care offered. If you are over 16, you may be able to give your own agreement to a treatment you are offered. If you are under 16 and fully understand the treatment, you may also be able to agree to it. But if you are too young to understand it fully, your parents or guardians may need to agree to your treatment.

Your care plan

The healthcare professional responsible for your care should make a care plan with you, which is looked at and kept up to date every time you see a healthcare professional about your CFS/ME. It should include the symptoms and history of your condition, plans of treatments and self-help techniques you may be using, information and support needs, plans for work or education, and contact details of the healthcare professionals caring for you.

Your care should be given in ways that are suitable for you. This may mean having some tests or treatments at home, or getting support and advice by telephone or email.

Managing CFS/ME

General advice

Your healthcare professional should fully explain and discuss all the options for managing your CFS/ME with you, and work with you to develop a care plan that suits you. If you have severe CFS/ME, your healthcare professional should get advice from a specialist.

There are no drug treatments for CFS/ME itself, but drugs can help with symptoms such as pain.

If you have severe CFS/ME, your healthcare professional should get advice from a specialist.

Diet and supplements

Your healthcare professional should advise you about the importance of eating a healthy balanced diet, with regular meals. They should help you work out ways of doing this if practical difficulties with shopping and preparing food or symptoms of CFS/ME are making it difficult.

If you have nausea (feel sick), you should be given advice about snacking on starchy foods, eating little and often, and sipping drinks slowly. If this doesn't work, and your symptoms are particularly severe, you may be offered drugs to control the nausea.

Special diets that exclude particular types of food are not generally recommended for people with CFS/ME. If you are planning to try one, your healthcare professional should get advice from a dietitian.

There is not enough evidence on using supplements such as vitamin B₁₂, vitamin C, co-enzyme Q10, magnesium, NADH (which stands for nicotinamide adenine dinucleotide) or multivitamins and minerals as a treatment for CFS/ME, and your healthcare professional should not prescribe these. If you take them, it is important to stay within the safe limits recommended by the Food Standards Agency. There is more information on the FSA website (www.eatwell.gov.uk).

Sleep, rest and relaxation

Your healthcare team should explain that people with CFS/ME often have changes in their sleep patterns that may make their symptoms worse. Common problems include being unable to get to sleep, having unrefreshing or restless sleep, needing excessive sleep, or needing to sleep during the day and being awake at night.

You should be given practical advice about establishing a normal sleep-wake pattern, because too much sleep generally does not improve other symptoms of CFS/ME, and too much sleep during the day can stop you sleeping at night.

Changes to your sleep pattern should be made gradually and your healthcare professional should review the situation regularly. If techniques to improve your sleeping pattern don't help, they should consider whether you have an underlying sleep problem.

You will probably need to take **rests** or breaks during the day and your healthcare professional should also give you advice about the best way to do this. This may include limiting the length of each rest to 30 minutes and teaching you how to use **relaxation techniques**. Your healthcare professional should also ask you about your rests regularly to make sure they are still as helpful as possible.

Rest for people with severe CFS/ME

If you have severe CFS/ME and need to spend much of your time in bed during the day, your healthcare professional should discuss this with a specialist. It can cause problems, including pressure sores and blood clots, as well as loss of strength in your muscles. These problems, and ways of reducing them, should be explained to you and your carers, and you should have regular checks to make sure these problems are not developing.

Equipment

If your symptoms are moderate or severe, your team should consider if you need any equipment or adaptations to improve your quality of life or independence, such as a wheelchair, blue badge (for parking concessions) or stairlift. This should be done as part of your overall management plan, taking into account the benefits and any possible risks for you individually.

Work and education

Your healthcare professional should be able to provide advice about work or education when you are ready and fit enough. With your agreement, your healthcare professional should give (or help you give) your employer, school or college information about your CFS/ME and how you are being cared for. They should suggest changes that could be made to help you get back to, or stay at, work, school or college and should contact organisations that can help with this, such as Job Centre Plus, your occupational health department and advisers at your local education authority.

What about other techniques?

Exercise

You should not be advised to take vigorous unplanned or unsupervised exercise (such as going to the gym or for a run).

Dramatically reducing activity or resting completely

Some people with CFS/ME have tried doing far less activity than they are capable of to allow the body spare energy to heal itself. But at the moment there is no evidence from research that this helps. There is also no research evidence that resting completely is helpful when symptoms are worse than usual (see 'Setbacks/relapses' on page 16).

You should also not be advised to take complete rest or more daytime rest if your symptoms get slightly worse, or to follow a rigid schedule of activity and rest.

