

Your child and M.E.

A guide for parents and families

action for **M·E**

Your child and M.E.

Looking after a child with M.E. is stressful for any parent, not just dealing with the demands of the illness, but making sure your child gets appropriate medical care, education and emotional support. It's a difficult balancing act, especially when you have other family members who need your attention too. It's natural to want to find out as much information as possible about your child's illness. There is no magic cure for M.E. and you may have to rely on a lot of common sense. This booklet was developed with parents of children with M.E., doctors and other professionals, to provide information on M.E. and to share ways of coping. We hope you find it helpful.

Trish Taylor
Chairman, Action for M.E.

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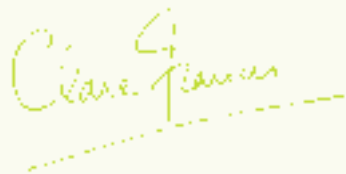
M.E. is also known as Chronic Fatigue Syndrome (CFS).
It may also be diagnosed as Post Viral Fatigue Syndrome (PVFS).

M.E. is a difficult illness for adults to cope with – dealing with the symptoms, the setbacks and other people’s attitudes on a daily basis. For children and young people, this can be overwhelming. M.E. often happens at a time in their lives when they are just beginning to discover their independence. For some children, even going to school is impossible, and they may need to be cared for at home, with all the problems of reduced social activities and possible loss of friends.

Sometimes you may feel you are fighting single-handed to find out what is wrong with your child, but you are not alone. M.E. affects as many as 25,000 children in the UK from all social and ethnic groups. The substantial impact of M.E. on the individual and the family has been officially recognised by the government’s Chief Medical Officer who, in January 2002, said that this is a real and debilitating illness (see page 40).

M.E. is a frustrating condition. There are no easy answers or shortcuts to make it go away. The most important thing to remember is to stay positive. The outlook for young people with M.E. is very good and most children will recover.

This booklet aims to answer some of your questions and suggest ways of coping for you, your child and your family. Accepting the limitations of M.E. and setting realistic targets will help your child on the road to recovery.



Clare Francis MBE
Founding President
Action for M.E.



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. It is also known as Chronic Fatigue Syndrome (CFS) and may also be diagnosed as Post Viral Fatigue Syndrome (PVFS). The illness can cause extreme fatigue, muscle pain, memory loss and poor concentration. Although M.E. is more common in adults, as many as 25,000 children in the UK are thought to be affected. Most young people develop the illness between the ages of 10 and 18 but children as young as five have been diagnosed with M.E.

What causes M.E.?

The cause or causes of M.E. are not fully understood. It often develops after a virus, like flu or glandular fever, but it can also happen gradually for no obvious reason. People with M.E. often have abnormalities in their immune and nervous systems, including the hypothalamus (the part of the brain that regulates appetite, sleep and temperature control). More research is needed to explain why this happens. In adults, M.E. is more common in women than in men, however in young people, the illness seems to affect girls and boys in similar numbers. Some research has suggested that genetics may influence M.E., as the illness may be more common in certain families.

There is evidence that certain factors can trigger the illness. These triggering factors include:

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

- **Immunisations**

immunisations are thought to be a trigger only in very rare circumstances. Other known triggers, such as infections, are also thought to have been factors in some of the reported cases. Overall there is little evidence that immunisations trigger M.E. in children; the risk is minimal, compared with the risks of developing the infections that immunisations protect against, and their potential consequences.

- **Toxins**

reports have suggested an association between pollutants found in the environment and the development of M.E. in isolated cases. It is not felt to be a common or widespread trigger.

- **Life events**

the evidence that life events can trigger M.E. is weak. Major life events are more likely to lead to a mood disorder such as depression, which can be misdiagnosed as M.E. Many people with M.E. do however report that increased stress seems common around the time they first get ill, or when another trigger like an infection occurs. Some children develop M.E. after a bereavement or major change in their life, such as starting a new school.

- **Physical injuries**

very occasionally an accident, operation or other significant childhood illness appears to trigger M.E.

What holds back recovery?

M.E. can be an extremely frustrating illness. It is much easier to exacerbate the symptoms, than to relieve them. Understanding what makes the condition worse is important for you and your child. Many factors can hold back recovery:

- **Sleep difficulties**

losing sleep can reduce energy levels even further

- **Overactivity**

doing too much can cause setbacks and result in the illness lasting longer

- **Mood problems**

depression and anxiety reduce a child's mental and physical ability to cope with their condition

- **Inactivity**

although some rest may be beneficial, prolonged inactivity can cause muscle wasting and weakness, and in this way might hold back recovery

'Jacob developed M.E. after a nasty virus. It started with a pain in his knees and by the end of the day he had a high temperature. I knew something was really wrong when he could barely get out of bed to go to the toilet. He was taken to hospital with suspected meningitis, but that was ruled out. Our GP came out twice to see him and he was sent back to the hospital for x-rays. He was seen by the orthopaedic department and then by a rheumatologist. By then he could just about walk across the ward, so he was sent home again. When we saw the rheumatologist for outpatient tests, he said he thought Jacob was "putting it on".

Two months down the line we were lucky enough to make contact with the school doctor. She was a blessing. She saw Jacob and told us immediately that he was suffering from post viral fatigue. The head teacher was lovely too. She phoned around her contacts at the education authority to make sure Jacob received the home tuition he was entitled to.

It's important to find support in other people and to take time out for yourself. I always try to go to my weekly yoga class. Sometimes it's the only time away I have. I've also trained as a parent partner volunteer. We offer impartial advice and support on educational issues to parents and carers of children with special educational needs, including those whose medical needs affect their education.

