



M.E.

A guide to
symptoms,
causes and
treatments



incorporating
WESTCARE UK

This booklet is for people who have been diagnosed with M.E. (also known as Chronic Fatigue Syndrome) and for family and friends. It explains what M.E. is, describes common symptoms and possible causes, and gives information on treatments and other approaches that can help.

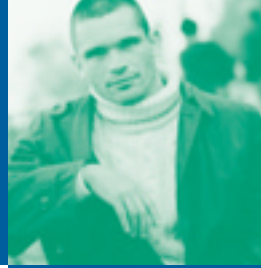
There is a great deal that we don't yet understand about M.E. but we do know that if you have just been diagnosed, or you think you might have M.E., the right information early on will help you to cope better with the illness and give your body the best chance of recovery. There is no easy route to recovery but most people do get a lot better over time.

Action for M.E. campaigns to improve the lives of all people with M.E. and we offer information and support. To find out how we can help see page 40.

This booklet has been prepared by Action for M.E.'s information service in conjunction with the charity's medical advisers, doctors and patients.

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What is M.E./CFS?

M.E. is a chronic illness that affects many body systems and their functions. The changes seem particularly to affect the nervous system and immune system, but they also affect other body systems. The illness can cause profound exhaustion, muscle pain, problems with mental function, such as memory loss and poor concentration, malaise and other symptoms.

The term M.E. originally stood for 'myalgic encephalomyelitis'. This literally means muscle pain (myalgic) and inflammation of the brain and spinal cord (encephalomyelitis). However, the term is not accurate scientifically (there is no evidence of inflammation in the brain) or as a description of the illness (not everyone has muscle pain). A new name is needed once more is known about the illness. Some people have suggested that M.E. could stand for myalgic encephalopathy, meaning muscle pain and an abnormality of brain function.

Many people know the condition as M.E. but the formal term used currently by the medical profession is Chronic Fatigue Syndrome (CFS). Some people consider that M.E. is distinct from CFS, or is a subgroup of it. Action for M.E. continues to use the term M.E. for now because many affected individuals prefer it, since the term CFS poorly describes those individuals in whom fatigue is not the most prominent symptom.

Who does it affect?

M.E. can affect men, women and children of all ages and backgrounds. It is estimated that there are over 240,000¹ people in the UK with M.E.; nearly two thirds of them are women. A recent study in the USA showed that about 1 in 250 people in the community have symptoms of CFS². Most people develop the illness between their early twenties and mid-forties. However M.E. does affect children and young people, generally those between the ages of 13 to 15 but sometimes children as young as five.

What are the symptoms?

M.E. is a highly variable illness; a wide range of possible symptoms can occur and these may change during the course of the illness. Each person will experience an individual mix of symptoms, in type and severity, and in how they change with time.

Some individuals may experience a dramatic decline followed by a relatively rapid recovery, while others may be chronically unwell for a long time.

The central feature of M.E. is the way in which symptoms behave. Fatigue, malaise, muscle pain and other symptoms are characteristically provoked by increased activity of any type, usually with a delayed impact.

This is notably seen with the highly common symptom of persistent and overwhelming fatigue. This feels very different from the everyday tiredness experienced by a healthy person and is described as being distinctive in its type and pattern. Physical or mental exertion characteristically provokes increased fatigue and a profound lack of energy, which typically doesn't impact until later in the day; the following day or even a number of days later. This effect can be felt as physical and/or mental fatigue and may be associated with malaise and an increase in other symptoms.



Symptoms

The following outline gives some of the symptoms commonly experienced by people with M.E. You may experience a combination of these. Don't be alarmed by the length of this list – these are only possible symptoms and it doesn't follow that you will suffer from all of them.

- **persistent fatigue**
- **post-exertional malaise** (a general feeling of being unwell after normal physical or mental activity) which can include flu-like symptoms
- **pain**
 - painful or aching muscles (with or without muscle twitching)
 - painful or aching joints
 - nerve pains/pins and needles
 - headaches/migraines
- **cognitive** (activities relating to thinking) **impairment**
 - reduced attention span
 - short-term memory problems
 - word-finding difficulties
 - inability to plan or organise thoughts
 - spatial disorientation
 - loss of powers of concentration
- **sleep disturbance**
 - unrefreshing sleep
 - waking in the early hours
 - light, dreamy, restless sleep
 - insomnia, problems getting to sleep
 - hypersomnia (sleep lasting for very long periods)

- **other nervous system symptoms**

- a feeling of poor temperature control
- dizziness on standing up
- dizziness (vertigo), balance difficulty
- increased sensitivity to light and sound

- **recurrent sore throat** (with or without swollen lymph nodes)

- **digestive disturbances**

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

These symptoms can be exacerbated by certain foods e.g. wheat and dairy products and high cereal fibre foods. Some people feel that yeast can aggravate symptoms, although there is no firm evidence or common agreement on this.

- **intolerances and increased sensitivity**, including to:

- alcohol
- some foods
- some medications
- other substances (wide-ranging intolerance is sometimes called multiple chemical sensitivity)

- **Particular features in children:**

Children commonly experience pain, tummy ache and headaches and are more likely to experience loss of appetite or weight gain, abdominal pain and nausea. Although these symptoms can be very unpleasant, children stand a very good chance of complete recovery.



Some symptoms that you experience may not be due to M.E. Your doctor will need to assess whether the symptoms are part of M.E. or are caused by something else. Remember that these symptoms are experienced by apparently healthy people from time to time. It is not only the symptom itself that the doctor will evaluate but also its detailed character and the way it behaves, as this helps to determine what is the most likely cause.

David Bradshaw

I was a fit 38 year-old, with two young children. I took a day off work, feeling 'unwell', and was not to return for five years! Looking back, I hadn't been 'right' for some time, but kept 'pushing through it'.