Pacing

Another type of technique that many people with CFS/ME find helpful for managing their symptoms is '**pacing**'. Different people use the word pacing to mean different things, but the general aim is to balance rest and activity to avoid making your fatigue and other symptoms worse. Research is being done into pacing, but as yet there is not enough evidence about whether this improves CFS/ME or whether it has any risks. Many of the ideas of pacing are used in **activity management**, **cognitive behavioural therapy** and **graded exercise therapy**, with the support of a specialist who will help you find the right levels and types of activity for you (see pages 15–16).

Complementary medicine

There is not enough evidence about whether complementary medicine is helpful for CFS/ME for healthcare professionals to recommend it. If you do want to try, you should use a registered therapist who has experience of working with people with CFS/ME.

You should not be advised to do vigorous unplanned exercise, such as going to the gym or for a run because this may make your symptoms worse.

Questions about management and support for CFS/ME

- Can you suggest ways to help me sleep better at night?
- Can you give me more information about relaxation techniques?
- Can you give me any advice about benefits?
- How will I know when it is the right time for me to go back to work or education?
- What can be done to help me with work, or going back to school or college?
- What support will I receive?
- What happens if I have a relapse or my symptoms get worse?

Specialist CFS/ME care

If you think that your care does not match what is described in this booklet, please talk to a member of your healthcare team.

Referring you for specialist CFS/ME care

Specialist care for CFS/ME is ideally given by a team of healthcare professionals with different areas of expertise. The team works together to diagnose and manage the condition. The team may include GPs with special knowledge of CFS/ME, hospital doctors specialising in the nervous system, the immune system, mental health, infectious disease and children's health, psychologists, dietitians, physiotherapists, occupational therapists and nurses.

Any decision to refer you to specialist CFS/ME care will be made jointly by you and your healthcare professional, depending on your needs and symptoms. You can be referred at any time, but if you have mild CFS/ME you should be offered a referral within 6 months of first seeing your doctor about the symptoms. You should be offered a referral within 3–4 months if you have moderate symptoms, and immediately if you have severe symptoms. Children and young people should be referred to a paediatrician for tests within 6 weeks of seeing their doctor about symptoms that could be caused by CFS/ME (see page 5).

Any general technique or therapy that you have found helpful should be continued after you are referred to specialist care.

Specialist care for people with severe CFS/ME

If you have severe CFS/ME, specialist healthcare professionals will be involved in planning and providing your care. Most people with CFS/ME will not need to go into hospital. But this may sometimes be helpful if you have severe CFS/ME. For example, if you are having a lot of tests or assessments, it may be less tiring to stay in hospital rather than make several trips.

You may also need access to other types of services provided in the community, such as nursing, physiotherapy or occupational therapy. One named healthcare professional should coordinate this.

Therapies used in specialist CFS/ME care

The aim of specialist therapy should be to help you with your symptoms and to maintain, or if possible gradually increase, the amount of activity you can do.

Your specialist team should explain what the different therapies involve, and their pros and cons, to help you reach a decision with your team. The decision should take into account your preferences, your age, and the symptoms you have and how severe they are. You will be in charge of how quickly to work through the therapy, and you and your team should regularly discuss how it is going and make changes if needed.

Some people may experience an increase in symptoms during these therapies. You should be advised to contact your healthcare team if this lasts more than a few days or is severe or distressing.

If you have mild or moderate CFS/ME you should be offered **cognitive behavioural therapy** (called CBT for short) or **graded exercise therapy** (GET for short). These are explained in more detail below. If you choose one of these therapies, you should be able to have it. But if neither is available or suitable for you, you may be offered some parts of them. You may also be offered **activity management** (see pages 15–16), and sleep management and relaxation techniques (see pages 9–10).

Therapy for people with severe CFS/ME

If you have severe CFS/ME, the main approach recommended is activity management (see pages 15–16), suited to your needs. This may be given at home, or by telephone or email. But some parts of the GET and CBT approaches may also be helpful for you. Your therapy should be reviewed regularly and often.

Some treatments may not be suitable for you, depending on your exact circumstances. If you have questions about the specific treatments and options covered in this booklet, please talk to a member of your healthcare team.

Questions about specialist therapies and medication

- Please tell me why you have decided to offer me this particular type of therapy or medication.
- What are the pros and cons of this therapy or medication?
- Please tell me what the therapy will involve. How long does it last, and how often are the sessions?
- How will it help me? What effect will it have on my symptoms and everyday life? What sort of improvements can I expect?
- What happens if I have a sudden increase in symptoms?
- What are my options for having therapies other than the recommended therapy or medication?
- Is there a leaflet or tape about the therapy or medication that I can have?
- What will happen if I choose not to take up the recommended therapy or medication, or decide to stop?
- What happens if I have a bad reaction?

