All about M.E.

symptoms and management

Transforming the world of M.E.

action for m·e

Foreword

Myalgic Encephalomyelitis (M.E.) is a chronic fluctuating illness. It is commonly also known as Chronic Fatigue Syndrome (CFS or CFS/M.E.). Sometimes it is diagnosed as Post Viral Fatigue Syndrome (PVFS).

The onset of M.E. can be gradual or sudden. The symptoms vary from person to person and they may be mild, moderate or severe.

Whatever your experience, you share something in common with every other person with M.E. – you want to make sure you're doing all the right things to help you get better.

Coping with M.E. is a challenge but there are ways in which you can take control and learn to manage the illness effectively.

This booklet has been developed with the input of professionals and people with the illness to help you find out about M.E. We hope you find it useful.

We are particularly grateful to Sue Pemberton, Dr Hiroko Akagi, Dr Philip Wood and Suzanne Moore, Leeds & West Yorkshire CFS/M.E. Service, for their guidance on updating this booklet and Dr Janet Gray, Medical Adviser to Bristol and Bath NHS CFS/M.E. services, for reviewing the section on healthcare.

"I had crossed the boundary between exhaustion into feeling very ill, yet I still didn't have any word to describe it except 'tired'."

Cover photo: www.istockphoto.com

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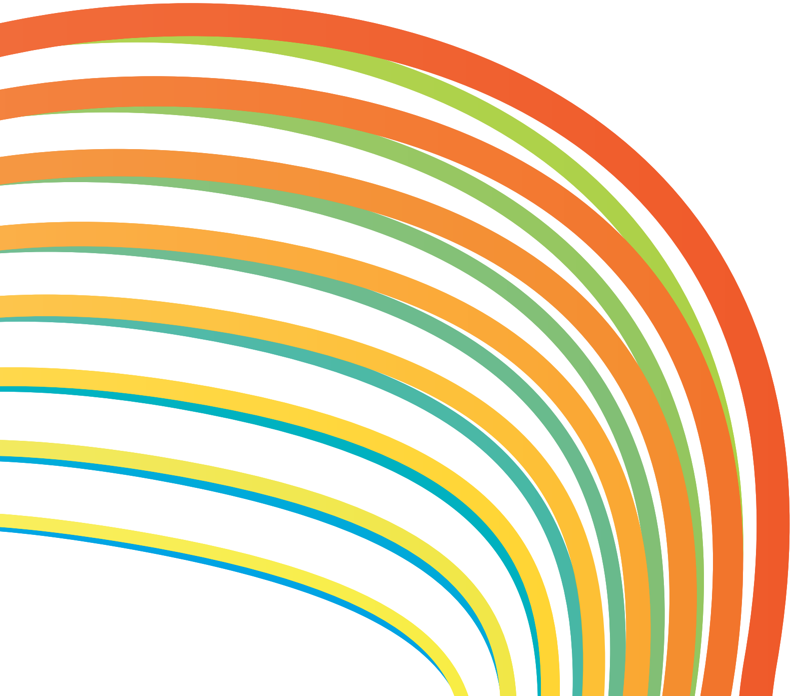
NHS guidelines

In 2007, the National Institute for Health and Clinical Excellence (NICE) published a clinical guideline on the diagnosis and management of CFS/M.E. for NHS healthcare professionals in England and Wales. It is available via links on our website www.actionforme.org.uk or directly from NICE by visiting www.nice.org.uk or by calling 0845 003 7783.

The guideline tells healthcare professionals that they should "acknowledge the reality and impact of the condition and the symptoms" and that "shared decision-making between the person with CFS/M.E. and healthcare professionals should take place during diagnosis and all phases of care."

In Scotland, NHS Scotland has produced a Good Practice Statement for healthcare professionals, Quick Reference Guide for GPs and leaflet for patients, facilitated by Action for M.E. The Guide emphasises that "All treatment should be collaborative and tailored to the needs of the individual patient." These documents are available on the NHS Scotland website, www.show.scot.nhs.uk and via links on our website, www.actionforme.org.uk. Or call us on 0845 123 2380.



Overview of M.E.

M.E. is a long-term (chronic) fluctuating illness that causes symptoms affecting many body systems, more commonly the nervous and immune systems. Many people will seek medical advice at some time because they experience persistent fatigue or pain. However, M.E. is characterised by a range of additional symptoms which can significantly affect your ability to live a normal life.

What are the symptoms?

Symptoms vary but may include persistent exhaustion ('fatigue'), muscle and/or joint pain, sleep disturbance, 'flu-like symptoms such as headache, sore throat, painful lymph nodes, dizziness and/or nausea and problems with memory and concentration. A more complete list is given on pp 9-11.

Who does M.E. affect?

Men, women and children of all ages and of all social and ethnic backgrounds can develop M.E., although it is most common in women aged 25-50. It is thought that around 250,000 people in the UK have the illness.

What causes M.E?

We don't fully understand what causes the illness. There are likely to be a number of factors involved. It sometimes affects more than one family member. The reasons are being studied but it seems your genetic make-up can play a part, as can the influence of your environment.

There is evidence that certain infections can trigger M.E. Many are viruses but M.E. can be triggered by other types of infection. Many of the infections which trigger M.E. seem to be ordinary flu-like infections, from which some people don't recover in the normal way. Find out more about triggers on p 8.

How is M.E. diagnosed?

There is no medical laboratory test currently available to detect M.E. Doctors diagnose the illness by assessing your medical history, recognising the typical symptom pattern of M.E. and conducting basic tests, for example on blood or urine samples, to rule out other conditions. Many illnesses can sound quite similar in their symptoms and excluding other conditions is a usual part of the process of reaching a diagnosis.

You may need to make several visits to your doctor before a final diagnosis is made. A provisional diagnosis should be made as early as possible.

The NICE guideline says a diagnosis should be made in adults if symptoms have lasted four months and other diagnoses have been excluded. In children or young people, diagnosis should be made (or confirmed by a paediatrician) after three months. The earlier that your illness is recognised, the sooner you can begin to manage and treat your symptoms.

When will I get better?

People with M.E. can vary enormously in their experience of the illness, and also how long their symptoms last. Many people make good progress quite quickly, while others can remain ill for a number of years.

Most people improve over time, especially with treatment (see p 20 onwards). For many, the illness fluctuates, with periods of remission and relapse. A small minority are severely affected (bedbound or housebound) for a long time.

People often find that they don’t go back completely to the way they felt before they became ill – but they do recover sufficiently and/or learn to manage their symptoms well enough to lead happy and fulfilling lives. This is similar to many other chronic illnesses.

Treatment (symptom management) can help by reducing symptoms and making the experience of illness much less unpleasant in the short term. More importantly, rehabilitative approaches that are suited to your level of severity can maximise the chances of recovery and the rate at which it happens, as well as reducing the risk of setbacks and relapses.

Hold on to hope, but be prepared in case the illness does last a long time.

Factors that can hold back recovery

M.E. can be an extremely frustrating illness, particularly as the intensity of the different symptoms can fluctuate. Managing M.E. requires patience and self control.

On good days, you will naturally want to do more – but do too much and 24 hours or more later, you may find yourself in a relapse from which recovery will seem painfully slow. This pattern is called ‘boom and bust.’ If it becomes the norm it can be very distressing and it can undermine your confidence. There are also strong indications that this pattern can prolong the illness.

It is important to get to know your limits and to set yourself small, realistic goals for getting better. This may mean that initially you have to reduce your overall activity levels so that you can achieve a routine that you can sustain. You will achieve more by working within your limits and increasing activities very gradually, than by pushing the boundaries all the time. There are many small changes you can make on a daily basis that will improve your health in the long term.

The key to managing your illness is to 'pace' your physical and mental (including emotional) activity – to strike a balance between activity and rest and to make any changes in your routine small and gradual.

In the early stages of the illness in particular, or during a relapse, adequate rest may be necessary and helpful. It is important to think about the quality of your rest, not just the quantity. Many people with M.E. find it difficult to relax and therefore do not get the full benefit from their rest periods.

However, while rest is very important, doing too little or being totally inactive can be harmful. Prolonged inactivity can cause muscle wasting and weakness, making it even harder for you to perform everyday tasks. Some gentle activity, according to your limits, is important.

Find out about pacing on p 36.

Relapses and setbacks

During your illness you may experience periods of better health or well-being, but there may also be times when your health deteriorates.

Having a relapse or setback is not uncommon at some stage. Relapses can be mild or severe and can happen for many reasons, but often because of trying to do too much. You will need to make changes in your daily routine to manage any setbacks. Most importantly, you need to understand what is happening and to have a plan of what to do. Don't be disheartened by these hiccups in your progress. Some people say that they experience relapses throughout their recovery but that over time they get shorter or less severe through learning ways to manage them better.

Just as a small step forward in your health doesn't guarantee that you will immediately get better, a relapse doesn't have to mean that the course of your illness is on a downward curve. It could be just a blip!

Tell me more about …what triggers M.E.