I ended up bedbound, unable to stand. Walking to the bathroom became as great a challenge as any of my previous mountaineering. I experienced chronic fatigue I can only describe as feeling pumped full of lead. I became highly sensitive – unable to tolerate people close to me, or noise, and my mood became volatile and emotional. My brain scrambled; I couldn't wade through the treacle to get the words out. I was so cold and desperately tired, but unable to sleep. It was difficult for me but even harder for my family to comprehend.

But there is hope! I gathered information, obtained a diagnosis, learnt about the importance of pacing, diet, personal reflection and relaxation techniques. I tried various therapies and my Christian faith helped a lot. It wasn't easy and it took time and a huge amount of effort.



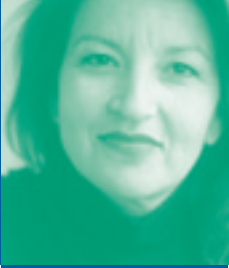
I still get my symptoms, though not as severely. I've now returned to part-time work. The journey is not over but I have come a long way.

How is M.E. diagnosed?

There is currently no single medical or laboratory test to diagnose M.E. This is also true for many other illnesses that do not have a known or single cause. Doctors are used to identifying such illnesses by recognising a pattern of symptoms together with features on examination and often through laboratory or other tests. In the case of M.E. they will do the same, looking for those features that characterise the illness, especially in the description of your symptoms, how they appeared and how they behave. They will diagnose M.E. (or CFS) based on the characteristic pattern, and when they are satisfied that they have also ruled out other possible conditions, some of which can be excluded by particular tests.

So, your doctor will want to discuss your medical history: you will need to describe what symptoms you have and how they affect you. Your doctor may also want to specifically evaluate your mental health and sleep pattern so that problems in these areas can be dealt with or excluded as soon as possible. Basic screening tests, including blood and urine, can exclude many other conditions but more specialised tests might sometimes be needed depending on your particular mix of symptoms. You may need to have several appointments with your doctor before a final diagnosis is reached. It is generally accepted that a provisional diagnosis of M.E. can and should be made early on, sometimes as part of a list of possible diagnoses, and should usually be confirmed by six months at the latest. Action for M.E. has free *Guidance on the management of CFS/M.E.* available for doctors.

A family doctor (GP) should be able to make the diagnosis, although some have limited experience of M.E. and may recommend referral to a specialist with an interest in M.E. In this instance, the particular speciality of the consultant is less important than their knowledge, experience and understanding of the condition. At present there is limited availability of specialist services and they vary in nature across the UK. Action for M.E. is campaigning to increase local services for M.E.



Diagnosis in the early stages of the illness is a positive step to being able to maximise your chance of recovery and minimise the impact of the illness.

Being diagnosed with any condition, especially one like M.E. that is difficult to understand and predict, can be frightening. But for many people, the knowledge that they have a name for their illness and that it is recognised can come as a relief. It can also reduce fear and uncertainty to know that other possibilities have been ruled out. This is particularly true if someone has been suffering a bewildering range of symptoms for some time.

When will I get better?

There is a very wide variation in the length of time that people suffer with M.E. Many people will make a good deal of improvement relatively quickly while others can remain ill for many years. People do commonly find that they don't completely get back to how they were before they became ill, but with adjustment are able to lead a normal and fulfilling life.

At times you may feel that you are never going to get better, so keep in mind that the majority of people do find a significant improvement in their health over time, especially with treatment, and aim to keep a positive outlook on your recovery. Improvement can still be seen if you have been ill for a long time or are severely affected. The important thing is to make the most of what you are able to do at any stage, so long as it doesn't interfere with the process of recovery. While this often means lowering your immediate goals, it can still include enough things that are important to you to make the compromise acceptable.

How will I be affected?

Physical health

Many people experience a sudden (acute) onset of the illness, while others will deteriorate gradually over a varying period of time. M.E. affects people in different ways, and for different lengths of time.

Symptoms vary enormously from person to person. The kind of symptoms you experience can be dictated by what triggered your M.E. (see pages 16 to 17). For example, if you developed M.E. following a virus you may experience recurrent sore throats and swollen glands. Your medical history also has a part to play. If, for example, you are prone to headaches or migraines you may suffer particularly with these symptoms. Women often find that their symptoms become worse before, and/or during their period.

Don't forget it is always important to get new symptoms checked out by your doctor.

The type of activities you undertake can also affect the symptoms: if you are physically active you may suffer more muscle pain; while someone who spends more time on mental activities may have more problems with memory and concentration. However, some people find that mental tasks also make physical symptoms worse, and vice versa. So it's not surprising that people find the illness confusing, especially as the impact is usually felt between one and three days later.

Most people find that their symptoms fluctuate from day to day. You may have days or even weeks when you feel relatively well but then 'relapse' into ill health. Trying to do too much activity on the good days, which you may feel you have got away with at the time, can intensify this pattern, because of the delayed setback. This cycle is sometimes described as 'boom and bust'.



This cycle is very undermining and unpleasant and there is also some suggestion that it can prolong the illness. See page 22 for information on 'pacing' yourself.

Sadly, some people with M.E. are so severely affected that they are unable to carry out the most basic daily tasks for themselves. They are housebound and may even be bedbound. People who are severely affected will often have more intense symptoms, for example being unable to tolerate any noise or moderate to bright light.

This booklet is a general introduction to M.E. and the content may not be applicable to all readers all of the time. See page 43 for further help on coping with severe M.E.

Mental health

Ill health can be very difficult and frustrating, coping with persistent symptoms or setbacks, along with losing the ability to do the things that you did before you became ill. Losing your health can be a similar process to grieving: one that may prompt denial, anger and sadness before finding the ability to accept the illness.