Jacob is 12 now. He's had M.E. for three and a half years. He had a setback this winter, but he's back at school now for three lessons a week. He still manages to keep in contact with three of his friends he's known since playschool. It seems like an extraordinary coincidence, but two of them have sisters with M.E.'



Esther, mother of Jacob, aged 12

What are the symptoms?



Young people experience most of the same symptoms as adults with M.E., but they can be particularly prone to tummy ache, pain in their limbs, feeling sick, losing their appetite or gaining weight. Feeling extremely tired most, if not all of the time, is one of the main symptoms of M.E. Often, children with M.E. find that performing simple mental or physical tasks can leave them feeling exhausted for hours and sometimes days afterwards. There is often a delay between the activity and its effect on symptoms, such as fatigue. The impact may not be felt until later in the day, the following day or even a number of days later.

M.E. affects people in different ways, as you'll see from the long list of symptoms. It also varies in degree. Your child may be affected by some of the symptoms listed below. You may find that their symptoms fluctuate, or that they go on to develop new symptoms at different stages of the illness.

- **Fatigue**
persistent and overwhelming tiredness, not related to physical exertion and not relieved by rest
- **Feeling generally unwell**
flu-like symptoms particularly after normal physical or mental activities
- **Pain**
 - aching muscles or joints
 - nerve pains or pins and needles
 - headache or migraine
 - twitching muscles
 - tummy ache
- **Problems with thinking**
 - reduced attention span
 - short term memory problems
 - word-finding difficulties
 - inability to plan or organise thoughts
 - loss of concentration
 - mood swings and irritability

- **Sleep disturbance**
 - hypersomnia (sleeping for a long time)
 - unrefreshing sleep
 - insomnia (unable to sleep)
 - waking in the early hours
 - light, dreamy, restless sleep
 - sleep reversal (for example, sleeping from 4am till midday)
- **Problems with the nervous system**
 - poor temperature control
 - dizziness on standing up
 - hyper-sensitivity to light and sound
 - sweating
 - loss of balance
- **Recurrent sore throat**
 - with or without swollen glands
- **Digestive problems**
 - nausea
 - loss of appetite
 - indigestion
 - excessive wind
 - bloating
 - stomach cramps
 - alternating diarrhoea and constipation
- **Intolerances and increased sensitivity, including to:**
 - odours
 - bright lights
 - noise
 - some foods
 - some medications
 - alcohol
 - other substances

How is M.E. diagnosed?

There is no medical test currently available to tell you whether your child has M.E. Doctors can diagnose the illness from taking a careful medical history and conducting tests to rule out other possible conditions.



Although your child may need to visit their doctor several times before it's possible to confirm a diagnosis, a provisional or working diagnosis can be made early on. The timescale for reaching a diagnosis in children or young people should be as short as possible. If your child's symptoms have led to difficulties in attending school for at least 15 working days, your doctor should take steps to find out the cause from a list of possible conditions, including M.E., as recommended in the *Chief Medical Officer's Report on CFS/M.E.* (see page 40).

Ideally your GP should be able to reach a diagnosis but because M.E. is relatively uncommon, they may want to refer your child to a child health specialist (paediatrician) for a second opinion or confirmation of a provisional diagnosis.

'Society likes labels. It's so stressful when your child is ill and you don't know what the matter is.'

It can be frightening to discover that your child has a chronic illness, but recognising the condition is the first step towards treating and managing your child's symptoms. A diagnosis of M.E. can sometimes come as a relief to parents whose children have been told by teachers or doctors to 'pull themselves together'.

'She was only diagnosed after 18 months of illness. It was a relief for us all when at last we knew what it was. She felt that she was dying, and now we could reassure her that she wasn't. However we had to adjust to the realities of M.E. – that we faced a long-haul and no known cure.'

It can be useful to keep a record of your child's symptoms, especially if they are very young and find it difficult to describe or remember how they feel. These notes can be helpful when meeting with your GP or paediatrician, who may use them as a basis for diagnosing and managing the illness. After a diagnosis has been made, you should encourage your child to keep a diary of their activity/ rest levels and their eating and sleep patterns, for some time. This will help you to keep a check on the progress of the illness, especially if they have a setback in their health or during periods of improvement. Try to involve your child as much as possible in managing their illness.



Encourage your child to make entries in their diary every day, even if they need your help to write it down. It can be difficult for them to remember how they felt the day before, especially if their symptoms are fluctuating.

When will my child get better?

M.E. is an unpredictable illness, so your doctor will not be able to tell you how long it will last, or whether it will get worse. Try to tackle the illness on a daily basis. Just because your child has mild symptoms now, doesn't mean that they will become worse.

Even if your child has M.E. and has to be cared for at home, or even in hospital, there is still an excellent chance they will get better.

Studies so far have indicated that children and young people tend to make a better recovery than adults, and most children recover, even after a long period of ill health. Do hold on to hope, but be prepared for the illness to last a long time so that anything less will be a bonus.

'When he became ill towards the end of the year, I set New Year as the target for his recovery. I was angry when I didn't meet my own deadline. Now I've learned to take each day as it comes.'

How can my doctor and others help?

Your GP may be able to diagnose M.E., and will be your best contact in terms of managing your child's illness on a regular basis. You may have a GP who has a special interest in M.E., but some GPs lack experience in dealing with such a complex illness, particularly in children. If this is the case you could ask if there is another GP within the practice who has an interest in M.E.



Children should ideally also be under the care of a paediatrician. They can help with diagnosis; co-ordinate care; advise your GP and also help with any educational and social issues that may arise.

Other healthcare professionals may need to get involved in your child's care. This will depend on the extent and stage of their illness and circumstances and may include occupational therapists, physiotherapists, social workers, nurses, dieticians and mental health professionals.

