



All about M.E.

an introduction

action for **M·E**

M.E. is an illness with many names and even more symptoms. You may have heard of the illness by another name. It's also called Chronic Fatigue Syndrome (CFS). Sometimes M.E. is diagnosed as Post Viral Fatigue Syndrome (PVFS).

M.E. and its wide range of symptoms can have a huge impact on your life. This has been officially recognised by the government's Chief Medical Officer who, in January 2002, described M.E. as a 'real and debilitating illness' (see page 33).

The onset of M.E. can be gradual, or sudden. 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 many 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.



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What is M.E?

M.E. (Myalgic Encephalomyelitis/ Encephalopathy) is a chronic illness that affects many body systems and their functions, particularly the nervous and immune systems. You may know it by another name. It is also called Chronic Fatigue Syndrome (CFS) and sometimes diagnosed as Post Viral Fatigue Syndrome (PVFS). The illness can cause extreme fatigue, pain, sleep disturbance and problems with memory and concentration.

Who does it affect?

Men, women and children of all ages, and of all social and ethnic backgrounds can develop M.E. It is thought that around 240,000 people in the UK have M.E., and that nearly two thirds of them are women.

For more information on children and M.E. see our booklet *Your child and M.E: A guide for parents and families*. We also have a website for children and young people affected by the illness at www.a4me.org.uk

What causes M.E?

We don't fully understand what causes the illness.

Studies have shown that M.E. affects many body systems, particularly the immune and nervous systems. One example is the disturbance to a part of the brain known as the hypothalamus, which regulates sleep, temperature control and appetite. We need more research to understand the exact role of these disruptions.

There is some evidence that certain factors can make people more prone to developing M.E:

- M.E. is more common in women than in men
- 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 good evidence that certain infections can trigger M.E:

- 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 which trigger M.E. seem to be ordinary flu-like infections, from which some people don't recover in the normal way.

The evidence on other triggers is less clear:

- In very rare circumstances, immunizations are identified as possible triggers of the illness, although this has usually been if they were given while the person was unwell.
- Reports have suggested an association between toxins in the environment and M.E., in isolated cases. It is not thought to be a common or widespread trigger.
- Physical injury or trauma, such as an accident or operation, may very occasionally trigger M.E.
- It is unlikely that life events, such as bereavement, can trigger M.E. on their own. However, many people with M.E. find that increased stress, such as that due to major life events, commonly occurred around the time they first got ill, perhaps at the same time as another trigger, such as an infection.

It often isn't possible to find out exactly what caused your illness and it is generally thought that it may be a combination of factors.



What are 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; you may only experience a few of them.

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 straight away 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 around the time of their period.

Fatigue

- persistent and overwhelming tiredness

Feeling generally unwell

- having flu-like symptoms

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 (for example sleeping from 4am till midday)
- hypersomnia (sleeping for a long time)

Problems with thinking

- reduced attention span
- short-term memory problems
- word-finding difficulties
- inability to plan or organise thoughts
- loss of concentration

Problems with 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

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

Intolerance and increased sensitivity, including to:

- odours
- bright lights
- noise
- some foods (for example dairy or wheat)
- some medications
- alcohol
- other substances

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

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

I ended up bed-bound, 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 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.'

David Bradshaw



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 and recognising the typical symptom pattern of M.E. They may conduct basic screening 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 of M.E. or Chronic Fatigue Syndrome should be made as early as possible and confirmed within six months at the latest. The earlier that your illness is recognised, the sooner you can begin to manage and treat your symptoms.



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

Will I need to see a specialist?

Your family doctor should be able to diagnose your illness, but many GPs will have relatively limited experience of M.E., and may need to refer you to a specialist. 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. In the treatment of M.E. the particular speciality of the consultant is less important than their knowledge, experience and understanding of the condition.

Depending on your symptoms and the challenges of your illness, 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. Their role in the management and treatment of your illness will be discussed later.

If you decide to see a specialist privately, it's important to keep your GP informed, so that your treatment can be coordinated and managed effectively. Action for M.E. has free *Guidance on seeing a private practitioner*, which highlights issues to consider before starting private treatment.

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.

People often find that they don't completely get back to the way they felt before they became ill, but with adjustment they can still lead fulfilling lives.

Treatment approaches can help by reducing symptoms and making the experience of illness much less unpleasant in the short term. More importantly, they can maximise the chances of recovery and the rate at which it happens, as well as reducing the risk of setbacks and relapses.