Common viral triggers include glandular fever or Epstein-Barr virus (EBV). Other herpes viruses such as herpes simplex, VZV (causes chickenpox/shingles), HHV-6 and CMV, may sometimes trigger M.E., as can viral meningitis or labyrinthitis, commonly caused by enteroviruses, gastroenteritis, Hepatitis A, B and C infection and in Australia, Ross River virus.

Unfortunately attempts to prove links with XMRV have been unsuccessful.

Non-viral triggers include toxoplasma, brucella, salmonella, tuberculosis, Q fever, and Lyme disease.

However, there is no clear evidence that M.E. is a form of persistent, chronic infection – it may be a consequence of infection.

It is not clear why some people get M.E. while others recover normally. People who get M.E. may be vulnerable genetically, or their recovery after an infection could be affected by, for example, trying to return to work too soon, doing vigorous exercise, or experiencing major stresses.

We know much less about other triggers, because they are less common. Some people may in fact have had an infection, but didn't notice it at the time.

In a very small number of people, the trigger may have been an immunisation, given perhaps when they were already unwell, or a physical trauma, such as a road accident, operation, radiotherapy or chemotherapy, or whilst rare, it is suspected that a very few cases may be triggered by certain toxic substances.

One big outstanding question is whether emotional stressors can be a trigger. Studies are not clear, some suggesting a link and others not. It is unlikely that stressful life events, such as bereavement, can trigger M.E. on their own. However, it may be a combination of factors, as many people with M.E. find that increased stress occurred around the time they first got ill, perhaps around the same time as another trigger, such as an infection.

Often it isn't possible to find out exactly what caused your illness – but you can still improve the symptoms, despite not knowing the exact trigger.

…the symptoms

M.E. affects people in different ways and to differing degrees. It's a very variable illness and your symptoms can change over time. Don't be alarmed by the long list of symptoms given below; you may only experience a few of them.

Fatigue

- persistent and overwhelming tiredness, which is experienced as both physical and mental exhaustion
- is not significantly improved by resting

Feeling generally unwell

- having flu-like symptoms ("general malaise")

Recurrent sore throat

- with or without swollen glands

Pain

- aching muscles or joints
- nerve pains or pins and needles
- headache or migraine
- twitching muscles or cramps
- abdominal pain (stomach or bowel problems)

Sleep disturbance

- unrefreshing sleep
- difficulty getting off to sleep
- waking for long periods in the early hours
- light, dreamy, restless sleep
- sleep reversal (eg. sleeping from 4am till midday)
- hypersomnia (sleeping for a long time)

more…

Concentration, thinking and memory

- reduced attention span
- short-term memory problems
- word-finding difficulties
- inability to plan or organise thoughts
- loss of concentration
  - all often described by people with M.E. as “brain fog”

Mood

- frustration
- anxiety
- panic attacks
- low mood, depression
- mood swings and irritability

Problems with the nervous system

- poor temperature control
- dizziness on standing up
- hyper-sensitivity to light and sound
- sweating
- loss of balance

Digestive problems (which can also be Irritable Bowel Syndrome)

- nausea
- loss of appetite
- indigestion
- excessive wind/bloating
- cramps
- alternating diarrhoea and constipation

Intolerance eg:

- odours
- some foods (eg. dairy or wheat)
- some medications
- alcohol
- other substances

M.E. fatigue is very different from ordinary tiredness

Feeling extremely tired or exhausted most, or all of the time, is one of the main symptoms of M.E. This feels very different from ordinary tiredness. Simple physical or mental activities, or combinations of activities, can leave you feeling shattered or struggling to function. You can also experience an increase in other symptoms. You may feel the impact straightaway but it can typically take a day or two to kick in. This is a key feature of the way M.E. affects people.

Women often find that symptoms worsen at different times in their menstrual cycle.

Always get new symptoms checked by your doctor, as they may be unrelated to M.E.

Healthcare for people with M.E.

The family doctor or General Practitioner (GP) is usually the first point of contact for health advice or treatment. GPs work as part of a team, known as a primary healthcare team, which may also include practice nurses, community nurses, health visitors, pharmacists and other healthcare professionals.

Sometimes it may be necessary for your GP to refer you to a specialist. A visit to a specialist is known as 'secondary' care and can only be arranged through your GP.

In England, Clinical Network Coordinating Centres (CNCCs) have been set up in some major cities to offer multi-disciplinary services for people with the illness. However, services across the UK as a whole are patchy and it is not always easy to see a specialist with experience of M.E.

What can I expect from my NHS primary healthcare team?

Ideally your primary healthcare team should be able to manage your illness in the same way that they would other chronic health problems, such as diabetes or asthma. However some GPs are more confident and experienced with the diagnosis and management of this complex illness than others.

A GP who has experience of other patients with M.E. may be able to provide an appropriate management programme together with other members of the healthcare team. This might include treatments and strategies to help control symptoms and improve your quality of life. Complementary therapies such as acupuncture may be helpful in managing problems like pain and are sometimes available on the NHS.

If you suspect you may have M.E. or you have already been given a provisional diagnosis and are looking for confirmation of this, your GP should be able to reach a firm diagnosis but it may take several appointments to achieve. Sometimes a referral to a specialist may be necessary.

If you have had a diagnosis of M.E. for some time it is still important to visit your GP. This will help to ensure that your condition is monitored and that any medication you are taking is reviewed on a regular basis. If you experience significant setbacks or relapses, or need help or assistance with benefit and insurance claims, it is helpful if you and your GP have an established relationship.

If your GP has limited experience in the management of M.E., there is NHS guidance available (see p 4).

How can I make the most of appointments with my GP?

Because time will be limited, it is helpful to clarify the purpose of your visit and what you want to achieve at the beginning of the appointment.

When you visit your doctor you can choose to take a friend or relative with you. There can often be a lot of information to remember, so it can be helpful to have someone with you to listen to what is being said and to make notes.

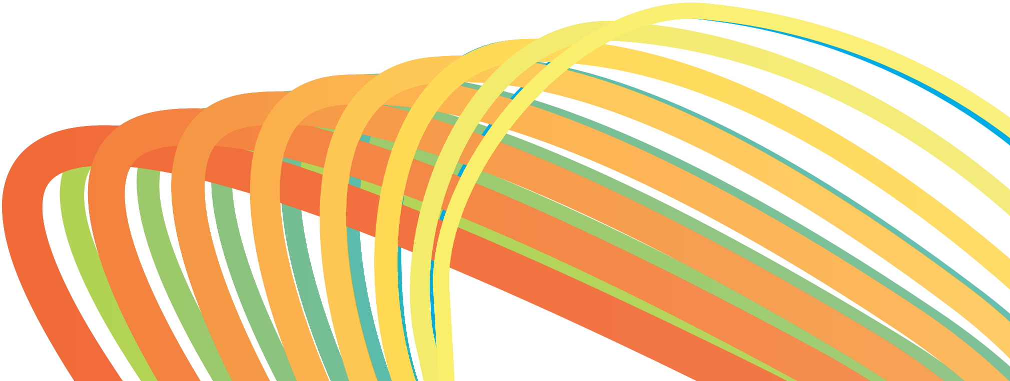
Sometimes it is possible to book a double appointment if you have a number of things you want to discuss.

It can help to write down questions you want to ask your doctor. Be sure to tell your GP about all the symptoms you are experiencing, even if they seem unrelated. They may be able to see a link which is not obvious to you.

If you develop any new health problems it is important that you discuss these with your GP so that they can assess whether the symptoms are part of your M.E. or are caused by something different.

You could try keeping a simple diary of your symptoms and problems to help you and your GP see a pattern and assess how your condition may be fluctuating. This can also be a helpful prompt if you see another healthcare professional or if you are filling out forms for benefit claims.

Make sure you understand everything your GP has told you before you leave the surgery. Don't be afraid to ask them to explain anything you're not sure about. It is important that you understand how to manage your care.



In summary:

- respect the 10 minute consultation – be brief and to the point
- ask for a double appointment next time if you think it necessary
- see your GP little and often – it works better that way
- try to be positive about what you can do, not negative about what you can't – you will win his/her admiration for being gutsy if you feel you are getting nowhere, try other doctors in the practice
- only change practices if absolutely necessary.

Don't over-exaggerate your symptoms – be accurate and concise. It's also best not to take in long print-outs from the internet – some GPs find that very irritating.

Remember that your GP is highly skilled at things like pain relief and other symptom management – you may just have to remind him/her that people with M.E. are generally more sensitive to drugs, so you may need to start with a lower than usual dose.

Even if your GP is not experienced at managing cases of M.E., he/she can still be supportive and helpful with symptom control and will, if handled right, learn from you. This is an enigma of an illness and your GP needs your help.

Advice by telephone

GPs are often happy to give advice on the telephone as it can save time for both you and them. Check with your surgery to find out if this is possible and if they have set times when they prefer patients to telephone. This could be convenient if you need specific advice but don't feel well enough to visit the surgery. If your GP is unavailable, you may be able to leave a message asking them to call you back when they are able to.

Seeing a different GP

There is often more than one GP in a practice and you can ask to see any of the GPs in the practice where you are registered. However, it is a good idea to try and see the same GP each time so that you can build a relationship with them.

Second opinion

You can ask to have a second opinion, but you are not automatically entitled to this.