It is not surprising then that many people with any complex, chronic illness, especially one that is stigmatised, can lose confidence and suffer low self-esteem, or that they may feel fearful or guilty and can become anxious, frustrated, depressed and angry. People who have had previous mental health problems may be more vulnerable to such consequences, as is seen in people with cancer, arthritis, HIV/ AIDS, multiple sclerosis and other chronic conditions.

Understandably, a lot of people with M.E. are extremely sensitive to any suggestion of depression because they are worried that their illness is being dismissed as psychological. But depression and other mood problems can be normal responses to the impact of any long-term illness and disability. You should not be afraid or embarrassed to seek help from your doctor or a support organisation (see page 42), particularly because treatment of any coexisting mental health problem is likely to help you cope better with M.E.

Friends, family and others

Although it is often amazing how well people with M.E. and those around them cope, M.E., like other complex chronic illnesses, can have a substantial impact on all areas of life, including relationships, work, finances, and education. Colleagues, friends and even family can find the illness difficult to understand, especially when you may visibly appear quite well. Giving them this booklet to read will help them to understand more about the illness.

Coping with M.E. can be made harder if you come up against people who are poorly informed about the illness, which may even include members of the medical profession. Some people face prejudice, disbelief, stigma and rejection. Action for M.E. is working hard to increase awareness and understanding of the illness and campaigning for M.E. to be treated with the same care and acceptance as other chronic illnesses. If your doctor doesn't seem to understand, or needs to know more about the illness, contact Action for M.E. for a free copy of *Guidance on the management of CFS/M.E.* that you can pass on.

If you are spending much of your time at home, or feeling very unwell, you may lose touch with people and feel isolated and alone, particularly if you are severely affected. Being a member of Action for M.E. can help and you may like to consider joining a local group to make contact with people going through similar experiences (see page 40).



Caring for somebody with M.E. can be physically and emotionally demanding and may cause a real strain on family relationships. Carers can commonly feel that 'their world has been turned upside down'. It can be helpful to seek support from your doctor and from an organisation that specifically understands some of the issues carers face (see page 42).

Roderick Floud

My wife and daughter are nearing recovery after more than ten years with M.E.

I remember bewilderment, anger, resentment, helplessness and isolation, all stemming from love, concern and confusion about the disease and its treatment.

In some ways, caring for an M.E. patient is like caring for anyone who is ill. One gives physical and emotional support, takes over childcare or household duties, explains what is wrong to friends and colleagues. But one difference is the way that M.E. usually begins, as a viral illness from which recovery is slow and uncertain.

The carer is in the same limbo as the patient. I shared the constant search for new remedies, the thoughts about practical ways of alleviating the condition and the usually unspoken question: 'Why me?' All lead to a kind of roller-coaster existence; hope alternates with despair.

Above all, one had to keep on hoping but not turn that hope into pressure on oneself or on the patient.



Welfare rights and employment

If you are unable to work for a period of time you may need advice on welfare rights. Action for M.E. has free introductory information on the types of payments that are available or you can contact the Department for Work and Pensions. Sadly, people with M.E. can sometimes encounter difficulties obtaining benefits because of the variable nature of M.E., the difficulty of getting a proper assessment of their actual disability, and problems with confirming a diagnosis. Members can call our Welfare Rights Helpline for expert help, or you can contact your local Citizen's Advice Bureau (see page 43).

When improving, it's often a good idea to start with voluntary work for short periods of time, and then to build up through part-time work, gradually, depending on how rehabilitation is progressing. Therapeutic work programmes can be agreed with your doctor and social security office as part of your treatment plan. You can do up to 16 hours of therapeutic work and earn a limited amount of money without losing any benefits. Some people choose to enter part-time education.

While in work, or when returning to work, it's important to be able to speak about your health situation in confidence. Many employers will have an occupational health service or doctor you can talk to, and these staff or human resources personnel should help negotiate an appropriate working arrangement for you.

Action for M.E.'s young people's service has information for young people, children, parents, schools, colleges and professionals. We aim to raise awareness and understanding from the young person/child's perspective about coping with, managing and recovering from M.E.





What causes M.E?

The cause of M.E. is not yet fully understood. Abnormalities have been found in the immune system and nervous system, including the functioning of the hypothalamus (a part of the brain that regulates basic functions like appetite, sleep and temperature control). More research is needed to understand the exact role of disruptions in these and other systems.

At the moment, some evidence exists on the factors that may make people more prone to developing M.E. (predisposing factors) and good evidence of factors that can trigger and maintain the illness. It is generally thought that an interplay of these factors contributes to the development of M.E.

Predisposing factors:

- **gender** M.E. is more common in women than in men
- **genetics** some studies have suggested M.E. may be more common in certain families

Triggering factors:

- **infections** around two-thirds of cases of M.E. are triggered by an obvious viral infection, including glandular fever, viral meningitis, viral hepatitis and, less commonly, infection with bacteria, or other organisms. Many of the infections reported as triggers appear to be quite common flu-like infections from which some people don't seem to recover normally. These may be due to enteroviruses, herpes virus and other common viruses, but the common cold does not generally seem to trigger M.E.