Don't be afraid to ask your doctor, or any of the other specialists you may meet, to explain anything you don't understand. It can be difficult to take in everything at once, particularly if you knew nothing about M.E. before. Take a partner, or friend with you during appointments for support, and don't forget to ask your child whether they have any questions about their illness.

Action for M.E. has a free information sheet giving advice on healthcare within the NHS (see page 39).

If you decide to see a specialist privately, it's important that they keep your GP and any NHS specialist informed so that your child's treatment is managed effectively. Action for M.E. has a free code of conduct for private practitioners and complementary therapists, which highlights issues you need to be aware of before starting any private treatment (see page 39).

Every parent wants their child to get better as soon as possible, but it's important to have realistic expectations about your child's M.E. Be prepared for the illness to run its course, however long it takes.

Will my child need to go into hospital?

Most children with M.E. don't need to be admitted to hospital, although your child may need to visit as an outpatient. This is usually for tests to rule out other conditions and sometimes to see other healthcare professionals for advice and guidance. Waiting around for long periods of time can be exhausting, even for healthy children, so make sure you bring along plenty of things to keep your child happy. Healthy snacks and drinks, magazines and listening to music can make the experience less stressful for your child (although some tests or investigations may require your child not to eat or drink beforehand). Waiting rooms can be noisy, so if your child is sensitive to noise, earplugs may be useful.

It is a traumatic time for any parent if their child has to be admitted to hospital. With M.E., this can be especially worrying, as you may not know how long your child will have to stay. Remember, in hospital they can receive the specialist care needed to manage their condition.



Try to make the experience as normal as you can. Bring books and toys from home and encourage regular visits from friends and family. However, do be careful not to overwhelm your child. They will need support in a strange environment but they also need space. Encourage your child to tell you when they need company and when they need time to be on their own. Older children especially will need to have some independence, as well as time for friends to visit.

'Our child had been on painkillers for about a year and still had terrible headaches, leg pain and other symptoms. Going into hospital for a week helped – if only to see that coming off all drugs made her no worse.'

How is M.E. treated?

There are a number of approaches available to help your child but there is no magic bullet that can cure M.E. There are differing medical opinions about treatment and here we try to present a balanced review of what may be offered.

Management of symptoms

Symptoms such as pain, sleep difficulties and mood problems can take over and get in the way of recovery. Your doctor will assess your child's symptoms and may prescribe some medication. It is recommended that children are started on half or less of the adult standard dose of a drug.

- **Pain**

low doses of some drugs normally used as anti-depressants or for treating epilepsy can help control pain that is not easily controlled by regular painkillers, such as nerve pain. Muscle pain with twitching or cramps can be helped by muscle relaxants. If your child has severe headaches it may be migraine, especially if the pain is on one side at a time, or associated with nausea, light sensitivity or visual disturbances, such as flashing lights or zig-zags. Sometimes migraine can be treated with simple painkillers, but there are special anti-migraine treatments available if they don't work.

- **Sleep**

it is important that your child establishes a sleep routine. Encourage them to go to bed at the same time every night and, if possible, to get up at the same time each morning. This will be easier if your child reduces or avoids sleep in the daytime, perhaps having regular rest periods instead. If they are having problems with sleep they may need medication. Small doses of anti-depressants can help. If pain is preventing your child from getting off to sleep, or waking them early, it is important to manage this at the same time.

- **Irritable Bowel Syndrome (IBS)**

symptoms can be helped by anti-spasmodic medication and changes to the diet (see page 22).

- **Dizziness or balance problems**

can be helped by medication.

- **Anxiety, depression and other mood problems**

need to be taken care of (see page 31).

Always involve your child with their treatment, as they will be the best judge of what makes them feel better. Each approach may take time to work, so don't expect results immediately. Sometimes it can take quite a long time to find the most effective medication and people with M.E. are thought to be more prone to side effects.


General management of M.E.

Your doctor may be able to advise you on how to balance your child's activity and rest, to help stabilise the illness and work towards recovery.

There are three specific strategies that can be helpful in managing the illness:

- pacing
- graded activity/ exercise
- cognitive behavioural therapy

However, research into their effectiveness both for children and the more severely affected is limited. Every child is entitled to a flexible treatment plan, designed with their input and regularly reviewed by all concerned.



'I do wonder if this condition has a pattern of its own which defies control. M.E. is so difficult to manage because when he is going through a good patch, he so wants to do things and it is such fun to see him enjoying himself.'

Pacing – what is it?

The concept behind pacing is that if you manage your energy wisely it will gradually increase. Like runners in a race, children and young people with M.E. need to pace themselves to manage the limited energy they have. Trying to do too much or too little can cause setbacks in your child's progress. Children with M.E. commonly tend to attempt too much activity rather than too little.

Make sure the expectations you and your child have are realistic. If you set out to run a marathon in four hours and limp home in six, you will feel defeated, despite the enormous achievement of completing the course. M.E. is not a race, although sometimes you may feel that there is a marathon task ahead of you. Many people find that they begin to improve once they accept their illness, understand how it works, and follow a realistic and achievable approach to getting better.

- Find a comfort level on which to base your child's routine of mental and physical activity. It doesn't matter if you start at quite a low level; it's more important that any activity is regular and paced.
- Start to build your child's activity gradually, making very small increases, especially at the beginning.
- It may be difficult for your child to accept that they cannot do what they did before their illness. Try not to compare things they do now with those before they were ill.
- Help your child prioritise activities such as schoolwork and play. They will be motivated by things they enjoy the most.
- Maintain a balance between mental and physical activities. They will benefit from *doing*, as well as thinking. It can be easy to overlook physical activity and play, especially if you are worried about your child's education.