Home visits

Your GP will decide if, and when, a home visit is required on the basis of your medical condition. This can be particularly important if you are severely affected with M.E. If you are unable to get to the surgery because you feel too ill to leave your home, it may be helpful to discuss this with your GP on the telephone or get a friend to do this for you. It may be possible for the district nurse to visit you, or for a friend or relative to go to the surgery on your behalf to discuss your condition. In this situation you would need to write a letter to your GP giving them permission to discuss your case.

Managing at home

Local Social Services/Social Work departments are responsible for providing home care services (formerly called home help) for people who need help at home with personal care, for example washing and dressing. There is normally a charge (which is means tested) for these services and the amount of help on offer varies across the UK. You can find the details of your local services in our online directory at www.actionforme.org.uk, or in the phone book, from Directory Enquiries, your local library or Citizens Advice Bureau.

Aids for people with disabilities are available from your doctor, other health care professionals involved in your care, local authority social services departments and a number of voluntary organisations. If your problems are severe it may be appropriate for you to be assessed by a community occupational therapist in order to receive modifications to your home such as ramps and stairlifts.

If you are experiencing significant problems with your diet and struggling to maintain an adequate food intake, discuss the possibility of a referral to a dietician with your GP or hospital specialist.

Complaints

If you have concerns, speak to someone directly involved in your care (GP, nurse, practice manager, receptionist), as they may be able to sort out the problem quite easily. If this doesn't resolve the matter try someone more senior. Each GP surgery and NHS organisation has a complaints procedure and you can speak or write to the person who deals with complaints. It is best to make your complaint as soon as you can as there may be a time limit within which complaints will be considered.

In England, there are Patient Advice and Liaison Services (PALS) available in all NHS and Primary Care Trusts which should be able to help you. PALS can give you information about the NHS complaints procedure and how you can get in touch with someone who can help. You can find your local PALS by contacting your local hospital, GP surgery or health centre. You can also call NHS Direct on 0845 4647.

For information on how to complain in Northern Ireland, Scotland or Wales contact the relevant NHS body on page 45.

Will I need to see a specialist?

Your GP should be able to diagnose your illness, but some GPs have limited experience of M.E. and may need to refer you to a specialist in secondary care. This can be because of the particular features of your illness, because of the severity or complexity of the problem, or to exclude other diagnoses. Discuss with your GP whether referral to a specialist would be helpful.

Specialists are usually based in hospital outpatient departments. They may be a specialist in other medical conditions but have an interest in M.E. Your referral may not be to your nearest hospital and there may be a waiting list.

In the treatment of M.E. the speciality of the consultant (eg. immunologist) is less important than their knowledge, experience and understanding of M.E.

Some places, mostly in England, have special NHS multi-disciplinary clinics for CFS/M.E., other areas may have just one healthcare professional with a special interest in the illness: it varies.

Depending on your symptoms, you may meet a number of professionals across the health and social welfare sectors, including physiotherapists, occupational therapists, clinical psychologists or other mental health professionals, nurses, dieticians and social workers (see opposite).

If you decide to see a specialist or therapist privately, it's important to keep your GP informed, so that your treatment can be coordinated and managed effectively. See p 18.

How can I prepare for my visit to a specialist?

To reduce stress and minimise the delayed fatigue that can so often be experienced with M.E. try to allow plenty of time for the journey to your hospital appointment. It is also important to allow yourself time to rest afterwards.

It is often helpful to be accompanied, for some or all of the appointment, by a carer or friend. They can help provide additional information or perspective during the consultation if needed. They can also make notes of any key points discussed during the appointment.

Your GP should send any relevant test results and other related information with your referral letter. You might find it helpful to prepare for the appointment by writing a simple summary of what has happened to you medically. This can be particularly helpful if your story is complicated and will be a useful prompt for you. A list of your main symptoms and how they affect you, plus an outline of your current level of activity and of your main concerns can help to focus discussion and make best use of the available time.

It is important to have a record of any other health professionals you have seen or are seeing. Also a list of the medication you are taking currently and in the past, the dose and whether you have felt any benefit or experienced side effects. It is also a good idea to ensure that the specialist is aware of any complementary therapies you are using or have tried.

What can I expect at the appointment?

The specialist will want to make a full assessment of your situation, leading to a diagnosis. They should also outline an overall plan of management and how it will be achieved and provide a rough idea of what the initial timescale and goals will be. This will be given as advice to you in person and in a letter to your GP. The plan may include advice on managing physical and mental activity, lifestyle changes and adjustment and coping. The details will depend on individual circumstances.

The specialist may discuss treatments. This may be medication or the use of other approaches that can help alleviate symptoms such as pain, sleep disturbance, mood disturbance, gut problems, dizziness, etc. If medication is suggested, this may be prescribed at the appointment or recommended to your GP for you to try later.

They may discuss the necessity of a referral to another specialist or professional for some specific aspect of your symptoms or condition. This could involve professionals such as physiotherapists, occupational therapists, dieticians, social workers, counsellors or clinical psychologists. Depending on the nature of the problem and the best options for treatment, any further referrals might not be conducted at the same hospital and there may be a waiting period for the first visit. If you do see another professional they will assess you and then plan further visits if necessary. They will also keep your GP and specialist updated.

Issues about welfare benefits, employment and/or education may need to be addressed. The specialist may be able to write letters in support, if appropriate.

What can I expect after my appointment with a specialist?

The specialist will decide with you and your GP the most appropriate medical supervision and follow-up arrangements. Your GP will be the main person for supervising your ongoing care, and will normally be the first point of contact for any problems that arise.

Please remember that if you decide to see a specialist privately it is important that they keep your GP and any NHS specialist informed so that your treatment is managed effectively.

What if I want to see a private practitioner?

Many people with M.E. try different approaches to help them manage their illness and their symptoms. Most private practitioners and complementary therapists are competent, ethical and caring. Surveys of our members consistently show that many people with M.E. value the approach of complementary therapists, which are discussed further on p 40.

Unfortunately, Action for M.E. also sometimes hears of practitioners who promise 'miracle cures,' charge excessively for treatments and even harm their patients. For this reason, we have set out the following guidance for people who are considering treatment with a private practitioner or therapist. This could be a private doctor, who operates outside the NHS or a complementary therapist.

- Always use a qualified therapist who belongs to a professional body.

  Most professional bodies will have a code of conduct which their members must follow. Ask what qualifications they have and which registered body they are affiliated to. Check that they have professional indemnity insurance. You could also contact the professional body to help you find a practitioner in your area.

- Find out about their experience. How many people with M.E. have they treated recently? What have their outcomes been? Do they keep a record/audit of treatment responses? At the moment, there is very little research into complementary therapies, so it can be difficult to know whether an approach is worth trying. Beware of any practitioner who tells you that their approach will cure you – there are no miracle cures. No one can be certain of how someone might benefit from a treatment. People with M.E. differ, sometimes greatly, in their response.

- Choose both a therapy and a practitioner that you feel comfortable with. You may be working with them for some time and so you need to feel 'at ease' with them, as well as feeling confident in their ability to treat you. You may choose to see someone who specialises in a therapy or you may prefer someone who can offer a range of therapies. Ask your local M.E. support group for feedback on a particular therapy you would like to try.

- When you are making your choice of practitioner you might want to think about your particular needs. For example, if you use a wheelchair is there good access?

- Ask about costs. What is the usual minimum, maximum and average cost of treatment? Ask specifically about the cost of tests, drugs or supplements. Explain that you would like to know about all possible costs before starting any treatment. Do they offer any concessions to patients on low incomes?

- Talk to your GP or specialist and ask for their advice, especially if your treatment involves taking pills or medicines. Ask them if they can recommend any therapies or practitioners. Make sure you thoroughly look into any therapy that is not prescribed by your doctor, as some treatments may be harmful. For example, some treatments may interact so should not be taken together. Check with your doctor if you're not sure. Think of complementary medicine as something that can work alongside, instead of replacing, your usual medical care.

A private doctor should inform your regular GP or specialist of any tests or treatment.

How is M.E. treated and managed?

There are no wonder drugs or treatments that can cure M.E. but there are many approaches open to you and your doctor that can make a difference to how you feel and give you back control over your situation.

It is important to establish a relationship with your doctor so that you can discuss all the management approaches available and 'problem solve' any issues together.

People with M.E. respond to treatment in different ways and what works for someone else may not be helpful for you, even if you share the same symptoms. It is important to adopt one approach or make one change at a time, to find out what works for you.

If left untreated, symptoms such as pain, sleep difficulties and mood problems can take over your life and get in the way of recovery. Your doctor and other healthcare professionals can help to treat these symptoms by prescribing medication and perhaps suggesting changes in your lifestyle. You will also discover tactics for yourself as you understand more about how M.E. is affecting your body.

You are the best judge of how you feel, so don't be afraid to discuss your treatment with your doctor, especially if you think it isn't working. Each different approach takes time to work, so be patient and don't expect results immediately. It may take some time to find the regime that suits you best, particularly as people with M.E. are thought to be more prone to side effects. It is advisable that drugs are started at lower doses than would normally be prescribed, to minimise side effects.