If a treatment described in this booklet appears suitable for you, but it is not available, you should talk to your local Patient Advice and Liaison Service (PALS) in the first instance. If they are not able to help you, they should refer you to your local Independent Complaints Advocacy Service.

Cognitive behavioural therapy

CBT is a psychological ('talking') therapy used to help in many illnesses such as cancer, heart problems and diabetes. If you are offered CBT, it does not mean that your healthcare professionals think your symptoms are 'in your head'. The therapy should be tailored to your individual needs and symptoms, and your current level of activity. The therapy should be given by a trained healthcare professional who is supervised and who has experience of using CBT to help people with CFS/ME. Your CBT therapist should:

- recognise your current symptoms
- explain how CBT can help people with CFS/ME by linking thoughts, feelings, behaviour and symptoms
- agree with you what your aims are
- build a supportive relationship with you.

Your CBT therapist should also help you to:

- become aware of and understand your thoughts, beliefs and behaviour related to your fatigue and your activity/rest patterns
- find a stable activity level at which you can function, which can be followed by a gradual increase in activity (or decrease if necessary)
- identify factors that may hinder your recovery and the way you manage your symptoms, such as feeling guilty about asking for help
- understand symptoms better so that you worry about them less and don't focus on them as much
- solve problems by learning to think in different ways
- manage any sleep problems (see pages 9–10).

Graded exercise therapy

If you have GET, it should be given by a trained professional with experience of using it to help people with CFS/ME, and given one to one if possible.

Planning your graded exercise therapy

If you are offered GET, it should be discussed and planned with you. It should be based on your own current activities, circumstances, routines, sleep patterns, work or school commitments and hobbies. You or your carers might be asked to keep a diary of these to help with planning. Your healthcare professional should discuss your ultimate goal from GET (for example, sitting up in bed to eat a meal, walking to the shops, or getting

back to cycling or gardening). It is important to be aware that it may take months or even years for you to reach your ultimate goal, so you and your therapist should agree some shorter-term goals.

Getting started

Your healthcare professional should first find out how much activity you are able to do normally (the 'baseline') and then agree with you a level of extra, low-intensity activity or exercise that you can manage, even on bad days. This might be sitting up in bed or brushing your hair, or a slow walk or gentle stretching. You should be encouraged to aim to do this activity at least 5 days a week or build up to this. This may slightly increase your symptoms for a few days, and your healthcare professional should discuss this with you.

The next stage

Once you are finding it fairly easy to manage the activity 5 days a week, you should be helped to try to gradually increase the time spent doing it. This should be done very slowly – for example, by increasing a 5-minute walk to 6 minutes – until you can manage about 30 minutes a day.

Over time, you may then be helped to work a little harder during the activity or exercise, with the aim of reaching a level at which you are increasing your heart rate, if possible. A trained professional should help you decide what level of activity or exercise is right for you, and you should be given a heart monitor to help you stay at the right heart rate level.

Where appropriate, you should be offered the chance to increase the exercise further if you wish, provided you are still able to manage other daily activities. When you have completed the therapy, you should be given support to continue using the techniques afterwards.

Activity management

When you start activity management, you and your healthcare professional should first work out a 'baseline' level of activity that you can manage to do regularly. You may need to try doing less or more of certain tasks to find out what this level is. Once you have decided this, you should agree together how to gradually increase your activity level over time, to suit your own needs and goals.

Your activity management should include:

- planning your time so there is a good balance of daily activity, rest and sleep, and more difficult tasks are spread over the day or week
- breaking activities down into smaller manageable tasks, which can gradually be built up
- avoiding doing too much on a day when you are feeling well, and then having to reduce your activity because your symptoms have got worse
- keeping a diary of activity, rest and sleep to help with finding your baseline, noticing patterns of over- and underactivity, and planning activity or exercise
- discussing how resting can help with CFS/ME, including the amount of rest best for you, and how to plan rest periods into your day
- regularly reviewing your activity levels and goals.

Specialist treatment for symptoms

If pain is one of your main symptoms, you may be offered a referral to a pain management clinic. Your CFS/ME specialist may offer you medication to help with symptoms, particularly sleep difficulties or pain. Occasionally, a child or young person may be offered a drug called melatonin to help with sleep problems. This should always be given by a paediatrician.

Setbacks/relapses

CFS/ME is a condition where the symptoms fluctuate or change, so from time to time your symptoms will become worse as a normal part of the illness. This does not mean you are not getting better. This is known as a 'setback' or 'relapse'. You should have a written plan to help you manage a setback/relapse, and get help when needed. This plan should be shared with those who care for or support you, and kept easily to hand.