Try not to set yourself unrealistic goals for getting better. There are many small changes you can make on a daily basis that will improve your health in the long term. Hold on to hope, but be prepared for the illness to last a long time. If you recover more quickly it will be a bonus.

'The fact that I've had M.E. for so long definitely contributed to a growing sense of failure. Why couldn't I recover when others had managed to? I don't know the answer to that, but I got there in the end. Don't give up hope, however long you've been ill.'

Factors that can hold back recovery

M.E. can be an extremely frustrating illness. It's important to understand what can make the condition worse, as many factors can hold back recovery. Unfortunately it can be much easier to exacerbate symptoms, than to relieve them.

On good days, you may try to do too much activity and suffer the consequences later when the impact kicks in, with increased symptoms and decreased functioning. 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. Try not to have a competitive attitude to M.E. You will achieve more by working within your limits and increasing activities very gradually, rather than pushing the boundaries all the time.

The key to managing your illness is to strike a balance between activity and rest and to make any changes in your routine small, and gradual. For more information on this see 'pacing' on page 16.

'I should be grateful that I can walk easily but I still want to run.'

While adequate rest is very important, doing too little, or being totally inactive will be harmful. This is because prolonged inactivity can cause muscle wasting and weakness, making it even harder for you to perform everyday tasks. However, in the early stages of the illness in particular, or during a relapse, a period of reduced activity may be necessary and helpful.

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 almost bound to happen 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. 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's probably just a blip!



'Sometimes, frustratingly, there is no discernable reason for a relapse, other than the natural rhythm of the illness, and this can often be the hardest to bear.'

How is M.E. treated and managed?

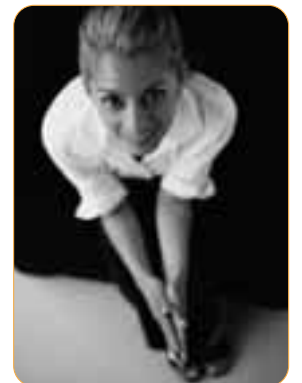
There are no wonder drugs or treatments that can cure M.E. but there are many approaches open to you and your doctor that can make a difference to how you feel and give you back control over your situation.

- Managing symptoms
- Pacing, or learning to balance activity and rest
- Graded activity/ exercise (GET)
- Cognitive behavioural therapy (CBT)
- Other approaches, including diet and nutrition and complementary therapies

In 2002 the Chief Medical Officer's Working Group identified pacing, graded activity/ exercise and cognitive behavioural therapy as potentially beneficial in modifying the illness, in the absence of a cure.

This section of the booklet aims to give you an introduction and balanced view of all the approaches listed above.

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.



Managing symptoms

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 treat and prevent 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.

Remember that 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.

Pain

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.

Sleep

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.

Irritable Bowel Syndrome (IBS)

Symptoms of IBS can be helped by antispasmodic medication, and changes to your diet (see page 22).

Dizziness or balance problems

There are medications available that can help with any problems you have with dizziness or balance.

Anxiety, depression and other mood problems

Your mental health is vital to your recovery, so it is important to seek medical help if low mood or anxiety becomes an issue for you. Remember that anxiety and depression are common consequences of any long term illness. They are not the cause of your M.E.

Your doctor may prescribe medication to help with any mood problems. Counselling and cognitive behavioural therapy (see page 21) are other options open to someone experiencing difficulties with low mood and anxiety.

For more information on managing pain, sleep disturbance and mood problems see our information booklet on *Controlling symptoms*.





Pacing

Learning to successfully manage activity and rest is often referred to as pacing. 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. Surveys of members of Action for M.E. have shown that over 90% find it helps them to manage their illness.

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

Pacing was highlighted as potentially beneficial in the Chief Medical Officer's working group report and the Medical Research Council is now funding a major trial to compare it with graded exercise therapy, cognitive behavioural therapy and 'treatment as usual'.

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. 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.

'I don't have to "do it right"; I have to get it "right for me", with my balance of physical and cognitive symptoms. What is very demanding for me may be easy for someone else.'

■ 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.

■ 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 contact us for a copy of our information booklet *Pacing: A guide for people with M.E.*

'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 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.'

Teleri Jardine



Graded activity/ exercise (GET)

The concept of graded activity/ exercise is much like pacing, but with the focus on gradual but progressive increases in aerobic exercise (e.g. walking or climbing stairs) and everyday activities (e.g. taking a bath or speaking to a friend).