- If you have particular difficulties with pain, see opposite
- If you have significant sleep disruption, see p 27
- If you have mood problems such as anxiety or depression, see p 31

Dizziness or balance problems may be treated with medication.

Irritable Bowel Syndrome, which may also be a symptom, can be alleviated by antispasmodic medication and changes to your diet, see p 42.

If you have particular difficulties with pain…

Pain is a common problem for people who have M.E. It can be extremely disabling and may worsen other symptoms, such as fatigue, anxiety, cognitive difficulties like 'brain fog' (see p 10) and sleep disturbance. Chronic pain can also lead to low mood, depression and restriction of activity.

Low doses of some drugs normally used as antidepressants or anticonvulsants can help to control pain, such as nerve pain, that is not usually helped by standard painkillers. Muscle pain with twitching or cramps can be relieved by muscle relaxants. Headaches should be helped by simple painkillers, but if you suffer from migraines, you may need specific anti-migraine medication to control your symptoms.

If pain is a problem for you it is important to discuss it with your doctor. To help your doctor understand the pain you are experiencing it can be useful to begin by writing down your particular pain problems.

Explaining your pain

Think about the following questions.

- Where is the pain? People with M.E. commonly experience pain in their muscles, often this generalised across the body and not just in one specific place. Sometimes pain and aching can be experienced in the joints. Headaches and migraines are common and so are cramps and pains in the lower gut. It will help your doctor if you are as specific as possible about where your pain is located. If you think the pain is unrelated to your M.E, is new, or localised to a specific area make this clear to your doctor.
- How long have you had the pain? Has it just started? Have you had it for a long time?
- How often do you get pain and does anything make it worse or better? Is your pain always worse at night or when you get up in the morning?
- Is it triggered by certain activities such as sitting at a desk or driving?
- Is it worse when you are feeling worried or stressed?
- Is it constant? Does it come and go?
- What type of pain is it? Try and describe the pain you experience in words. Is it a sharp pain, shooting pain or a burning sensation? Is it an aching feeling, dull or cramplike? Is the pain an odd sensation like 'pins and needles' or would you describe it more like an 'electric shock'?

- Do you get other symptoms with the pain? For example, visual disturbances or nausea with a headache may indicate migraine.
- What have you tried so far to relieve the pain? Give your doctor the name and dose of any medication you have tried. Tell them how effective this has been and describe any side effects you have experienced. Think about other techniques you have used in an attempt to relieve the pain. Have you tried massaging or rubbing the area, heat or cold, or complementary therapies?

Rate your degree of pain. It can be helpful for you and your doctor to rate the pain on a scale of 0-10 (where 0=no pain, 10=worst pain). You could keep a simple pain diary. This can be a very useful way of measuring the effectiveness of new painkillers. Write down the times you take the medication and then rate your pain at intervals throughout the day.

The Pain Society has produced a pain rating scale to assist in the assessment of pain. These are available in many languages and can be downloaded from their website at www.britishpainsociety.org/

Medication

Your doctor may suggest that you start new medication or may increase the dose of any medication you are already taking. There are a variety of painkilling drugs that act in different ways to control different types of pain. Painkillers can be very useful drugs, especially if used regularly to prevent pain or to control pain to a tolerable level.

However, people with M.E. often have a limited tolerance to drugs, so lower doses than usual may be needed. Some individuals may have difficulty in taking a sufficient dose to ease pain. In this case it may be useful to also try other methods of pain control too (see p 24).

Paracetamol can be helpful for mild pain. It is generally well-tolerated, especially in low doses, but it may have little effect on moderate to severe pain. Paracetamol overdose can be very dangerous – read the instructions carefully and do not exceed the recommended dose. Be careful if you are taking other over-the-counter and prescription painkillers as they may also contain paracetamol (eg. co-proxamol and codydramol). Some over-the-counter preparations contain caffeine and other substances that may not be well tolerated by people with M.E.

Non-steroidal anti-inflammatory drugs (NSAIDs) are commonly used for pain due to inflammation, such as inflamed joints, and also for period pain. This group of medications include asprin, ibuprofen, diclofenac and naproxen.

Some people experience significant side effects, such as gastrointestinal irritation or allergic reactions. Aspirin should not be given to children under 16 years of age (unless supervised by a consultant).

Ibuprofen and aspirin can be bought from chemists and soluble preparations may be useful as a gargle for sore throats (spit out afterwards to avoid too much getting into the bloodstream). NSAIDs are also available as ointments (worth trying for localised pain relief) or suppositories for use at night to relieve morning stiffness. Some NSAIDs have a sustained release formula to prolong their action. Lower doses should be used to start with and NSAIDs should never be taken on an empty stomach.

Opiate based painkillers are usually effective for moderate to severe pain that is deep, or internal in origin. They include codeine and morphine and are derived from opiates found in the opium poppy, which are similar to the body's endorphin painkillers.

Side effects may include nausea, dizziness and drowsiness, particularly with stronger agents. Constipation is very common but this can be beneficial for people with diarrhoea. Opiates can be sedating and some people find that they worsen their fatigue. Also, long term use of opiate based painkillers can result in chronic headaches in themselves. Regular use leads to tolerance (a need for increasing doses to achieve the same effect) and dependence (a reliance on the drug). However, addiction seems rare when these drugs are genuinely needed for pain control. Individual effects vary widely and depend on the particular drug used.

Codeine can be bought over the counter and is often combined with paracetamol and aspirin. It can be helpful to relieve mild to moderate pain. Stronger opioid based painkillers have limited use in relieving chronic M.E. type pain.

Tricyclic antidepressants can be effective at suppressing pain. They include amitriptyline and nortryptiline. If taken for pain relief they can be used at a much lower dose than is usual for the management of depression. At a low dose they can also have other benefits such as restoring better quality sleep and controlling some features of Irritable Bowel Syndrome.

Different drugs have different effects on symptoms and they also differ in their side effects. If you find that a drug is ineffective or cannot be tolerated, it is worth systematically trying others.

Drugs used to treat epilepsy which can be effective for 'nerve type' pain and some types of headache include carbamazepine, sodium valproate, gabapentin and pregabalin. They have broad effects on nervous system functioning, including altering the pain threshold ('gating out' pain).

Muscle relaxants and anti-spasmodic drugs are useful for muscle cramps, spasms, and twitching and include baclofen, methocarbamol, and quinine. Drugs that can help with abdominal cramps include mebeverine, alverine, and buscopan.

5-HT^1 agonists or triptans such as sumatriptan (Imigran) may be useful for acute migraine attacks but frequent use can lead to 'rebound' attacks. For severe, frequent migrainous headaches, cluster headaches and facial pain, drugs such as pizotifen, sodium valproate and gabapentin can be helpful.

Other approaches to managing pain

Some supplements and herbs are reported to help pain. It is however important to remember that they may act in the body like drugs, so can cause side effects and may interact with any other medication you are taking. For this reason you should tell your GP or specialist if you are taking any herbal or nutritional supplements. Very little research has been done on the effectiveness of these approaches. However, those that are supported by limited evidence include:

- Feverfew for prevention and treatment of migraine. However, as with all herbs and nutrients, preparations differ in their contents and not all formulations have been found effective.
- Essential fatty acids such as cod liver, evening primrose and starflower oils. Some clinical evidence suggest that certain essential fatty acids might be helpful for joint pains, period pains, breast pain (mastalgia) and some other inflammatory conditions, although the research findings are not clear cut.
- Limited studies on the plant, cat's claw, have found that it might be helpful for arthritis-related pain and inflammation.

Many non-drug measures exist that may improve pain, alone or in combination with painkillers and other drugs. However, not all these interventions are of proven benefit and some may have side effects.

Cognitive Behavioural Therapy (CBT) is used widely for many forms of chronic pain, with good trial evidence. CBT can help with the management of pain and improving quality of life for people with chronic pain (see p 38).

Transcutaneous electrical nerve stimulation (TENS) is of proven benefit for lower back pain and might be helpful for other types of localised pain, although little research exists on its use by people with M.E. One theory is that the application of a small current to the nerves interferes with the transmission of pain messages to the brain, and may also stimulate release of the body's endorphin painkillers. TENS and other such methods may become less effective over time and can have adverse effects, so seek professional advice before investing in such a device yourself. TENS may be available from your local physiotherapy department on the NHS.

Acupuncture is used widely in Chinese medicine and more recently in western countries for pain relief. Use of needles, electrical stimulation and other methods to stimulate certain 'acu-points' is said to prompt release of endorphins and possibly other chemicals. The benefit of acupuncture in certain clinical situations is supported by some evidence. However, the effect varies depending on the nature of the pain and the types of acupuncture. For example, acupuncture has been investigated for pain felt with fibromyalgia. Although some people benefited, the results indicated that for some the pain got worse initially and then improved, while others had either no response or even worse pain. Acupuncture is available on the NHS in some areas.

Self-help techniques such as hot baths, massage, stretching, and hot or cold applications to painful areas may be useful; all of these seem to work by generating nerve impulses that compete with pain signals. Other people have reported benefit from learning self-help approaches such as deep relaxation, sometimes incorporating visualisations and meditation or breathing exercises.