- Make time for rest and relaxation. Resting means just that: doing nothing. Reading and watching TV can be relaxing, but they still require the brain to be active. Sitting somewhere comfortable, or lying down, and maybe listening to gentle music or something soothing can be a good way to relax. Encourage your child to find out what relaxes them the most. People have different ideas about what they find relaxing, so it may not be something that you would find relaxing yourself.



'When she went back to school the P.E. teacher asked her if she would like to go on a run. She said "yes". She did want to go, but that was the wrong question. She collapsed after five minutes and needed a week off school to recover. Close liaison between teachers and parents is vital if pacing is to work.'

Is there evidence that this approach can help children?

There has been very little research into pacing in children or adults with M.E. and no randomised controlled trials. Randomised controlled trials (RCTs) are considered to be the 'gold standard' measure or test of whether a drug or therapy is effective or not.

Surveys of adult members of Action for M.E. and feedback from young people consistently show that the vast majority find pacing a very useful energy management strategy that helps bring structure to the day and gives back a sense of control.

The effectiveness of pacing in adults is to be compared with Graded Exercise Therapy and Cognitive Behavioural Therapy in a major Medical Research Council trial.

'She found it helpful to describe her energy levels like a battery level, with marks out of ten. This gave her a feeling of control and responsibility.'

Graded Exercise Therapy – what is it?

The concept of Graded Exercise Therapy (GET) is much like pacing, but with the focus on gradual but progressive increases in aerobic exercise, such as walking or swimming. There is evidence to suggest that inactivity and the resulting loss of physical strength and fitness (deconditioning) can be an important factor in M.E. GET seeks to reverse this deconditioning effect, with reported positive effects on overall fitness, physical capacity for other activities, sleep, mood, aches and pains, stiffness, and general well-being. GET can also act as a rehabilitative behavioural therapy, by gradually reintroducing those affected by M.E. to an activity or exercise that has been avoided, helping to improve confidence.

A good GET programme starts and progresses at a manageable and realistic pace: when the body adapts positively to one level, it is challenged slightly more to allow a further increase in strength and fitness. Often walking is the chosen exercise, maybe starting at a few paces or five minutes. Other more traditional types of exercise such as cycling or swimming, can be incorporated if preferred. For children who are severely restricted, rolling over in bed or walking a few paces could be an appropriate starting point. Stretching and strengthening stiffened and weakened muscles may also play a part where appropriate.

Action for M.E. prefers to refer to the approach as graded activity, rather than exercise, because the best practitioners do not just focus on exercise, but include targets for everyday activities.

Is there evidence that this approach can help children?

GET has proved controversial, and we have observed differences between reports from members of Action for M.E. indicating it can be harmful and research studies that have found no evidence of harm. Our own surveys indicate that the differences may result from poor practice, initiated by practitioners unfamiliar with M.E. This is to be further tested in the Medical Research Council trial comparing pacing, GET and Cognitive Behavioural Therapy.

The best practitioners start programmes from very low baselines, agreed with their patients and build up gradually over time, taking into account any setbacks and making adjustments to the programme where appropriate. They will also encourage improved stability in activity, to help control the ups and downs. Bad practice tends to start too high, be imposed rather than agreed with the patient and be inflexible.

Action for M.E. is unaware of any research studies into GET and children, and we suggest that parents make careful checks to ensure that programmes are led by practitioners with experience or training in M.E., and that they meet the above standards.

Cognitive Behavioural Therapy – what is it?

Cognitive Behavioural Therapy (CBT) is used to support people through a variety of chronic illnesses. Its use does not imply that the cause of the illness is psychological. CBT can help people to adjust to some of the consequences of being unwell. This therapy can help people to identify, understand and modify any beliefs and behaviours which impact on their illness e.g. a tendency to overdo it, or being unable to say 'no'.

CBT can be particularly helpful for people who find it difficult to manage and pace their mental and physical activity. It may be able to help towards achieving improved physical functioning. It can help your child to find ways to cope with issues such as demoralisation, frustration, anxiety, panic and depression, to help them feel more in control of the illness rather than controlled by it. CBT can be used one to one, or in a family setting.

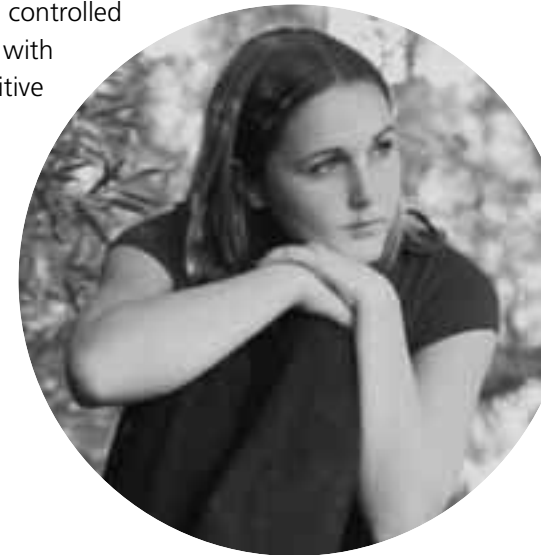
CBT can help with practical issues such as:

- 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

Is there evidence that this approach can help children?

There have been no published randomised controlled trials looking at the use of CBT in children with M.E. but studies in adults have shown positive results in some people well enough to attend an outpatient clinic. It is believed that it can be a beneficial strategy for some children if administered by an appropriately trained therapist.

As with graded exercise, CBT can make people worse if activity scheduling is too rigid or the therapist does not have appropriate training and experience of caring for patients with M.E.