Graded activity/ exercise programmes are usually delivered by physiotherapists and occupational therapists. Action for M.E. prefers to refer to the approach as graded activity, rather than exercise, because the best practitioners focus on everyday activities as well as formal aerobic exercise, such as walking. They tailor the programme to make it relevant to a person's own goals and individual circumstances.

There is some evidence to suggest that inactivity and the resulting loss of physical strength and fitness (deconditioning) can be an important factor in M.E. Graded activity/ exercise seeks to reverse this deconditioning effect. Positive effects are reported on overall fitness, physical capacity for other activities, sleep, mood, aches and pains, stiffness, and general well-being.

Surveys carried out by Action for M.E. suggest that graded activity/ exercise can be harmful when misapplied. For example, people can be told by their doctor to join a gym and find themselves exercising without support or guidance. Or they can be referred to a practitioner who has no knowledge of M.E. and be prescribed an exercise programme more suited to someone recovering from a heart condition. Or they might be encouraged to increase their activity too quickly or find that their programme starts at too high a level.

For graded activity/ exercise to be effective, the practitioner must have a sound knowledge of M.E., be appropriately trained and be able to work with you in a collaborative and flexible way.

'My occupational therapist helped me to break down ordinary tasks into manageable bits.'

A good GET programme starts and progresses at a manageable and realistic pace: when the body adapts positively to one level, it is cautiously challenged to enable a further increase in strength and fitness. It is a very gradual process and takes into account any setbacks or relapses, making adjustments if necessary. Stability in activity is also encouraged to help reduce the ups and downs of the illness.

Often the chosen exercise is walking, perhaps starting at a few paces or minutes. For people who are severely restricted, rolling over in bed or walking from the bed to a chair could be an appropriate starting point. Stretching and strengthening stiffened and weakened muscles may also play a part where appropriate.

'If some weeks I didn't feel up to increasing it I waited until my symptoms stabilised again. It was up to me to decide what I felt comfortable doing.'

Randomised controlled trials (the gold standard for research) into this approach in adults with M.E. have shown some positive results in people well enough to attend an out-patient clinic. These trials were carried out in major M.E. centres with knowledgeable and skilled therapists. There have been no published randomised controlled trials of GET in children or the more severely affected.



Cognitive behavioural therapy (CBT)

Cognitive behavioural therapy (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 e.g. 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 be particularly helpful for people who find it difficult to manage and pace their mental and physical activity. It can help you to find ways to cope with issues such as demoralisation, frustration, anxiety, panic and depression, and to feel more in control of the illness rather than controlled by it. CBT can 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.

'For me, CBT has been a lifeline, working with all my other therapies to make them more effective.'

Evidence from randomised controlled trials in adults with M.E. has shown some positive results in people well enough to attend an out-patient clinic. There have been no published randomised controlled trials of CBT in children or the more severely affected.

Other approaches

Diet and nutrition

The effort required to buy food and prepare nutritious meals 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 needed 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 the 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 dairy products and can result in an irritable bowel and other symptoms. It may be worth trying to avoid these foods, one at a time and each for a few weeks, to see if that makes a difference. Seek the advice 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.



'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.'

Complementary therapies

It is helpful to think of any therapy outside of those prescribed by your doctor as 'complementary': 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
- Nutritional therapy



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

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 for example if you are pregnant.

Action for M.E.'s free *Guidance on seeing a private practitioner* will help you to think through the issues.

'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. People with M.E. do not have the tolerance to take such practices; be kind to yourself and accept the illness rather than fight it.'

Yvette Andrewartha



Living with M.E.



Emotional well-being

M.E. will probably have a dramatic effect on your life. It may affect your relationships, career or education, family life and friendships. Dealing with the mental and emotional impact of the illness is just as important as treating the physical symptoms.

'M.E. not only affects the person suffering, but all the family as well. Even though they don't actually have the symptoms they go through many of the same emotions.'

Low doses of antidepressants, prescribed by your doctor, can be used to improve your quality of sleep and suppress pain and other symptoms. This can also indirectly help mood and how you feel generally. Antidepressants can be prescribed specifically to improve mood problems, such as anxiety, depression and mood swings, and to help you to cope. You may also find it beneficial to meet with a counsellor, or other professional to discuss any problems with anxiety or depression. This could be face to face with your GP, a community nurse, or a professional counsellor.