It can be helpful to experiment with different positions when in bed or sitting. Careful placing of cushions or rolled up towels can help to relieve painful and aching muscles and joints. It can also help to relieve and prevent pressure sores in people who are severely affected by M.E. and are very restricted in their movement – see overleaf.

When side lying (see below) use as many pillows under your head as required. To support the arm which is uppermost, put a doubled pillow underneath. A pillow is then placed along the length of the back and 'tucked in' a little underneath you. This prevents you from rolling backwards. One or two pillows are placed between the knees and this puts the hips and knees into a position of comfort and prevents the pelvis from rolling forwards.

When 'crook lying' (see below), lie on your back with your knees bent, use as many pillows to support your knees as you feel you need. This puts the lower back in a comfortable and well-supported position. Support your head with one or two pillows. Place each arm on a pillow giving support from behind the shoulder along the length of the arm, wrist and hand.

Physiotherapy may be beneficial as it can help to keep your joints and muscles moving and prevent muscle wasting, weakness and joint stiffness. This in turn can help to reduce pain. Physiotherapy may be available on the NHS depending on your specific circumstances.

If you have significant sleep disruption...

People with M.E. commonly experience a variety of sleep disorders. Left untreated, sleep problems are likely to delay recovery. Good quality, restful sleep allows the body and the brain to rest and relax fully. The rate of repair of body tissues is greatest during sleep. It is important for maintaining higher brain functions, such as thinking, concentration, planning and memory.

If you are experiencing sleep difficulties, it's important to establish a sleep routine, ideally going to bed at the same time each night and rising at the same time every morning. You will find this easier if you are not sleeping during the day. If you have trouble sleeping, or if pain is preventing you from going to sleep, low doses of certain medications also used as antidepressants are among the drugs that can help. Different medications of this sort may have differing effects on helping to initiate sleep, but all aim to improve the quality and structure of sleep.

Sleeping too much can be as much a problem as not getting enough sleep, as long sleep does not guarantee restorative sleep and tends to reduce the overall quality of the sleep.

What types of sleep difficulties do people with M.E. have?

Sleep disorders seem to be part of the underlying disease process in M.E., probably because the brain's control mechanisms for sleep are affected.

Problems can also occur as a result of other symptoms or factors in M.E. For example, you might be kept awake at night by muscle pain or worry. This can create a vicious circle where lack of sleep worsens symptoms and reduces your ability to cope with the illness.

Sleep difficulties common to people with M.E. include:

- insomnia or difficulty getting to sleep
- light, dreamy, restless sleep (excessive REM sleep, where REM means 'rapid eye movement')
- interrupted sleep, waking up repeatedly during the night
- unrefreshing sleep
- hypersomnia (excessive sleepiness or sleep lasting for very long periods)
- sleep reversal (for example, sleeping from 4am till midday).

You may also find that your particular sleep problems change over time.

What can I do about sleep difficulties?

There are several ways that you can work at improving your sleep. It's worth experimenting with different methods to find what works for you. It may be useful to keep a sleep diary to note when you are sleeping, problems that you experience and measures that help.

It is important to start with simple measures such as establishing a sleep routine. At the same time if you have identified other problems that are affecting your ability to sleep, such as pain, anxiety or depression, these need to be addressed.

Simple measures to try first

1. Start to get ready for bed one to two hours before your planned bedtime. Some people find that a warm bath, perhaps with calming aromatherapy oils, can help. A hot milky drink or herbal teas, such as camomile, can be relaxing.
2. Avoid food or drink that contains stimulants, such as tea, coffee, cola and chocolate. Tobacco is a stimulant and alcohol will give you a poor quality night's sleep. Some people find reading helps them to relax, listening to music, or watching TV.
3. Try and go to bed at the same time every night and get up at the same time every morning. Your body and brain like a routine and your brain will get used to switching off at a set time every evening. If you have got into the habit of not going to bed until the early hours of the morning, eg. 3am, it is more effective to address this by tackling the getting up time. It is a good idea to bring your waking time forward gradually – maybe by half an hour each week. Adjusting your sleep time too quickly can be counterproductive.
4. Make sure that the room temperature is right for you. If light stops you from sleeping, try black-out blinds or curtains, or maybe an eye mask. If noise is a problem, consider ear-plugs. Make sure you have a good quality mattress that is comfortable. If possible use your bed and bedroom only for night-time sleeping.
5. Try not to sleep during the day as this is likely to interfere with night-time sleep. If you have an overwhelming need to sleep, short naps of up to 30 minutes can be a good way of recharging your batteries.
6. Relaxation techniques can be useful if you are restless and can't relax even when tired, or if you are worried or stressed. Techniques can be learned from classes (eg. yoga or meditation), from self-help books, or from relaxation or self-hypnosis tapes that can be listened to in bed.

7. If worrying keeps you awake at night it can be helpful to set aside a few minutes each day to write down any worries and problems. You can then write down any possible and realistic steps to resolving them. If you then wake in the night or can't get off to sleep, you can remind yourself that you are dealing with any issues that are bothering you.
8. If pain is an issue or you are feeling anxious or worried, or think that you might be depressed, it's important to discuss it with your doctor.

Coping with sleepless nights

It's useful to find ways of getting through the night when you can't sleep. Lying awake can be intensely frustrating, but fretting over being awake, clock-watching, or trying too hard to sleep does not help! One strategy is to stay in bed and rest, using relaxation techniques or other passive ways of occupying your time (eg. listening to the radio or a talking book). Or get out of bed and occupy yourself with unstimulating or monotonous activities, which preferably use your hands, such as jigsaws, model-making, knitting or sewing. Take time to find out what works for you.

Medication

Tricyclic antidepressants, eg. amitriptyline, can be helpful in restoring sleep quality and rhythm. It's important to start with the lowest possible dose and monitor effects on sleep and daytime tiredness before making any increase in the dose.

Sometimes it may be necessary to try different tricyclic antidepressants to find the one that works best for you with the least side effects. Some antidepressants come in liquid form, which allow very small doses to be taken. These drugs can also help to relieve pain.

Over time, tricyclic antidepressants may show a slightly reduced benefit, at which point modest dose increases can be useful to restore positive effects.

Sedative drugs and 'sleeping pills' can help in the short-term to establish a better sleep pattern, especially if you have difficulty getting off to sleep. They range from herbal remedies that you can buy from a chemist or health food shop, through to drugs that are only available on prescription such as zopiclone, zaleplon and zolpidem. Sedatives can be useful for occasional use, such as before an important event or to break a pattern of poor sleep – but may simply sedate rather than benefit the underlying quality of sleep.

Regular use leads to tolerance (a need for increasing doses to achieve the same effect) and dependence (a reliance on the drug). Even herbal remedies, if used regularly, will require a bigger dose to achieve the same effect. All sedatives can impair concentration and some can lead to excessive sedation the following day.

Sedative antihistamines including nytol and phenergan can be bought from a chemist without a prescription. These may be helpful for occasional use but are likely to cause drowsiness the next day.

Benzodiazepines including diazepam (valium), temazepam and nitrazepam are prescription-only drugs. They are best avoided as they are likely to result in dependency.

Other approaches

Many herbs have sedative properties, such as valerian, skullcap, passion flower, lemon balm, hops and camomile. Herbal treatments seem less prone to cause dependence and tolerance, but like sedative drugs, these remedies may simply sedate rather than benefit the underlying quality of sleep. They may act in the body like drugs so can have side effects.

Nutritional approaches may be useful if other symptoms suggest food sensitivity as some evidence links food allergies and intolerance with poor sleep. Sometimes, dips in blood sugar level during the night can cause nightmares, unrefreshing sleep and night time waking with feelings of hunger, anxiety and sweating. It may help to have a healthy bedtime snack or milky drink if this is a problem for you.

Some nutritional supplements are promoted as useful. For example, certain brain chemicals including serotonin are thought to influence sleep, so some nutritionists recommend foods rich in the serotonin precursors L-tryptophan such as milk or bananas or a night-time supplement such as 5-hydroxytryptophan (5HTP). However, the role of serotonin in M.E. is complex, so this strategy could be ineffective or perhaps worsen symptoms in some individuals. An overactive serotonin system can cause agitation and unpleasant physical symptoms and it is important that 5HTP is not tried if you are on other medication that works on the serotonin system.

Melatonin is the hormone which helps to regulate the sleep-wake cycle and some research (but not all) suggests that certain people with M.E. have disordered secretion of melatonin. For this reason, some researchers suggest taking melatonin at night. Melatonin was available in the UK from health food shops until it was withdrawn by the Medicines Control Agency (MCA). It is now licensed on prescription in the UK for those under 18 and over 55. As a result, some doctors may be prepared to prescribe it 'off label' for other patients.

Melatonin taken in small doses at specific times can reset the body's internal clock, so is sometimes used by those crossing time zones to help combat jetlag. In larger doses, the supplement also has a sedative effect.

It is not clear exactly how melatonin should be taken and which people with M.E. will benefit, although those most likely to respond positively are the elderly and people with clear disruptions of their body clock and sleep-wake times. Anecdotal evidence from Action for M.E. members taking melatonin supplements to aid sleep includes both good and occasionally very bad reactions.