- **immunisations** rarely, some people seem to develop M.E. after immunisations
- **life events** increased stress (e.g. bereavement) can be common around the onset of symptoms or a triggering event, such as infection, and perhaps contributes to the failure of usual recovery mechanisms. Stress is also recognised as a trigger for setbacks
- **physical injury** trauma, including an accident or operation can sometimes be a trigger
- **environmental toxins** there is increasing awareness that potentially toxic substances may be found in our environment, such as organophosphates, carbon monoxide, toxic solvents and other chemicals. These have sometimes been implicated in individual cases of M.E., though such a link is not established and not common

Maintaining factors:

- **sleep difficulties** any deficit in sleep can become part of a vicious cycle
- **mood disorders** depression and anxiety are relatively common in chronic illness and disrupt our ability to cope with illness
- **overactivity** any activity beyond a level that an individual can tolerate can cause a delayed worsening of symptoms. It seems that people who have a pattern of overactivity, followed by setbacks, (the 'boom and bust' cycle) can be ill for longer
- **inactivity** although inactivity is a usual consequence of M.E., it might also maintain the illness, especially if it is more than is necessitated by the individual's illness



Models of illness

It is useful to have a model of an illness to help people think about and discuss that illness, so long as the model doesn't cause harm, either through what the individual thinks or does, or through other people's reactions.

One model for M.E. is that an infection, or some other trigger, sets off an initially usual reaction from the body's immune system, but that the changes persist after the infection has been controlled. The persistence may result from genetic factors, stress, another infection or unidentified influences.

The altered state of the immune system then causes changes in the functioning of other body systems, especially in the nervous system. These changes may then be maintained by attempts to get back to usual functioning prematurely, and/or by secondary sleep and mood disturbances.

Later the illness can also be aggravated by other influences, such as loss of confidence or social consequences.

Managing the illness carefully can allow the body to rest and heal itself, although this may take time.



What treatments exist?

There is no treatment that can cure M.E. The limited understanding of the mechanisms underlying the illness adds to the problems of finding more effective and focused treatments. You may hear of 'miracle cures' through the press, various therapists, well-meaning friends, other patients or even some doctors, but be cautious and try to find out on what basis these claims are made.

Don't despair though because there is still plenty that can be done to increase your chances of recovery and to help you to feel less unwell, as the experiences of many of Action for M.E.'s members have shown. People with M.E. differ, sometimes greatly, in their response to treatments, so it is important to adopt one approach or make one change at a time, to find out what works for you. Although finding information yourself can be difficult in practice, or an energy drain, individuals who are informed about treatments and treatment options may get more benefit out of those treatments. Action for M.E. is here to help with diverse information needs.

The approaches listed on the following pages are pragmatic and include those based on experience in patients with M.E.; those validated in clinical trials and those found useful from clinical experience. Action for M.E. does not take a position of advocating, or advising for or against any form of treatment.

We recommend that you discuss any approach with your doctor or other practitioner, and ideally incorporate this into an overall individualised and flexible management plan to tackle your illness.



All the following approaches have been found helpful for some people but they have also had no effect on others, and may have made some people feel worse. Consequently your doctor or other therapist needs to explain the potential benefits and possible problems of any treatment before you go ahead. This is true for all approaches in all illnesses, although some approaches are considered to have a better balance of risk and benefit than others.

It will be important that any treatment is adjusted to your particular experience and features of M.E. and there will need to be regular monitoring of your symptoms with any treatment used.

A management plan may include specific therapies as well as various treatments to ease symptoms and aid rehabilitation, where necessary using the skills of different health professionals. For example, a physiotherapist who understands the condition can give guidance on gentle exercise and activities while an occupational therapist can give advice on the practicalities of daily living. These allied health professionals and mental health experts (e.g. a psychologist) may be useful to provide ongoing emotional and psychological support.

Your doctor may refer you to a specialist consultant when additional skills or wider experience of the condition are needed to help you.

Energy or activity management

Managing energy is about finding the right balance between activity and rest for you, your particular experience of the illness, and the phase it is in.

Rest

In the early stages of the illness periods of complete rest are very important. In a survey of people with M.E.³, carried out by Action for M.E., over 70% found this helpful.

Many people find that they need total quiet for refreshing rest, while others benefit from listening to gentle music. If possible, stretch out on a sofa and leave your bed for night-time sleep. It can be helpful to learn a relaxation technique to aid your rest, and tapes and books can help you to do this. Many people are used to relaxing in rather active ways, so you may need to change your approach. It is as important to rest from mental activity and emotional stress, as from physical activity.

The need for rest periods will become less frequent as and when you are able to build up your activity levels. During recovery periods you need to be wary of excessive rest because it might be harmful, by causing what is known as 'deconditioning' of the body. This means your muscle tone and power becomes reduced and heart and lung function may be affected through underuse. Deconditioning is also thought to cause balance and temperature control problems, loss of confidence and sleep difficulties. People with M.E. are particularly vulnerable to deconditioning because of the fatigue and muscle pain that are features of the illness: some doctors state that understandable anxiety and fear about the consequences of exercise can cause some people to rest too much.



If you are feeling extremely ill you may need to rest in bed for some of the time but, within limits, try to get up each day, even if it is just to walk to the bathroom. Spending a little time sitting in a chair will help to maintain the tone of your circulation. If you are not well enough to do this, even minimal movement may be beneficial: try to move your limbs regularly and do some deep breathing. It is important to change your position in bed, by rearranging pillows from time to time, and to sit up slowly if you have been lying down for a long period.

Pacing

Management of limited energy is often referred to as 'pacing'. The aim of pacing is to work out a level of activity that can be sustained, preventing the unhelpful pattern of 'boom and bust'. You can follow the principles of pacing by yourself or discuss a long-term programme with your doctor or other practitioner. The concept behind pacing is that if you use your energy wisely, it will gradually increase. There is very little specific research into pacing as yet, but Action for M.E.'s survey² found that around 89% of people found it helpful, including those who are severely affected³. Using the principles of pacing can help bring structure to your day and can start to give you back a sense of control.

When put into practice, pacing is a strategy to discover which activities you can and cannot manage without causing setbacks, especially those with a delayed impact.