You also need to prepare mentally and emotionally, for the time when you get better. Returning to work, taking on new challenges and making future plans can be difficult when you've lived your life day to day. Sometimes illness may lead you to reassess your priorities in life, and to make new considered choices as a result of what you have learnt about yourself.

'It was daunting to leave the world of illness, which, despite my hatred of it, was all I had known for many years.'

'I've had M.E. for just over three years. In the beginning I wasn't able to do anything apart from sleep. I was bedridden for more than a year. My muscles and head ached terribly, and it even hurt when people touched me. I am gradually getting better, but only with lots of rest. I now work part-time and am doing a performing arts course at college. Although my life is returning to normal, I still have to pace myself and if I start to feel unwell, I rest and won't go out. It's hard but it's much better to feel well and healthy, a lesson I've learnt the hard way. I have been very low and depressed at times, and often felt that I was being left behind. M.E. has taken a year out of my life that I will never be able to get back. But on the whole I have tried to have a positive outlook on life. My friends have been the best, always making me feel wanted and included, despite my physical limitations. I know I'm a better and more confident person for having had M.E. It has changed my life and changed me as a person.'

Pia Cato



Coping with 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 even confined to bed for periods of time. However, only a small minority of patients remain bed or wheelchair bound for any length of time. 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.

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 the 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.

Carers

A carer is someone who provides regular and substantial care to a relative or friend without being paid. There are nearly 5.7 million carers in Great Britain and it is estimated that between 19,000 and 51,000 are young carers.

Carers may need help and support to provide the day to day care for someone with M.E. and they may also need to take regular breaks from caring. Carers can have their own assessment with social services to discuss the help they need, in the same way as the people they care for.

Caring can put a strain on even very strong relationships. If you are a carer, make sure that you regularly communicate how you feel, as you and the person you are caring for may both find yourselves in very different roles from what you are used to. You may find that relationship or family counselling can help to deal with problems before they become serious.

'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 rollercoaster existence: hope alternates with despair.'

How can my family and friends help?

M.E. doesn't affect just you, your whole family will have to adapt to the demands of the illness. It can be especially difficult if you are caring for children or other dependents. Try to make the most of your support network of family or friends. Don't feel guilty about asking a partner or older children to do more to help you.

Remember that no one else will fully understand how you are feeling, especially if your mood and energy levels are changing every day. To other people, you may appear to be coping well, even if you are feeling close to breaking point.

On the other hand, many people will be able to cope with straightforward requests for practical help, including regularly taking over tasks from you. This can help you a lot, and they can show their support for you more readily this way. You must feel able to ask.

Long term planning becomes difficult when you have M.E. and you may find that your whole pattern of living changes. Holidays may need to be postponed, and family time together may have to be adapted to include more home-based activities, rather than going out. It is important that you can enjoy time on your own too, so that you can relax and re-charge.

What about my job?

Having M.E. may mean that you have to cut back on working hours, change your terms and conditions of employment, or even give up your job. This can cause problems both financially and psychologically. It can be especially difficult if you are the main breadwinner in the family; if you live by yourself; or if you are a lone parent. It is important that you get advice on your employment and welfare rights.

It may be difficult and awkward to discuss your health with your line manager or human resources personnel at your work. Your health is your concern, but they may need to know what impact a health problem is having and what changes may need to be made in working hours or conditions.

Larger organisations will have an occupational health department or a contract with a doctor. You can work in confidence with them and others looking after you to offer your manager a plan about what changes may need to be made. If your work does not have such an arrangement, or you are not comfortable with this, discuss with your GP or specialist what and how to tell your work.

If you have concerns about your employer's attitude towards your illness, you may find it helpful to talk to an adviser at your local Citizens Advice Bureau, or the government's employment advice body ACAS (see pages 33 and 34). Most employees will be entitled to a period of sick leave – check your employment contract for details of your workplace arrangements. If you are still unable to work after the period of your sick leave ends, you may qualify for statutory sick pay from the government.

Having to scale back your job, or leave work altogether can affect you psychologically. You may feel isolated from friends, especially if you usually socialise with your work colleagues. When you feel up to it try to keep in contact with work friends by telephone or email, and encourage them to visit you. If you hope to go back to the same job, keeping in touch will make your return to work smoother and less stressful, both personally and professionally.

If you are not going back to an existing job, it is a good idea to consider doing some voluntary work when your health and functional level starts to improve and then to build up gradually to part-time work. This means that you can have a dry run for work-like activity, without the pressure. You can then try switching to the work setting at the same level, before later increasing it.