If you have mood problems such as anxiety or depression...

Your mental health is vital to your recovery, so it is important to seek medical help if low mood or anxiety become persistent. They can aggravate your fatigue and pain symptoms and get in the way of recovery by reducing your drive or reducing your zest for life and self esteem. Anxiety, depression and panic attacks are common consequences of any long term illness and people with M.E. are not an exception. It does not mean that they caused M.E., nor that it is an indication of personality weakness. Some people have had anxiety or depression before the onset of M.E., and having M.E. can result in their depression and anxiety worsening. Either way, you end up having to fight two conditions instead of one.

People with M.E. often worry that their illness will be dismissed as 'all in the mind,' especially with a diagnosis of anxiety or depression. As mentioned before, mood problems are common in any long-term illness and health professionals are becoming increasingly aware that untreated depression and anxiety can affect the long term outcome of many medical conditions.

Difficulties can arise because symptoms of M.E. and symptoms experienced in mood disorders seem to overlap. Sometimes people are wrongly diagnosed as being depressed when they have M.E. It is also the case that people who have developed depression have been wrongly diagnosed as having M.E.

Like any other distressing symptom, mood problems need to be tackled. Left untreated, they can reduce your ability to cope with the illness and exacerbate other problems such as sleep difficulties or cognitive problems.

How do I know if I have a mood problem?

Feeling low, anxious, frustrated, frightened or angry are normal responses to a long-term illness. It can be difficult to decide when these feelings and emotions have taken over to become all-consuming and hard to recognise when you need extra help. You may realise that your motivation and interest levels have declined, although this can be quite subtle. Sometimes, feeling unusually tearful or irritable can be a warning sign; or the people around you, such as family and friends, can be the first to notice that something seems wrong.

If you have previously experienced depression or anxiety you are more likely to develop a mood problem as a result of your M.E. than somebody who does not have this history.

How do I manage a mood problem?

If it is at a mild to moderate level, counseling or CBT may help you work out how to manage your mood better. If your M.E. is at a level where regular sessions are not feasible, or your depression is moderate to severe, you may be advised to take antidepressants.

Medication

Antidepressants work by altering the level of different neurotransmitter chemicals in the brain. These chemicals are responsible for passing electrical signals between nerve cells.

Many depressive symptoms such as low mood and poor motivation are linked with low levels of these chemicals for example serotonin, dopamine, and noradrenaline, which is why antidepressant drugs that increase the levels of these neurotransmitters are thought to alleviate symptoms. However, these neurotransmitters seem involved in many other processes throughout the nervous system. This explains why antidepressants have benefits other than improving depression, for example regulating sleep. It is also why they can cause side effects such as a dry mouth and constipation.

Neurotransmitter changes in people with M.E. have not been well-researched. Detected abnormalities differ between individuals, so for example, serotonin might be either low or raised, which may explain why some people find antidepressants can help some of their other symptoms while other people can feel worse.

Because people who have M.E. can be less tolerant of medication, antidepressant drugs should be started at a low dose. It is common to experience side effects when you start new medication but these usually subside as your body gets used to them.

It is important that you keep in regular contact with your doctor, particularly early on, so that the dosage can be monitored and changed as necessary. It can take at least two weeks before you start to feel any benefit but many people can notice improvements to symptoms before this. Even if there is no early benefit, an antidepressant should be taken for at least a month before deciding that it has been ineffective at that dose.

Some people find that the first antidepressant they try gives them side effects and they have to stop. It is important to give other antidepressants a try, as often it is possible to find one that suits you without giving you side effects that you can't tolerate.

If it is your first course of antidepressants, it is advisable that you continue on the medication for six to nine months after you feel back to your normal self, mood wise. It is important to complete the course as stopping the medication too soon can make it more likely for you to experience a relapse in the future. At the six to nine month point, you and your doctor may agree to try stopping antidepressants. This should be done gradually with small reductions in the daily dose under regular medical supervision. Even if you get better on antidepressants, do not stop them suddenly as sudden withdrawal could lead to a relapse of symptoms, perhaps accompanied by depression and/or anxiety.

Types of antidepressant drugs

Different classes of antidepressants exist, which have somewhat different effects on neurotransmitters and nervous system function.

Selective serotonin-reuptake inhibitors (SSRIs) are effective antidepressants, improving mood and motivation, and some are licensed for anxiety and panic problems. They include citalopram (Cipramil), Escitalopram (Cipralex), sertraline (Lustral) and fluoxetine (Prozac). They increase the amount of serotonin available at nerve junctions.

SSRIs may help symptoms such as sleep disturbance, cognitive function and motivation. They can however be stimulating rather than sedative, particularly fluoxetine. SSRIs should therefore be prescribed carefully in people with M.E., particularly those with sleep disturbance or anxiety.

Noradrenalin and serotonin reuptake inhibitors (NSRI) are relatively new and effective treatments for depression. They include venlafaxine and duloxetine. However, experience is limited in people with M.E. and they may be poorly tolerated as they may make the person feel over stimulated.

Reboxetine works primarily on the noradrenaline system and may be suitable for people who did not benefit from SSRIs.

Mirtazapine is one of the newer antidepressants, with a slightly different mode of action. At a low dose, it is a sedating antidepressant and some people find this helpful. For others, they find that it is over-sedating but the sedation tends to reduce at higher doses of the drug and increasing the dose may help in this situation. Some people find that it stimulates appetite and this is something people may need to watch out for.

Tricyclic antidepressants affect not only mood but also the transmission of other nerve impulses and they are widely used for pain at low doses. They include amitriptyline, dusulepin and nortriptyline and are thought to work by altering the available levels of noradrenaline and serotonin in the brain. For people with M.E., these antidepressants at a low dose can be very useful at controlling symptoms such as pain and sleep disturbance. However, they are less effective at treating depression as most people with M.E. are unable to tolerate the side effects that are common at the normal prescribed dose. A related antidepressant, trazodone, is used similarly but it is the most sedating of these medications, which can be a problem side effect.

Monoamine-oxidase inhibitors (MAOIs) block the destruction of certain neurotransmitters but are rarely used as a first choice for depression, whether or not the person also has M.E.

Other approaches

There are various forms of psychological help including cognitive behavioural therapy (CBT – see p 38), psychotherapy, counselling and specific relaxation training which are of proven benefit in the treatment of depression, anxiety, panic attacks and phobias.

Although research findings differ over the relative benefits of each kind of intervention for different problems, they are all established treatments and can be very helpful for mental health problems and symptom control in people with M.E., especially those who can't tolerate drugs.

There is some evidence that certain complementary therapies can help to treat depression and/or anxiety, although the trials are often small, short-term, or of poor quality. Improvement in depressive symptoms has been documented with acupuncture, certain types of meditation, specific yoga exercises and music therapy.

Supplements such as the essential amino acid L-tryptophan and the derivative 5-hydroxytrptophan (5-HTP) have shown a similar effect to antidepressant drugs in a few small trials but many studies have shown no beneficial effect. There have also been serious safety concerns about their use. The body uses L-tryptophan from the diet to make serotonin and other brain chemicals, although the amount found in most foods is very small. Good sources include bananas, sunflower seeds, milk and turkey.

St John's Wort (Hypericum perforatum) is a herbal antidepressant that has been tested in several clinical trials. Most trials have found that various preparations have a similar antidepressant effect to pharmaceutical antidepressants for milder depression, although the effect is likely to vary depending on the specific extract used. St John's Wort can interact with various prescribed medications, including the contraceptive pill. If you are thinking of trying St John's Wort or are currently taking it with prescribed medication, it is important to discuss this with your GP.

Small trials have found that passion flower (Passiflora incarnata) has an anti-anxiety effect.

What is pacing?

Learning to successfully manage activity and rest is often referred to as pacing. There are various forms.

A form of pacing known as adaptive pacing therapy (APT) was one of the therapies – together with cognitive behavioural therapy (CBT) and graded exercise therapy (GET) – studied in the PACE trial. All participants received specialised medical care (SMC). Patients receiving one of the therapies were compared with others who had SMC alone. All saw mild to moderate improvement over a 52 week period. The particular form of pacing (APT) used in the trial was less likely to be effective than CBT or GET. However, both CBT and GET included elements of incremental pacing, gradually increasing baseline activity. Surveys by Action for M.E. and other charities have consistently shown that the majority of people with M.E. find pacing helps them to manage their illness (see p 41).

Think of your energy as a battery

People with M.E. find that their energy levels vary from day to day and it can be easy to do too much when having a better day. Unfortunately this can lead to a setback the next day or the day after, creating the vicious cycle of 'boom and bust.' Pacing organises your day into sustainable activity and regular rest to avoid this damaging pattern.

Think of your available energy as being like a mobile phone battery. If you completely drain the battery you have to wait for it to recharge before you can use the phone again. If you use some of the battery and make regular top ups, then your phone will always be ready for use. Managing your energy through planned periods of activity and rest will mean you are more likely to be able to do the activities you want to do.

Learning to pace can give you the best chance of recovery. It gives stability and a sense of control, making things more predictable and enhancing your confidence. It can improve your ability to cope with the illness.