Diet and nutrition

Catering for your child's dietary needs can be a source of conflict, even with a healthy child. It is very important that young people with M.E. have a balanced diet and drink plenty of fluids (about 6-8 glasses per day). This can be difficult, especially if your child has developed stomach or bowel problems. Your child may also have little desire to eat, or lack the energy to be bothered with food. It can be useful to see a dietician, who may recommend a special diet for your child. In addition to the energy required to cope with their illness, your child is still growing and needs a healthy diet to balance these demands.

Some children experience stomach problems because they have become intolerant of certain foods. The most common tolerance problems are experienced with higher fibre diets (cereals, brown bread, etc), wheat, or sometimes dairy products. It may be worth trying to avoid these (one at a time, each for a few weeks) to see if that makes a difference. If you plan to cut something out of your child's diet long term, seek professional advice, as it is really important to make sure your child is still getting all the essential nutrients. Although it's better to obtain all the body's vitamin and mineral requirements through diet, intolerance to some foods may mean that supplements are advisable. Some parents also favour using organic foods to maximise available vitamins and minerals and reduce the possible effect of pesticides.

If your child gains or loses weight, in most cases it is a direct result of the illness. However, some young people can have stomach problems or nausea around food, leading to a reluctance to eat – in itself harmful. Try to use common sense and neither force or withdraw food. Eating disorders can develop in young people as a way to control one aspect of their lives, when they are in a situation that makes them feel powerless. The Eating Disorders Association offers advice to parents and children (see page 41).



Complementary approaches

There is no miracle cure for M.E., so watch out for any therapy that makes claims to this effect. Any therapy you consider for your child, outside of those prescribed by your doctor, should be seen as complementary: to be used alongside, rather than instead of conventional treatment. Complementary treatments are also known as 'alternative', 'natural', or 'holistic'. Some treatments aim to treat the body and mind as a whole, rather than focusing on specific areas.

Therapies include:

- Osteopathy
- Aromatherapy
- Homeopathy
- Massage
- Reflexology
- Acupuncture
- Herbal remedies

Some complementary therapies, such as homeopathy and acupuncture are practised by medical doctors, and may be available on the NHS. There is little research into the use of these therapies in M.E., although some are associated with an increased feeling of well-being. Make sure you thoroughly look into any therapy that is not prescribed by your doctor, as some treatments may be harmful. For example, some treatments should not be taken together, and some remedies are unsuitable for young children.



'Our paediatrician suggested that we also try homeopathy, and we did. When our daughter recovered after three years, we don't know what helped the most – but a combination of approaches with good communication worked for us.'

What is a relapse?

The fluctuating nature of M.E. means that your child will experience good and bad times during their illness. A relapse or setback means that your child's health has deteriorated. They can be mild through to severe.

Relapses can happen for many reasons, but they are often caused by trying to do too much. If your child is doing more than their body can cope with, their symptoms will become worse. This can happen gradually, so you may not be aware that anything is wrong.

Listen to your child's description of their symptoms. They will probably vary from day to day. You will need to base any activity around them. It can be difficult to find a balance between doing too much or too little. Base your child's activity levels on what is comfortable and achievable for them, making small increases very gradually.

'We found things started to improve for our daughter when we took bold decisions. During a relapse, we took her away from school for three weeks, rather than three days. This made a huge difference.'

Sudden relapses can be caused by the usual colds and viruses all children get. Your child may take some time to recover because of this extra strain on their body. Don't be disheartened by relapse periods, even if their length is uncertain. With support and treatment, children usually recover more quickly than when they first developed M.E.

'My husband and I found our son's relapse very demoralizing especially as we had been trying so hard to pace his lifestyle. He seemed to accept it as part of the illness. He does feel frustrated, but chooses to enjoy what he can do rather than moan and groan about what he can't. He could teach us all a few lessons.'

'Before Sarah was diagnosed, one of the most difficult things was working with mixed messages. Our GP would say "go to school". By 9.30am, the school would phone us saying "Sarah is ill again" and "why did you bring her to school?" Sarah was made worse by the muddle and it frightened her.

Once her M.E. was diagnosed, we all started pulling in the same direction in a positive way. We gave the school information from Action for M.E., and we had a meeting with her teachers. Everything changed from then on.'

Jonathan, father of Sarah, aged 13



Education

Although a child may have M.E., they are still entitled to an education. All pupils should continue to have access to as much education as their medical condition allows, as recommended in *Access to education for children and young people with medical needs* (see page 41). It is good practice for children with a long-term medical condition such as M.E., to have an individual education programme drawn up in collaboration with their school, Local Education Authority, the child themselves and their parents. Your first point of contact for discussion should be the school. Children with M.E. need a lot of support from their teachers, school and education services. Some children may only be able to attend school part-time and for others, long absences may occur.

It is not only their education that your child will be losing if they are away from school. They will also miss the company of their friends and the social environment of the classroom. Even if your child is away from school for only a few weeks, they may be nervous about returning. Starting new studies, catching up with missed work, or meeting a new teacher, can all be stressful.

Try to avoid pushing your child too much when they first become ill. This is a vulnerable time, and too much pressure to keep up with their studies may result in your child having a setback. Help them to maintain some link with school.

When your child is ready, give them as much encouragement and support as possible to help them return. Sometimes a fresh start is more beneficial than struggling and failing to keep up with their current studies.



Part-time study

When your child is well enough, it is recommended that they try to attend school, even for very short periods. This will help them to keep up with their work and maintain relationships with their friends, classmates and teachers. If your child is attending school part-time they may have to choose a reduced number of subjects, rather than doing a little bit of everything. You may experience some difficulties in persuading your child to give up some subjects, as many children want to do exactly the same thing as their friends. This kind of reduced study can be beneficial, if your child is studying things they like, but they will have to include the basics, like English and Maths in their choice, so that they don't restrict their educational or employment opportunities later.