- The first step is to find a stable and sustainable baseline of physical and mental activity.
- You can then start very carefully to build up activity, making very small increases, especially at the beginning.
- It is unrealistic to try to do what you did before your illness so try not to compare your current activity levels with those before you were ill. You need to allow your body and mind time to rest and relax.
- Accept that for now you will need to prioritise what you can do in a day, and focus on achieving the things that you value most.
- You may have to stop some activities before you have finished and come back to them after you have rested, or leave them for another day.

People can become skilled at conserving their energy but still achieving what they want. It may take twice as long but there are different ways to achieve the ultimate aim.

Finding a balance is the key: between activity and rest; between physical and mental tasks; between the things that you have to do and things you want to do, and between work and leisure – it is still important that you make time for things that you enjoy in life and you shouldn't feel guilty about this.

Teleri Jardine

My life changed so much after receiving medical advice on pacing. Working out and then sticking to a daily activity level wasn't easy at first: I did get really bored. You need to be very disciplined and determined, but the rewards are worth it. In planning my day, I worked out a balance of mental and physical activities. As mental activities are less tiring for me, I can allow more time on these. Some cognitive symptoms have all but gone now and I can read books again, which was one of my goals. To combat boredom I try to find enjoyable things to do that don't use much energy.

I'm happier and more comfortable living within my daily activity limits. Before I learnt about pacing, the amount I did each day was very erratic. If I felt ok I had a tendency to overdo things, which would make me feel worse. Working out daily activity levels has brought things under control. By adding extra rest periods, I also occasionally 'save up' daily energy rations to use on a larger activity, like a trip out. Thanks to pacing, my physical energy levels are better and the number of good days I'm having is growing steadily.



Setting activity levels

The aim is to improve within limits that avoid too little or too much activity. A pacing programme will set daily activity levels that can gradually and carefully be extended.

The emphasis is on consistency and sustainability.

- Keeping a diary that you fill in during the day for a few weeks is a useful way of charting how specific activities affect you, and for starting to see a pattern that will help you to pace yourself.

This can be particularly helpful as the reaction to excessive activity may not be felt for anything from one to three days or more afterwards. It can be a surprise to find out what things affect you most – it isn't necessarily the physical tasks, as mental and emotional tasks are often more draining of energy for people with M.E.

- Once your condition has stabilised and you have been able to assess what level you can best function at, the amount of activity can then gradually be increased and the amount of rest decreased.

Some adverse reactions to activity may be usual and expected (e.g. those resulting from long unused muscles) but others may indicate that you are doing too much at a time, and that you may need to readjust your level. It is ok to make mistakes, so long as you learn from them!

The aim is to *control your illness*, not to be controlled *by* your illness. Keep aiming for improvement or recovery and be prepared to make some adjustments or compromises along the way.

- Goals can be negotiated with your doctor or other practitioner, though many people do it by themselves once they understand the general principles.

These may involve a variety of specific tasks, including a mix of social, work and leisure activities. These may be short walks, for example, or tasks carried out in even chunks throughout the day, interspersed with rests.

For those people who are severely affected, the goals may involve minimal activity but it is important to set and attain achievable targets.

- Try to switch between mental and physical activities or different types of activities.
- Make space in your day for new or bigger tasks or if you have additional stresses going on.
- The goals are gradually built up as tolerance to symptoms and confidence increases and until longer term targets are reached. This usually takes several months.

Ideally, your doctor or therapist should discuss with you beforehand how you will manage fluctuations in your health. You need to know what to do if you have setbacks, when symptoms recur or worsen. It is important to try to identify what triggered the setback – was it a stressful life event, an infection or a period of over-exertion? This will increase your understanding of what affects your illness. You will probably need to return to a lower level of activity and continue this for a week or more before attempting to move on. Use the information you have learned and don't let the 'blip' undermine your confidence. If you do have an especially good day try not to blow it by overdoing it with a 'catching-up' day, or you may lose the next week feeling ill!

A sleep routine

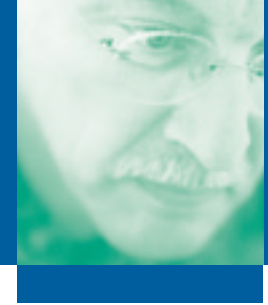
It is important to try to establish a sleep routine as early as possible. Again it may be useful to keep a diary of when you are sleeping and problems that you are experiencing, so that you can discuss this with your doctor.

At the beginning, you may find you are sleeping for a long time every day, but as time progresses you may start to have problems getting to sleep or waking up still feeling tired.

In order to develop a good sleep routine try to go to bed and get up at pre-planned times. Try cutting out caffeine, smoking and other stimulants, especially in the evening, and establish a calming and relaxing routine before bedtime.

Reducing or eliminating daytime sleeping may improve the quality of sleep but small catnaps during the day do not necessarily disrupt night-time sleep and you may find you need to do this. Remember to try to save your bed for night-time sleep if possible. If sleep continues to be of poor quality, it may be useful to consider specific treatments that can prolong or restore more refreshing sleep, as otherwise sleep deprivation adds to your problems.





Graded activity/exercise

Graded activity is a form of structured and supervised activity management that aims for gradual but progressive increases in aerobic activities, such as walking or swimming. It is based on the principle that inactivity, and the subsequent deconditioning, plays a part in maintaining the illness, which graded and supervised increases in activity can help to reverse.

Action for M.E. prefers to refer to this approach as graded activity, rather than exercise, because the best practitioners do not just focus on *physical* rehabilitation but take a broader approach to activity. In the early stages, graded exercise programmes should ideally be carried out only by therapists, such as occupational therapists, physiotherapists and sports therapists, who are trained to care for patients with M.E.