Pacing is highly individual and varies from person to person. However, there are key areas that form the basis of successful pacing:

Types of activity

Activity doesn't just mean physical tasks; it also means tasks that involve mental exertion or social interaction. This includes pastimes that you may think of as relaxing, such as talking to friends, reading, watching television or listening to music. It also includes hidden mental activity like emotion and worry. This is much harder to measure and predict, yet for many people it is the biggest drain on energy. Pacing needs to be applied to all these activities and your day should include a balanced mix of different sorts of activity.

Rest and relaxation

Short, regular rest periods are essential to recharge your batteries. For your mind and body to benefit, you need to be fully relaxed and properly resting your brain. True rest is needed, and this can be difficult for people who usually relax through active pastimes. Gentle music or relaxation tapes and CDs can be helpful.

Finding a baseline

Before you can start to plan a pacing programme you need to know how much activity you can comfortably manage on a daily basis, without causing an increase in symptoms. This is called your baseline. Baselines sometimes need to start at very low levels and should be manageable, even if you're not having such a good day. To help you become aware of highs and lows of activity (boom and bust) keep a simple diary of your current activities, and how they make you feel.

Remember that working to your baseline does not mean that you have to restrict your life to that level forever, but you do need a stable foundation from which you can begin to build.

Planning and goal setting

Planning your time is essential. You need to prioritise activities and tasks to include those that you have to do, but also those that you enjoy. Once you have established a steady routine you can very gradually, in small steps, build up your activity. This process should take weeks rather than days and you need to approach a goal step by step. It's important to develop awareness of how your body is coping, to sense if you are pushing yourself too hard, or if you have become wary of moving forward.

To find out more about pacing and how to put it into practice, we strongly advise you to download a copy of our booklet *Pacing: a guide for people with M.E.* free from www.actionforme.org.uk or order a copy on 0845 123 2380.

"Thanks to pacing, my physical energy levels are better and the number of good days I'm having is steadily growing."

What is Cognitive Behavioural Therapy (CBT)?

CBT is used to support people through a variety of chronic illnesses, helping them to adjust to some of the consequences of being unwell. It can help people to identify, understand and modify any views and behaviours which impact on their illness eg. a tendency to overdo it, or being unable to say 'no.'

Its use does not imply that the cause of the illness is psychological.

CBT can help you to find ways to cope with issues such as demoralisation, frustration, guilt, anxiety, panic and depression, and to feel more in control of the illness. CBT may help with practical issues such as: managing energy and activity, setting up a sleep routine, dealing with reactions or attitudes to M.E. that can slow recovery, goal setting, psychological support, achieving improved physical functioning.

For CBT to be effective the therapist should have a sound knowledge of M.E., be appropriately trained and be able to work with you in a collaborative and flexible way.

What is Graded Exercise Therapy (GET)

The National Institute for Health and Clinical Excellence (NICE) defines Graded Exercise Therapy (GET) as: "An evidence-based approach to CFS/M.E. that involves physical assessment, mutually negotiated goal-setting and education."

It says: "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/M.E. symptoms and functioning, aiming towards recovery."

Some researchers and clinicians believe that inactivity and the resulting loss of physical strength and fitness (deconditioning) may be a factor for some people with M.E. GET seeks to reverse this deconditioning effect.

Do CBT or GET help?

The PACE trial found that adults with CFS/M.E. who were well enough to participate in its study (ie. not housebound or bedbound) showed moderate improvements in fatigue and physical function following 52 weeks of standard medical care plus CBT or GET. The proportion of participants rating themselves as "much" or "very much" better in each case was 41%.

The trial concluded that GET is safe with few adverse effects. However, surveys carried out by Action for M.E. and other patient groups suggest that graded exercise may be harmful if it is delivered inappropriately (see p 41).

The National Institute for Health and Clinical Excellence (NICE) says CBT and GET should be delivered: "by a suitably trained CBT/GET therapist with experience in CFS/M.E., under appropriate clinical supervision; one-to-one if possible."

People with M.E. who wish to try GET should ask to be referred to a specialist CFS/M.E. clinic, where this expertise exists, if at all possible. Details of clinics are available in our online directory, or by calling us on 0845 123 2380.

There have been no published randomised controlled trials of CBT or GET in children or the more severely affected.

What about Graded Activity Therapy (GAT)?

Graded Activity Therapy (GAT) is a person-centred approach to managing a person's symptoms by using activity. Activities are selected, adapted and graded for therapeutic purposes to promote health and well-being.

Therapy 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.

There have been no published randomised controlled trials of GAT. In our 2010 survey of physical rehabilitation therapies, 39% reported an improvement after GAT, while 26% said that they were worse.

Please note

Specialist services may not refer to CBT, GET, GAT or pacing but to fatigue, energy or condition management.

They may draw on elements of CBT, GET, GAT and/or pacing in programmes which focus on learning how to relax/rest, respond to demand/stress, grade and manage activities, control symptoms, consider the impact of different factors eg. diet/sleep on energy, deal with relapse, come to terms with M.E. etc.

What about complementary therapies and alternative approaches?

It is helpful to think of any therapy outside of those prescribed by your doctor as 'complementary' ie. to be used alongside, rather than instead of conventional treatment. Complementary treatments are also known as 'natural,' or 'holistic.' Some treatments aim to treat the body and mind as a whole, rather than focusing on specific areas.

People with many different problems and illnesses can find complementary approaches extremely useful. Currently there is little research into these, particularly in their effect on M.E., although some are associated with an increased feeling of well-being. Bear in mind that the impact of these approaches can be due to the therapist, as well as the therapy.

Therapies include: osteopathy, aromatherapy, homeopathy, massage, reflexology, acupuncture, herbal remedies and nutritional therapy, to name just a few. More recently, new approaches such as Lightning Process or Reverse/Mickel therapy have been offered by some private practitioners. Like other approaches, they seem to work for some people but not for everyone.

Action for M.E. strongly advises people to examine with scepticism any treatment, therapy or other approach which claims to offer a cure, has not been subject to research published in respected peer-reviewed journals and requires the payment of large sums of money.

Some complementary therapies, such as homeopathy and acupuncture, are practised by medical doctors and may be available on the NHS. There are NHS homeopathic hospitals in Bristol, Glasgow, Liverpool and London.

There are many different forms of complementary therapy, and it's sensible not to try lots of therapies at the same time. Many of them are based on quite different ideas about how the body works from orthodox medicine. Some use medical or medical sounding terms, but with quite different meanings, so make sure you really understand what is intended. There is no miracle cure for M.E., so watch out for any therapy that makes claims to this effect.

Ask about the therapist's experience of M.E., and the benefits and potential hazards of a therapy, just as you would with conventional medicine. If you give the therapy a fair trial and find that it makes no difference, or makes you feel worse, don't press on.

Make sure you consult your doctor about any new therapy, as some treatments may be harmful if taken with other medications, or if you are pregnant.

Our survey results

Action for M.E. has undertaken surveys of its members and other people with M.E. and asked them which treatments they have found helpful. While our surveys are not scientific studies and we cannot guarantee the results are representative of all people with M.E. (only those who knew about, were able and have chosen to participate in a survey), you may find them interesting.

Our 2008 health survey of 2,763 people with M.E. asked which treatments people had tried in the past three years. The findings are summarised below:

Results on treatments in 2008 *(compared to 2001)*

Treatment	**Helpful** 2008 (2001)	**No change** 2008 (2001)	**Made worse** 2008 (2001)
GET	45% (34%)*	21% (16%)	34% (50%)
CBT	50% (7%)	38% (67%)	12% (26%)
Pacing	82% (89%)	15% (9%)	3% (2%)
Rest inc. bed rest	86% (91%)	13% (8%)	1% (1%)
Pain medication	74% (61%)	22% (28%)	4% (11%)
Sleep medication	76% (67%)	17% (17%)	7% (16%)
Dietary changes	68% (65%)	30% (32%)	2% (3%)
Supplements	61% (62%)	37% (36%)	2% (3%)
Medication to help mood	64% (n/a)	22% (n/a)	14% (n/a)
Other medication eg. for nausea	71% (n/a)	23% (n/a)	6% (n/a)
Other approaches			
Acupuncture	56%	34%	10%
Herbal remedies	58%	36%	6%
Reiki	63%	32%	5%
Lightning process	53%	31%	16%
Reverse/Mickel therapy	45%	34%	21%

*In our 2010 survey, only 22% reported any degree of improvement after GET.

A word about diet and nutrition

The effort required to buy food and prepare nutritious means can mean that people with M.E. find it difficult to maintain a healthy diet. It can be made harder by loss of appetite or intolerance to some foods. But eating balanced and healthy meals is important during your illness, to provide you with the energy and nourishment you need for better health.

Maintaining a good intake of fluids is important too, as well as reducing your consumption of stimulants such as caffeine and depressants like alcohol. Some people choose organic foods to maximise available goodness and reduce the possible effects of pesticides.

Although it's better to obtain all your vitamins and minerals through your diet, intolerance* towards some foods may mean that supplements are advisable.

The most common tolerance problems are found with higher fibre diets (cereals, brown bread etc), wheat or diary products and can result in an irritable bowel and other symptoms.