Access to education

Pupils should not be at home without access to education for more than 15 working days (see page 41 to find out more information about the government's guidelines on access to education). For children unable to go to school, or for those who can only attend a few lessons a week, keeping up with some schoolwork may mean that they can rejoin their friends in the same year, once they are well enough to return. A home tutor can help your child to keep up with some school work, even during difficult periods in their illness. You will need to explain to the tutor about your child's M.E. Study times should be built into your child's daily routine, and paced, as any other activity. The amount of time they can study should only be increased very gradually, and reduced during bad days or relapses. You should be able to arrange home tuition through your local education authority. One-to-one work with a home tutor can be as taxing for your child as being part of a group in a classroom, so be careful not to overload your child.

'Rosie was in her second year at secondary school when she suffered a severe bout of tonsillitis. She didn't really ever improve after that. She had severe headaches and swollen glands and lost a lot of weight. A few months later, when she was 13, our GP diagnosed post viral chronic fatigue and we were referred to a paediatrician.

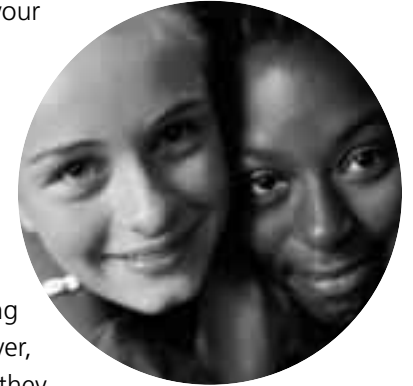
The paediatrician recommended that Rosie should keep going to school. This really didn't work for us. Even when Rosie was very unwell, he insisted she should still attend school five times a week, if only for fifteen minutes a day.

Rosie had some tutoring at home and was able to attend a special education unit, where she managed to get two GCSEs. When Rosie tried to start college we found it a real problem, as the college weren't willing to be flexible and she was forced to give up her course. Things are improving now. With the new Disability Act, colleges are having to work harder to meet the educational needs of students like Rosie. This year she's hoping to go back to college to study art and photography. Education's important but health comes first.'

Christine, mother of Rosie, aged 17

Emotional well-being

M.E. will probably have a dramatic impact on your child's life. It will affect their education, play, friendships and family life. Young people often find the transition to early adulthood traumatic. This is especially so, coping with the demands of a chronic illness. Your child's personality will be developing at this time, and the mood swings associated with puberty and adolescence will also affect a child or young person's ability to deal with their illness. However, many children cope well with the adjustments they need to make because of M.E., as they are going through a time in their lives when there are naturally a lot of changes.



'Whenever holidays and big events happen he seems to be able to raise his level for a while and we all stare in amazement, but there is always a pay back in pain which sometimes takes a while to show itself.'

Children with M.E. sometimes seem mature for their age because they have experienced the fear and stress of coping with a chronic illness. They may also spend a lot of time in adult company, especially if they are away from school for long periods. Although your child is unwell, they still think like any other young person so remember to respect their space and privacy.

Maintaining as normal a routine as possible will help your child feel settled. Encourage regular contact with friends if your child is unable to go out, but make sure they are well enough to cope with visits.

Your child will probably want to find out more about their illness, or share their experiences with other young people with M.E. A great way to do this is via the internet. Action for M.E. has a young people's website at www.a4me.org.uk

You can also encourage your child to express their feelings creatively through activities such as art, poetry, music or story telling.

'Alexander was only seven when he developed M.E. Since that time we have seen many ups and downs – this is a most unpredictable and frustrating condition. He was really poorly at the beginning of the illness, then made good progress and has now levelled off at around 40% of his previous activity levels.

He hasn't really been in school for much of that time at all, so it has been difficult to keep up with his friends in the usual way. Keeping in touch with other friends at school has been harder work, especially when he moved up to middle school. In his first year there Alexander received very little contact or understanding of his situation at all. After much work by myself I think we have finally cracked it! He now has three new friends who email him most weeks to exchange boys' stuff. We found that it has been better to try to get to know a few children rather than the whole class. After all, most children don't make friends with all the children in their class!

It is difficult to keep in touch with friends especially when they are tiring for him to have around. I have found you have to put a lot of work into it and be creative in ways of keeping in touch – particularly in the school environment! I think Alexander at last feels that he has a network of people who know and care about him, and who he can share a joke with. He seems happy with this – what more can we ask for.'

Barbara, mother of Alexander, aged 11



Dealing with anxiety and depression

Some children become depressed after developing M.E. It's not easy for them to accept being ill. They may have to stop taking part in their usual leisure and school activities. Some children can only attend school part-time or may have to withdraw altogether. They miss being with their friends and many feel isolated and excluded. Having M.E. makes them different, often at a time when they want to be the same as their peer group. They may experience bullying or unhelpful comments from other children or adults. Young people with M.E. may not have the energy to be involved with normal activities but that doesn't mean that the desire has gone away.



Some children benefit from taking a low dose of an anti-depressant, which can be prescribed by their GP. These drugs can improve their quality of sleep and suppress pain, as well as helping with mood problems.

It can be useful for your child to meet with a counsellor, or other professional, even if they are not very depressed or anxious. They can flag up any potential problems before they become serious. For some people, there is still a stigma associated with mental health. This can be especially so with M.E., particularly if you have already fought a battle with your child's school or GP, to prove the illness isn't 'all in the mind'. Remember that if your child experiences depression and anxiety, these are symptoms or consequences of M.E., not the cause of the illness. Family sessions may also be beneficial, as the whole family may be affected by your child's illness.



'We had some family therapy sessions with a psychologist and a social worker. They helped us to handle M.E. together as a family, and we were able to notice that our other child was feeling isolated. M.E. was part of her life too, as her family had changed.'