During a setback

You and your healthcare professional should try to work out what may have caused your setback (for example, it might be extra or unplanned activity, an infection, or another illness or stress), but this is not always possible. Your healthcare professional should also help you develop a plan, depending on how severe the symptoms are, how long the setback has lasted, and any therapies or techniques you are using. They should encourage you to:

- use relaxation techniques
- keep up your activity levels if possible, but take more rest if needed
- talk to family and friends

- try to avoid distressing thoughts about the setback, such as, 'This means I will never get better'
- look at the ways your symptoms are being controlled and whether any changes are needed.

Sometimes you may need to reduce your activity levels. This should be done in discussion with your healthcare professional, and you should try to avoid increasing the amount of sleep you get during the day.

After a setback

When you are able, after a setback you and your healthcare team should discuss gradually increasing your activity levels and having fewer rest periods. If relaxation techniques are helpful, you should keep using them even when you begin to feel better. If any causes for your setbacks can be identified, it may be possible to plan for them and manage them in the future.

Regular review of your care

All people with CFS/ME should have planned, regular reviews of how their condition is being managed. How often this is done will depend on how bad your symptoms are, how well any treatments or therapies are working and on your needs. Each review should include where appropriate:

- assessing whether your symptoms are getting better or worse
- any problems or unwanted effects of treatments you are having
- any investigations you are having
- considering whether investigations should be repeated (for children and young people, repeating investigations should be considered if there is no improvement after a year)
- looking again at the diagnosis of CFS/ME, especially if your symptoms have changed significantly
- considering whether you should be referred to specialist CFS/ME care
- looking at any equipment you may need, and advice about benefits you may be entitled to.

More information about CFS/ME

The organisations below can provide more information and support for people with CFS/ME. Please note that NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

- Action for ME, 0117 927 9551, www.afme.org.uk
- Association of Young People with ME, 08451 232389, www.ayme.org.uk
- The ME Association, 0870 444 1836, www.meassociation.org.uk
- The Young ME Sufferers Trust, 0845 003 9002, www.tymestrust.org

NHS Direct online (www.nhsdirect.nhs.uk) may also be a good starting point for finding out more. Your local Patient Advice and Liaison Service (PALS) may also be able to give you further information and support.

NHS Expert Patient Programme (www.expertpatients.nhs.uk) offers courses for people with long-term conditions such as CFS/ME. They are run by other people with long-term conditions and help people get the most out of their lives.

Explanation of medical terms

Activity management A way for people to manage their symptoms by learning to analyse and plan activities so that they can achieve more at home, at work and at leisure.

Cognitive behavioural therapy A psychological ('talking') treatment that looks at how a person's thoughts, beliefs, behaviour and physical symptoms all fit together. CBT can help people feel more in control of their symptoms and to understand how their behaviour can affect the condition, such as if they tend to 'overdo' things on days when they are feeling a bit better. It does not mean that healthcare professionals think the person's symptoms are 'in their head' or 'made up' – it is used to help in many other illnesses such as cancer, heart problems and diabetes.

Exercise Any kind of physical activity, including general tasks of daily living. For example, brushing hair or getting dressed, sitting up in bed and walking about are all exercise.

Graded exercise therapy An approach for managing CFS/ME that involves planned increases in activity or exercise, working towards goals that are important for the person with CFS/ME. The first step in GET is to help to stabilise the amount of activity a person can do, then a manageable level of exercise is added. This is gradually increased towards aerobic exercise if and when the person is able, aiming towards recovery.

Pacing Different people use the word pacing to mean different things, but the aim is to balance rest and activity to avoid making fatigue and other symptoms worse. Many people with CFS/ME find pacing helps their symptoms, but as yet there is not enough evidence about whether it improves CFS/ME or whether it has any risks. Activity management, CBT and GET use many of the ideas of pacing, with help from a specialist.

Rest Short periods of time when a person is neither sleeping nor doing things. Rest periods are an important part of any therapy for CFS/ME.

Relaxation techniques These include learning how to relax your muscles progressively and breathing techniques. They can be used to help with sleep problems, stress, anxiety and pain, and can be included in rest periods.

About NICE

NICE produces guidance (advice) for the NHS about preventing, diagnosing and treating different medical conditions. The guidance is written by independent experts including healthcare professionals and people representing patients and carers. They consider the best available evidence on the condition and treatments, the views of patients and carers and the experiences of doctors, nurses and other healthcare professionals working in the field. Staff working in the NHS are expected to follow this guidance.

To find out more about NICE, its work and how it reaches decisions, see www.nice.org.uk/aboutguidance

This booklet and other versions of this guideline aimed at healthcare professionals are available at www.nice.org.uk/CG053

You can order printed copies of this booklet from the NHS Response Line (phone 0870 1555 455 and quote reference N1303).