There is controversy over whether graded activity is an appropriate treatment for the nature of the illness and for patients who may already be functioning at, or very near, maximum levels of activity. Research on some relatively mobile patients supports the use of graded activity, finding improvement in fatigue and disability, but there is no research in children or severely affected patients who are unable to attend clinics.

Successful programmes do not start by forcing people into exercise beyond their capabilities but establish a baseline and start gently. They also stop when patients need a break from the programme, because they have reached a limit, and then continue after an agreed pause. This is not so different from careful pacing.

Almost 40% of people in Action for M.E.'s survey³ who had tried graded activity found it helpful: an equal number found it made them worse. This is possibly connected to the fact that some practitioners have not recognised the physical limitations of M.E. and have not listened to patients' reactions to activity, or allowed for pauses in the recovery process. Of the severely affected⁴ 34% found it helpful and 50% found it made them worse.

It is essential that the programme is mutually agreed between you and the therapist, that it is based on your current physical capacity, however limited, and that it is flexibly applied.

Cognitive behavioural therapy

Cognitive behavioural therapy (CBT) aims to support rehabilitation and is widely used as a therapy in other chronic conditions, including cancer. The therapy is broadly based on the idea that what we think and do impacts on any illness experience, and that negative patterns can be altered by individuals, usually done best with assistance.

Recovery from M.E. can be delayed by several factors, including over-vigorous exercise, attempting to resume normal activities too early, beliefs and fears about what is happening, and feelings of demoralisation, frustration, anxiety, panic and depression. CBT aims to address these problems, helping people to improve their quality of life.



The specific model varies but can include:

- energy/activity management
- establishment of a sleep routine
- dealing with reactions to the illness that may impede recovery
- goal setting
- psychological support

Usually patients have one or more assessment visits to explore their present situation. The patient and therapist then plan specific approaches and objectives for the therapy programme. Practitioners are likely to start by advising patients to reduce their activities to a safe baseline and then work gradually towards recovery.

In Action for M.E.'s survey³, around 55% of people who had tried CBT found it helpful; while 13% found it made them worse. Of the severely affected⁴, only 7% found it helpful. The vast majority of people who were severely affected found it made no difference and 26% found it made them worse. Research has shown the treatment can be of benefit to some people, but significant problems have been encountered if the therapist has limited understanding of M.E. and tries to impose an inflexible plan.

Counselling

Counselling can never magic M.E. away, but it may help to reduce some of the tremendous emotional strain on the individual with M.E., their carer, or family members. Counselling may come in the form of general psychological support and information provision offered by clinicians as part of their practice, or a more structured form of support by specifically trained professionals.

Counselling options:

Face to face: If you are well enough to leave the house, the British Association of Counsellors (see page 42) can provide a list of local counsellors. There is normally a charge but some counsellors can be flexible. Private counsellors can also be found in local community directories – it is important to check that the counsellor is both qualified and under supervision.

GP counselling: this is normally free of charge if time-limited – don't be put off by waiting-lists as you can always withdraw your name if you access help from another direction in the meantime. Consultants and M.E. clinics may also be able to provide counselling services.

Community nurses: most health authorities have well trained community nurses (sometimes attached to mental health teams) who are often trained counsellors. They can visit you at home to provide support. In some areas you can refer yourself to this service, while in other areas you may need to go via your GP. Again, this is a free service.

Telephone counselling: often the best solution for people with M.E. and their carers. This varies from regular counselling by telephone with a named counsellor; to 'dropping in' on one or more of the services when a listening ear or a counsellor is available and you need to off-load. Action for M.E. provides telephone support and counselling.

Some M.E. support groups may provide information about local counselling facilities or may have established their own support networks. There are also special support groups for carers, such as the Princess Royal Carers' Trust operating in some areas (see page 43).

Before you begin any counselling sessions there are a number of things you need to know about your counsellor:

- is your counsellor aware of M.E. or are they willing to learn about it from you?
- does their training lead them towards open-ended and 'person-centred' therapy or do they tend to work in a more structured way?
- if you are paying, what arrangements will you come to if you have to miss a session?
- how much notice does your counsellor need?
- is your counsellor in supervision, and are they a member of a counselling organisation?

It would help your counsellor to have the following information about you:

- the time of day that you are at your personal 'best'
- how easily you tire and whether you would prefer to negotiate short sessions of 20 to 40 minutes rather than an hour long session
- if you have had counselling or therapy before and what worked best then
- whether you want counselling to be open-ended or focused towards a goal or theme
- what you hope counselling will be able to offer you

Controlling symptoms

Your doctor can treat and prevent symptoms by suggesting changes in your lifestyle or diet, or through prescribing some medications. You will also discover many tactics for yourself, as you gain greater understanding of how M.E. is affecting your body. Action for M.E.'s members' magazine InterAction features suggestions and experiences on coping with different symptoms.

Pain, sleep and mood disturbance are common and, if they are intrusive, can delay recovery, as well as being unpleasant. In many such situations your doctor will consider approaches that are used when the same type of symptoms are experienced with other diseases.

For example, some types of antidepressants, when given in low doses, can be helpful in restoring better sleep quality and in easing pain, especially nerve pain and headaches. Patients with M.E. who are also depressed may be helped by carefully chosen antidepressants, especially those that have less of a tendency to promote agitation and anxiety. However, aside from the uses described in this booklet antidepressants have not been shown to be a useful treatment for M.E. itself.





Similarly, individual patients may benefit from anti-spasmodic treatments for irritable bowel syndrome; muscle relaxants for muscle pain and twitching/cramps; preventive and/or therapeutic drugs for migraines; special medications for nerve pains; pills or exercises for balance problems; anti-nausea medication and so on.

However, many people with M.E. have difficulty tolerating medication, so it may be better to start with lower doses than usual (for adults, often the dosage specified for children or the elderly and for those groups, half or less of the standard dosage) and adjust them carefully depending on the response. If there are difficulties with the medication, a variation or an alternative can usually be found so it is important to go back to your prescriber with any suspected adverse effects.