Work programmes can be agreed with your doctor and social security office as part of your treatment plan. You can do a set number of hours of Permitted Work and earn a limited amount of money, without losing benefits.



'After two and a half years off work – including a year virtually housebound – I was able to go back part-time. A year later I was back full-time, firing on perhaps three out of four cylinders but able to do what I had to do. Since then I've had two major relapses as a result of pushing myself much too hard but recovered within nine months each time, essentially because I now know that stopping everything and a lot of rest does the trick. Boring, but for me it works.

I still get bad patches but fortunately there's no significant downturn in energy. Some of the 14 symptoms I had at my worst point recur from time to time in a milder form, but nothing that prevents me doing anything I want to do. So these days I remain effectively recovered.'

Tony Golding



Claiming benefits

If you are unable to work because of your illness, you may be entitled to statutory sick pay and other employment and welfare benefits. These issues can be difficult and complex, so do seek advice where appropriate. Action for M.E. has information sheets on a range of benefits, as well as a welfare rights helpline for members (see page 32).

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 accept your illness and recovery is more likely to follow in time.
- 5 You are not alone. An estimated 240,000 people in the UK have this illness. To get information and support join Action for M.E. Your support will also enable us to help others with M.E.

Action for M.E. How we can help

Giving you information

Our information sheets and booklets give clear, balanced information to help you manage M.E. Our magazine for members, InterAction, is packed full of the latest M.E. news, plus tips and real experiences.

Giving you support

Our telephone support service can make a real difference to living with M.E. Our welfare rights helpline for members gives expert advice on claiming benefits. Around 150 independent local support groups across the UK provide friendship and understanding.

Giving you hope

We're campaigning on your behalf to increase recognition of M.E. as a serious illness urgently in need of better services and more research. Add your voice to our campaigning and be a force for change.

Visit our website at www.afme.org.uk for more information

Become member of Action for M.E. and help us to help you.

Membership costs just £15 for adults and is free for children and young people under 18. You can join online at www.afme.org.uk and young people under 18 can join at www.a4me.org.uk.

Call us on **01749 670799** or email admin@afme.org.uk.

Sources of support

M.E.

Action for M.E.

PO Box 1302, Wells, Somerset,
BA5 1YE
tel: 01749 670799, fax: 01749 672561
website: www.afme.org.uk
Young people's website:
www.a4me.org.uk
email: 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

25% M.E. Group

(for those with severe M.E.)
SAE to 4 Douglas Court, Beach Road,
Troon, Ayrshire KA10 6SQ
website: www.25megroup.org

Contact Action for M.E. for details of other M.E. patient organisations and local support groups.

Health

NHS Direct

tel: 0845 46 47 local call rate
website: www.nhsdirect.nhs.uk

The Chief Medical Officer's Working Group Report on CFS/M.E.

website: www.doh.gov.uk/cmo/publications.htm

Action for M.E. produces a free guide to the publication

The Samaritans

tel: 08457 90 90 90
website: www.samaritans.org

Education and employment

National Bureau for Students with Disabilities (SKILL)

Chapter House, 18-20 Crucifix Lane,
London SE1 3JW
helpline: 0800 3285050
(Mon-Thurs 1pm-4.30pm)
website: www.skill.org.uk

ACAS

tel: 08457 47 47 47
website: www.acas.org.uk

Nutrition and complementary therapies

British Nutrition Foundation

High Holborn House,
52-54 High Holborn, London,
WC1V 6RQ
tel: 020 7404 6504
website: www.nutrition.org.uk

Complementary Medical Association

67 Eagle Heights, The Falcons,
London SW11 2LJ
website: www.the-cma.org.uk

Carers

Carers UK

20-25 Glasshouse Yard, London
EC1A 4JS
tel: 020 7490 8818
website: www.carersonline.org.uk

Benefits

Department for Work and Pensions Benefit Enquiry Line for people with disabilities

Helpline: 0800 882 200

Advice and Legal

National Association of Citizens Advice Bureaux

See your local phonebook for
your nearest branch
website: www.nacab.org.uk

Disability Rights Commission

tel: 08457 622 633
website: www.drc-gb.org



PO Box 1302, Wells, Somerset, BA5 1YE

Information and membership

tel: 01749 670799

fax: 01749 672561

website: www.afme.org.uk

email: admin@afme.org.uk

Young people's website: www.a4me.org.uk

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