It may be worth trying to avoid these foods, one at a time, for a few weeks each, to see if that makes a difference. Seek the advise of your GP or specialist and/or a dietician before excluding or eliminating any foods.

Be careful not to cut out everything you like. For example, you may still be able to enjoy some rich foods and alcohol in moderation. Even if your diet is limited, you can make food more interesting by trying out new ingredients and recipes or improving the presentation of your meals.

*True food allergies do not seem to be a cause of, or more common in people with M.E. Allergy tests are rarely helpful and intolerance tests are difficult to interpret.

"I had no appetite at all. Food tasted like cotton wool and my throat felt tender and lumpy, as though I had a piece of glass in my throat. I talked myself into eating by telling myself that the food would nurture my body."

Severe M.E.

Some people will be more severely affected by M.E. They may be unable to leave the house without the use of a wheelchair, or be confined to bed for periods of time. However, only a small minority of patients remain bed or wheelchair bound. If your illness deteriorates to this level, there is every chance you will improve in time. Careful management is needed, based on a problem solving multi-disciplinary approach.

The book, *Severe M.E./CFS: a guide to living*, by Emily Collingridge, has been widely recommended. Priced £5.99, including P&P, it is available online at www.severeme.info or by calling the Association of Young People with M.E. on 08451 232389.

It is important to maintain a relationship with your doctor and obtain extra help from community nurses and therapists, if and when required. Although your community team may have limited experience of caring for someone with M.E., they can still advise you and any carers, as well as regularly monitoring your health.

If you are confined to bed you need to be assessed by a district nurse to ensure that secondary problems such as pressure sores and muscle wasting are prevented.

If help is needed with personal care, social services can assess you. This is called an assessment of need.

Careful management of activity and rest is still required, even if you are confined to bed or dependent on a wheelchair to get around. A structured day is important and good quality rest should be alternated with activity appropriate for your situation. Realistic goals should be identified, however small, and the principles of pacing applied. Occupational therapists with good knowledge of the illness can advise on this.

The 25% group is run by people with severe M.E. for people with severe M.E. Contact them on 01292 318611 or go to www.25megroup.org

Further information

Action for M.E.
The UK's leading charity for people with M.E. and their carers
PO Box 2778, Bristol BS1 9DJ.

Tel: 0845 123 2380
Email: admin@actionforme.org.uk
www.actionforme.org.uk

Association of Young People with M.E. (AYME)
Information, advice and support for people with M.E. under 26 and their families

Helpline: 08451 232389 (10am to 2pm, Mon-Fri)
www.ayme.org.uk

Emotional support

Samaritans
Confidential, non-judgemental, emotional support for people who are experiencing feelings of distress or despair

Tel: 0845 790 9090 (24 hours)
Email: jo@samaritans.org
www.samaritans.org

Support Line
UK charity offering confidential emotional support to children, young adults and adults by telephone, email and post

PO Box 2860, Romford, Essex RM7 1JA
Tel: 01708 765200
Email: info@supportline.org.uk
www.supportline.org.uk

Health services

NHS Direct
Health advice and information on local services in England and Wales

Tel: 0845 4647 (24 hours)
www.nhsdirect.nhs.uk

Patient Advice and Liaison Service (PALS)
Information about patients' rights and health services available in England

www.pals.nhs.uk

Health and Social Care in Northern Ireland
Health advice and information on local services in N Ireland

www.n-i.nhs.uk

NHS Inform (Scotland)
Health advice and information on local services in Scotland

Tel 0800 22 44 88
www.nhsinform.co.uk

Health Rights Information Scotland
Information about patients' rights and health services available in Scotland

www.hris.org.uk

NHS Direct Wales
Health advice and information on local services in Wales

Tel 0845 46 47
www.nhsdirect.wales.nhs.uk

Welfare and work

Action for M.E. Welfare Rights Line
Information and advice on welfare benefits, disability discrimination, employment and insurance issues

Tel: 0845 122 8648 (call for opening times)

Benefit Enquiry Line
Information for disabled people and carers on the range of benefits available

Tel: 0800 882 200
www.direct.gov.uk/disability-money

Citizens Advice Bureau
Information on benefits, tax credits and employment rights

www.adviceguide.org.uk

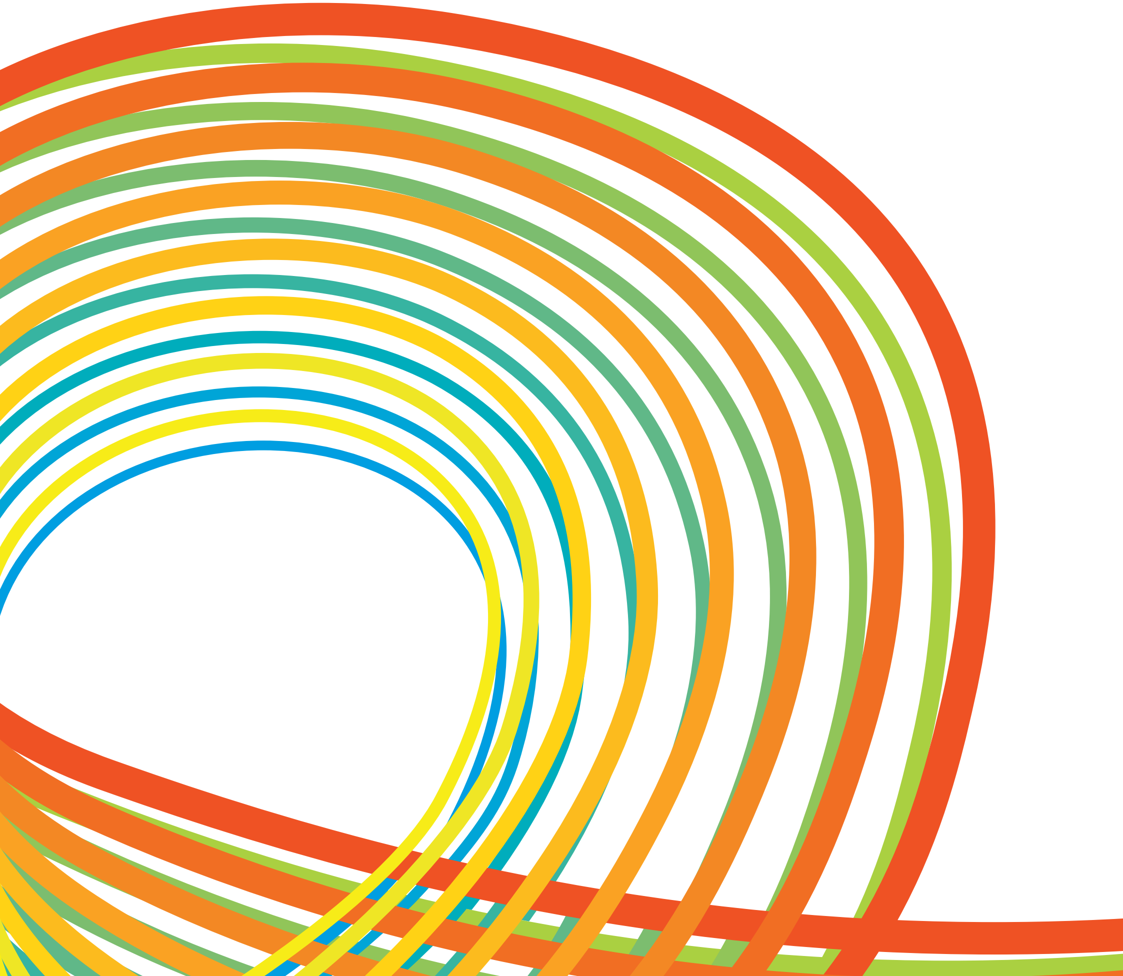
Carers

Carers UK
A charity for carers, led by carers

Advice line 0808 808 7777
E-mail: adviceline@carersuk.org
www.carersuk.org

Carers Direct
Information, advice and support for carers via the NHS

Helpline 0808 802 0202
www.nhs.uk/Carersdirect



M.E. checklist

1. Learn to manage your energy and activity – both physical, mental and emotional. Become an expert at managing your illness and stay in control.
2. Deal with the major symptoms that can take over your life, such as pain, sleep disturbance and low mood. Uncontrolled symptoms can get in the way of recovery. Your doctor can help you to manage these with medication. Other strategies can also be helpful, such as pacing your activities, relaxation techniques and complementary therapies.
3. Establish a relationship with your GP. This can take time and in some cases may be difficult, but the partnership between you and your GP can be crucial to stabilising your illness and enabling recovery.
4. Remember that people do recover from M.E. Learn to recognise and accept your illness and recovery is more likely to follow in time.
5. You are not alone. An estimated 250,000 people in the UK have this illness. To get information and support join Action for M.E. online at www.actionforme.org.uk or by calling 0845 123 2380.

www.actionforme.org.uk

“I was a fit 38-year old with two young children. I ended up bedbound, unable to stand. But there is hope! I gathered information, obtained a diagnosis, learnt about the importance of pacing, diet, personal reflection and relaxation techniques. I still get my symptoms, though not as severely. I’ve now returned to part-time work. The journey is not over but I have come a long way.”

David

action for m·e

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