Diet and nutrition

Buying, preparing and cooking food can be difficult for people with M.E. but it is important to eat well, to fuel the body's recovery.

Try to aim for regular, good quality meals, and a diverse diet, incorporating the four different food groups of proteins, fats, carbohydrates and sugars. This is likely to provide a balance of vitamins and minerals and may include fruit and vegetables; bread, potatoes, pasta and cereals; meat, fish, eggs, pulses, nuts and seeds.

Many members of Action for M.E. report benefits of organic food although this can result in additional work and expense. Remember to wash organic vegetables well as they may have been fertilised with animal manure. You also need to maintain an adequate fluid intake, especially if you are feeling exhausted.

Although the foods described above are suitable for a basic, healthy diet it is very common for people to develop intolerances to certain foods, such as wheat and dairy. However, if you need to cut out foods from your diet it is important to consider how you are going to replace the lost nutrients, or to get advice from a nutritional expert. You may find that you need to reduce or cut out alcohol and caffeine intake. Many patients with irritable bowel syndrome can find that high fibre intake, especially cereal fibre, can increase their symptoms.

Special diets and supplementation can be a great source of confusion for patients with M.E. Different therapists offer a great range of dietary approaches with different purposes. Many people do report benefits with widely different strategies, but others find that such approaches are costly, time and energy consuming, and their benefits do not outweigh the effort involved. Sometimes, part of a diet may help, but not necessarily for the reason given. Get independent advice if you are in doubt, preferably from



more than one source, for example a nutritional expert, a recognised internet site, the British Nutrition Foundation, or Action for M.E.

Combining different exclusion diets can be especially hazardous, as you may become deficient in essential nutrients. Supplements are often recommended with limited diets and many people with M.E. and other chronic illnesses continue to take numerous supplements and do report benefits. However the scientific evidence for these benefits is not strong, and many doctors will not recommend supplementation with more than a general multivitamin unless people are deficient in the nutrient, to replace likely missing elements from the diet, or as a specific therapy.

If a diet or supplementation isn't suiting you, don't persist with it for too long. On the other hand, if you find that a particular diet does suit you, then stick with it, though you may need to be flexible later if you find your food intolerances changing or if your diet seems nutritionally inadequate; it may also be possible to be flexible later, as you improve.



Complementary and alternative medicine

The term 'complementary and alternative medicine' covers a wide range of approaches to improving health and well-being which are not considered part of mainstream medical care. People with many different problems and illnesses can find them extremely useful.

Action for M.E.'s founders were convinced that people with M.E. needed to take a wider approach than that offered by orthodox medicine alone. Many people with M.E. have found one or more complementary approaches to be helpful in alleviating symptoms and improving energy and well-being.

Helpful complementary approaches (which can also be known as 'natural', or 'holistic') include osteopathy, homeopathy, massage, reflexology, acupuncture and some herbal therapies. Sadly there is little research evidence, so to aid people to make informed choices about complementary therapies Action for M.E. will be systematically collecting evidence from members and others.

In the absence of a rigorous assessment of complementary approaches and M.E. it is helpful to consider the House of Lords' Report on Complementary and Alternative Medicine (CAM)⁵ which identified three separate groups of therapies:

'The first group embraces what may be called the principal disciplines, two of which, osteopathy and chiropractic, are already regulated in their professional activity and education by Acts of Parliament. The others are acupuncture, herbal medicine and homeopathy. Each of these therapies claims to have an individual diagnostic approach and are seen as the 'Big Five' by most of the CAM world.



Yvette Andrewartha

I can track the start of my M.E. to a long period of extreme stress, a viral infection which left me with an asthma-like condition and to cap it all off, gastro-enteritis. At this point, I was grinding to a halt. After a year of this, I was feeling very low and spoke to a friend about how I felt. I saw my GP and he diagnosed M.E. For me, giving what I had a name was the biggest breakthrough. It gave me the confidence to slow down and rest. I discovered a homeopathic doctor who had some success in treating M.E. Gradually my energy returned and the odd feeling of chemical imbalance subsided.



Homeopathic medicine helped me but it is so difficult to judge the credentials of your adviser. My only advice is not to try anything too extreme or experimental. M.E. sufferers do not have the tolerance to take such practices; be kind to yourself and accept the illness rather than fight it.

The second group contains therapies which are most often used to complement conventional medicine and do not purport to embrace diagnostic skills. It includes aromatherapy; the Alexander technique; body work therapies, including massage; counselling, stress therapy; hypnotherapy; reflexology and probably shiatsu, meditation and healing.

The third group embraces those other disciplines which purport to offer diagnostic information as well as treatment and which, in general, favour a philosophical approach and are indifferent to the scientific principles of conventional medicine, and through which various and disparate frameworks of disease causation and its management are proposed. These therapies can

be split into two sub-groups: Group 3a includes long-established and traditional systems of health such as Ayurvedic medicine and Traditional Chinese medicine. Group 3b covers other alternative disciplines which lack any credible evidence base such as crystal therapy, iridology; radionics; dowsing and kinesiology.'

Complementary therapists often have more time to spend with an individual than orthodox doctors do and people can find benefit in a gentle, understanding approach, which treats the person as an individual and encourages self-healing. However, bear in mind that not everything that is natural is necessarily good for you, and orthodox practitioners can be holistic too.

Most therapies are not available on the NHS and you should ensure that you understand the costs involved before embarking on any treatment. You should also be wary of practitioners that claim a cure for M.E. and where possible investigate the qualifications of the practitioner and also how much experience they have had of M.E. As with conventional approaches, not everyone is helped by every therapy and some can be harmful, particularly if used in conjunction with other treatments, so check with your doctor. Likewise, try to make only one change at a time, so you can identify what change is having what effect.