What if my child is bullied?

Bullying, whether physical or verbal, is a serious matter and needs to be resolved. Children may not always want to talk about being bullied but it's important to discuss it and let the school know what is happening. Finding out that your child is being bullied is a stressful and distressing experience for any parent. For more support see page 41.

Explaining to other children at school about their illness will be a hurdle your child will have to face. Some children may express dismissive attitudes to M.E., often after picking up on misinformed opinions. Keep a close eye on your child after they return to school. Having a good relationship with your child's teachers can help you to identify any problems before they get out of hand.

When my child becomes an adult

Unfortunately a small number of young people with M.E. continue to experience symptoms and relapses into adulthood. This has implications for their education and future employment, the management of their condition, any benefits they receive, their housing needs and independence.



Although your child is officially an adult, they will still need your support, especially if they have experienced little independence due to their illness. It can be depressing for many young people to see their friends going away to college, or starting their first job, but they may find they can continue their studies part-time and even live independently with support.

Action for M.E. has a range of publications for adults with M.E., including information on claiming benefits. It can be helpful talking to a trained counsellor too. Action for M.E. has a Telephone Support Line and Counselling Service available to people with M.E., their carers and families (see page 40).

Universities and colleges are well briefed on the needs of students with M.E. Contact their Learning Support Advisers before applying, to find out what different institutions offer.

Your child could speak to a Connexions adviser to discuss learning and educational opportunities (see page 41).

You and M.E.



You may find that your relationship with your child has changed. You are now a carer as well as a parent. This can be difficult for you and your child because M.E. often develops in young people at a time when they are discovering their sense of independence. They may resent having to rely on you for basic support and you may find it hard having to reorganise your life around supporting one child.

'My wife and I felt quite angry about M.E. We asked why M.E., and why us? It was important to recognise our anger.'

You may find that you have to become a carer full-time, giving up work commitments and social activities. You will not necessarily be thanked for your sacrifice! It is important that you take some time for yourself, to rest and socialise. You won't be able to give your child your full support if you are constantly exhausted, frustrated or depressed.

'People often ask me how I cope. I say I've no idea! You do what you have to, to get through.'

Remember to:

- Stay positive, most children do get better
- Hold on to hope, but be prepared for the illness to last a long time and anything less will be a bonus
- Keep your friendship networks going and take time for yourself
- Seek help from support services within your local community, such as social workers, carers' support agencies, religious or spiritual advisers
- Listen to your child
- Keep reminding your child's school about their needs
- Ask for help when you need it
- Take each day at a time and enjoy the good days
- Keep your own work or business going where possible, although you may have to be flexible

Your family and M.E.

As M.E is difficult to diagnose, some families experience conflict in the early stages of the illness, when family members may be reluctant to accept M.E. as the cause of your child's ill health. This can be a difficult situation, but it is important that your child feels that the whole family is supportive.

You may find that your whole pattern of living changes. It can be hard finding time for the rest of the family and changing plans at the last minute. Holidays together may have to be postponed and long-term planning becomes difficult. It is important to recognise that a child with M.E. affects the whole family. Be careful to ensure your child is not feeling guilty about this. With love and support, you can reassure them that M.E. is not their fault. Family therapy sessions with a professional such as a counsellor or psychologist, can also provide practical support and address some of the emotional issues surrounding your child's illness.

What do I tell my child about their illness?

It is very important that your child feels you are taking their illness seriously. They need to know:

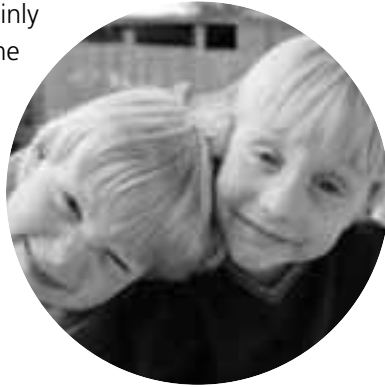
- M.E. is a real illness
- You don't think they're faking it
- They are not dying
- You don't always understand what they're going through
- It's ok to feel angry about M.E., it isn't fair
- Their family and friends are supporting them to get better
- Most children do get better in time, so try to be patient!

How much attention does my child need?

Most parents are anxious to make sure that their child has everything they need, especially when they are unwell, but over-indulging a sick child can be damaging. Early on in your child's illness, it may be difficult for you to judge when they are being reasonable and when they are being over-demanding. You know your child best and once you have established a routine, you should find it easier to reach a balance. Some children can become too reliant on their parents/ carers. It is hard for children to feel independent, especially when they can do little without help, but try to encourage the desire to do things for themselves. Children need to have boundaries set for them, otherwise as they develop into adulthood they may become either too assertive or unable to speak up for themselves.

What about my other children?

If you have other children, they will almost certainly go through phases of feeling jealous about all the extra attention focused on their sibling. This is difficult to avoid, even when your other children can reason that their sibling needs help. Try to involve the whole family in the progress of the illness. You can encourage your other children to understand more about the illness, through tools such as Action for M.E.'s young people's website (see page 40).



This is a situation that needs careful handling. Your sick child may resent everyone having an opinion on their health, and your other children may feel that they are 'put upon' and have too much responsibility. Try to create opportunities to do something special with your other children.

'I love my brother having pen-pals and e-mates because they make him happy and it's difficult for him to have friends round to play. I like him when he's happy.'

Your friends and M.E.

Sometimes you may have to make difficult choices to care for your child, but don't isolate yourself from other means of support. Your friends and other carers in a similar position can be a lifeline to help you get through difficult times. Don't avoid meeting up with people because you feel you've got nothing positive to talk about. Looking after a sick child will test your patience to the limit sometimes, so don't feel guilty if you need to discuss your frustrations with friends. Time away from home will help you to focus on the positive aspects of your relationship with your child.