Action for M.E. has a free Code of Conduct for Private Practitioners, relevant to orthodox and complementary approaches, which will help you to think through some of the issues before starting any treatment.

Action for M.E.'s information service has a range of information sheets covering subjects raised in this booklet. Contact Action for M.E. for further details.



How can Action for M.E. help?

Action for M.E. is a national charity working to improve the lives of people with M.E. We are run *by* people with M.E. *for* people with M.E. to give you, your family, friends and carers the help and support you need.

We offer a range of up to date, comprehensive **information** on M.E. treatment and care for patients and health professionals. Action for M.E.'s information service is working to help you make informed choices about your illness and how you manage it, based on members' experiences, expert medical knowledge and research. We embrace a holistic approach to care that includes orthodox medicine and complementary practices. Our magazine for members, *InterAction*, is published four times a year and is packed full of the latest news about M.E., members' experiences, views and ideas. For many people, it is a real lifeline.

A network of over 150 local **support groups** across the UK gives you the chance to meet up, or make contact, with other people with M.E. Finding support and new friendships in your own community can be a huge boost as you exchange information on what helps and what local support is available. A support group can also give you the opportunity to campaign locally for improved services and better understanding of M.E.

Members of the charity have access to **telephone helplines**. A trained counsellor runs our counselling open line and can help you to cope with the emotional difficulties of living with a long-term illness. Our welfare rights helpline can give you expert advice and support on accessing benefits.

We are **campaigning** on your behalf to ensure that M.E. is widely recognised as a serious illness which merits high quality research, better services and improved funding. We work with the government, health professionals, the media and other key opinion formers to bring about real change.

How can being a member help?

Thousands of people have decided to join Action for M.E. because membership gives you:

- clear, unbiased information on many aspects of M.E.
- our magazine, *InterAction*, which keeps you up to date on M.E. news and members' experiences
- telephone helplines on counselling and welfare rights
- over 150 local support groups across the UK
- access to a postal library of books and relaxation tapes
- the opportunity to add your voice and be a force for change

For more information about Action for M.E.'s services for children and young people contact us for a copy of our introductory guide.

'Sometimes the only thing that keeps me going is to know that you're there and dealing with thousands of other people going through the same thing'

Stacy Hart, Watford

To find out about becoming a member of Action for M.E. call us on 01749 670799 or e-mail admin@afme.org.uk. You can join on-line at www.afme.org.uk or write to us at the address on page 42. It's quick and easy to join and your support is vital to our work.

Sources of support

Action for M.E.

PO Box 1302, Wells, Somerset BA5 1YE
Tel: 01749 670799, Fax: 01749 672561
Website: www.afme.org.uk
E-mail: admin@afme.org.uk

Association of Young People with M.E.

PO Box 605, Milton Keynes MK2 2XD
Tel: 01908 373300
Website: www.ayme.org.uk
E-mail: info@ayme.org.uk

Benefits' Agency Enquiry Line for people with disabilities

Helpline: 0800 882 200

British Association for Counselling

1 Regent Place, Rugby, Warwickshire CV21 2PJ
Tel: 0870 443 5252

British Nutrition Foundation

High Holbourn House, 52-54 High Holbourn, London WC1V 6RQ
Website: www.nutrition.org.uk

Complementary Medical Association

The Meridian, 142a Greenwich High Road, Greenwich, London SE10 8NN
Website: www.the-cma.org.uk

MIND (National Association for Mental Health)

15-19 Broadway, London E15 4BQ
Tel: 08457 660163
Website: www.mind.org.uk
E-mail: info@mind.org.uk

NHS Direct

Tel: 0845 46 47 local call rate
Website: www.nhsdirect.nhs.uk

National Association of Citizens Advice Bureaux

Myddleton House, 115-123 Pentonville Road, London N1 9LZ
Tel: 020 7833 2181
Website: www.nacab.org.uk
E-mail: adviceguide@nacab.org.uk

Princess Royal Carers' Trust

142 Minories, London EC3N 1LB
Tel: 020 7480 7788, Fax: 020 7481 4729
Website: www.carers.org

25% M.E. Group (for those with severe M.E.)

SAE to 4 Douglas Court, Beach Road, Barassie, Troon, Ayrshire KA10 6SQ
Website: www.btinternet.com/~severeme.group

Contact Action for M.E. for details of other M.E. patient organisations.

References

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- 3 Report on Survey of Members of Local M.E. Groups, Dr Lesley Cooper (sponsors: Action for M.E. and the M.E. Association). A total of 730 questionnaires were distributed and 347 respondents replied. November 2000
- 4 Severely Neglected: M.E. in the UK, Action for M.E. March 2001. A total of 7,529 surveys were distributed and 2,338 respondents replied.
- 5 House of Lords Select Committee on Science and Technology, Complementary and Alternative Medicine, 21 November 2000. www.parliament.the-stationery-office.co.uk



incorporating
WESTCARE UK

Information, membership and administration

Action for M.E.
PO Box 1302 Wells Somerset BA5 1YE

tel: 01749 670799

fax: 01749 672561

website: www.afme.org.uk

e-mail: admin@afme.org.uk

Press, campaigns and fundraising (registered office)

Action for M.E. 73 Watling Street London EC4M 9BL

tel: 020 7329 2299 **fax:** 020 7329 3600 **e-mail:** london@afme.org.uk

Services

Action for M.E. 155 Whiteladies Road Clifton Bristol BS8 2RF

tel: 0117 923 9341 **fax:** 0117 923 9347 **e-mail:** bristol@afme.org.uk

Registered charity number: 1036419

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