Claiming benefits

Your child may be entitled to benefits in the more severe stages of their illness. The main benefit available is Disability Living Allowance, which helps towards mobility and basic care needs.

Disability Living Allowance is broken down into two components, mobility and care:

- mobility consists of two levels, higher and lower. A Blue Badge and Vehicle Exemption Tax are automatically awarded with the higher rate.
- care consists of three levels, higher, middle and lower. If your child is on the middle or high rate, you may be able to claim a carer's allowance.

If your child has to attend hospital appointments on a regular basis you may also be able to claim help with travel costs.

Following their sixteenth birthday your child will be able to claim benefits as an adult, but you can still claim Disability Living Allowance if your child continues to meet the criteria.

Action for M.E. has information sheets on Disability Living Allowance for children, and other related benefits (see page 40). Action for M.E.'s Welfare Rights Helpline is also available to members who need help or further information.

Lone parents and M.E.

Caring for a child with M.E. can be especially difficult if you don't have the emotional or financial support of a partner. If you are struggling with work commitments and a sick child, it can be particularly tough. Try to make the most of the support network you have. Family and friends, your GP and other health professionals can make coping with your child's illness easier. You may also be entitled to benefits. Members of Action for M.E. can call our Welfare Rights Helpline for expert advice (see page 40), or you can contact your local Citizen's Advice Bureau (see page 42).

When my child gets better

Most children with M.E. do get better over time.

Parents have described how liberating and wonderful this is. Even when recovered, your child may feel that they have missed out on a lot of opportunities in life, and this will take time to work through and adjust to. In some ways it is similar to a grieving process.

'Our family will never be the same. Seeing our child in pain without being able to do anything about it is something we will never forget. Thank God that is now behind us, we are picking up our family life again, and wondering how we got through it all. After three to four years, our child is well again. To other parents we always say – have hope!'



Action for M.E. How we can help

Action for M.E. is a national charity dedicated to improving the lives of people with M.E.

We can help you and your child by

Giving you information

Our information sheets and booklets give clear, balanced information to help you and your child manage M.E. Call 01749 670799 for information. 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, counselling services and face-to-face clinics can make a real difference to living with M.E. Call 0117 923 9341 for details. Our Welfare Rights Helpline for members gives expert advice on claiming benefits. Almost 200 independent local groups across the UK provide friendship and understanding. Call 01749 670799 for details.

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.

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

Membership costs £15 for adults and is free for children and young people under 18. Call us on **01749 670799** or email **admin@afme.org.uk**.

You can join online at **www.afme.org.uk** and young people under 18 can join at **www.a4me.org.uk**

Sources of support

M.E.

Action for M.E.

PO Box 1302, Wells, Somerset, BA5 1YE
 Information service and general enquiries tel: 01749 670799
 Services enquiries tel: 0117 923 9341
 fax: 01749 672561
 website: www.afme.org.uk
 email: admin@afme.org.uk
 Young people's website: www.a4me.org.uk

Association of Young People with M.E.

Free to under 25s, also has a parents' network putting carers in touch with one another
 PO Box 605, Milton Keynes, MK2 2XD
 tel: 01908 373300
 website: www.ayme.org.uk

Parents of Children with M.E. Support Group

Contact Action for M.E. for details of this group and for information on other M.E. patient organisations

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 report

Health

NHS Direct

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

The Patients Association

PO Box 935, Harrow, Middlesex, HA1 3YJ
 helpline: 0845 608 4455
 website: www.patients-association.com

Eating Disorders Association

103 Prince of Wales Road, Norwich, NR1 1DW
 tel: 0870 7703256
 adult help: 0845 634 1414, youthline: 0845 634 7650
 website: www.edauk.com

Education and employment

Department for Education and Skills

website: www.dfes.gov.uk/sickchildren
Access to education for children and young people with medical needs

The National Association for the Education of Sick Children (NAESC)

Regus House, Herald Way, Castle Donnington, DE74 2TZ
 tel: 01332 638586
 website: www.sickchildren.org.uk

National Bureau for Students with Disabilities (Skill)

Chapter House, 18-20 Crucifix Lane, London, SE1 3TW
 helpline: 0800 328 5050
 website: www.skill.org.uk

Connexions Service National Unit

Department for Education and Skills, Moorfoot, Sheffield, S1 4PQ
 website: www.connexions.gov.uk

Anti-Bullying Campaign and Bullying Online

tel: 020 7378 1446
 Bullying Online: www.bullying.co.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, Bramlands Close, London, SW11 2LJ

tel: 0845 129 8434

website: www.the-cma.org.uk

Carers

The Princess Royal Trust for Carers

142 Minorities, London EC3N 1LB

tel: 020 7480 7788, Fax: 020 7481 4729

website: www.carers.org

Benefits

The Department for Work and Pensions Benefit Enquiry Line for people with disabilities, their carers and representatives

helpline: 0800 882 200

textphone: 0800 243355

form filling service: 0800 441144

Advice and legal

National Association of Citizens Advice Bureaux

See your phone book for a local office

website: www.nacab.org.uk

The Children's Legal Centre

University of Essex, Wivenhoe Park, Colchester, Essex, CO4 3FQ

tel: 01206 873820

website: www.childrenslegalcentre.com

The Family Rights Group

The Print House, 18 Ashwin Street, London, E8 3DL

tel: 020 7923 2628

website: www.frg.org.uk





PO Box 1302, Wells, Somerset, BA5 1YE

Information and membership tel: 01749 670799

Services tel: 0117 923 9341

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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Registered charity number: 1036419 Limited by guarantee Registered in England no. 2906840

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