

Your child and M.E.

A guide for parents and families



Foreword

M.E./CFS affects an estimated one in every 100 secondary school children in the UK aged between 11 and 16 years, from all social classes and ethnic groups. However, M.E./CFS does not just affect teenagers. The youngest child diagnosed was aged two.

Looking after a child with M.E./CFS 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./CFS and you may have to rely on a lot of common sense.

However, the outlook for young people with M.E./CFS is very good and most children will get better. Accepting the limitations of M.E./CFS and setting realistic targets will help your child on the road to recovery.

This booklet was developed by Action for M.E. and the Association of Young People with M.E. (AYME) with parents of children with M.E./CFS, doctors and other professionals, to provide information on M.E./CFS and to share ways of coping. We hope you find it helpful.

We are particularly grateful to Dr Esther Crawley, Consultant Pediatrician, Bath/Bristol CFS/M.E. service, for reviewing the contents.

**“After three to four years, our child is well again.
To other parents we always say – have hope!”**

Contents

NHS guidelines	4
What is M.E./CFS?	5
What are the symptoms?	7
How is M.E./CFS diagnosed?	10
Treatment: how can our GP and others help?	12
Management of symptoms	14
Pacing, CBT and GET/GAT	17
If a stay in hospital is necessary	21
Complementary approaches	22
When will my child get better?	23
Set-backs and relapses	24
Diet and nutrition	25
Emotional wellbeing	26
Education	29
What if my child is bullied?	32
Higher education	33
You, your family and M.E./CFS	34
How much attention does my sick child need?	34
What about my other children?	35
Your family and M.E./CFS	35
Lone parents	37
Claiming benefits	38
When your child gets better	41
Parent's checklist	42
Useful contacts	44

NHS guidelines

In December 2004 the Royal College of Paediatrics and Child Health (www.rcpch.ac.uk) published its *Evidence-based guideline for the management of CFS/M.E. in children and young people*.

In 2007, the National Institute for Health and Clinical Excellence (NICE – www.nice.org.uk) published a clinical guideline on the diagnosis and management of CFS/M.E. for NHS healthcare professionals in England and Wales.

Both are available via links on our websites, www.actionforme.org.uk and www.ayme.org.uk

The NICE guideline for healthcare professionals says that “shared decision-making between the person with CFS/M.E. and healthcare professionals should take place during diagnosis and all phases of care” and that “engagement with the family is particularly important for children and young people, and for people with severe CFS/M.E.”

In Scotland, NHS Scotland has produced a good practice statement for healthcare professionals, facilitated by Action for M.E., which is available on the NHS Scotland website, www.show.scot.nhs.uk and via links on our website, www.actionforme.org.uk. Or call us on 0845 123 2380.

Jonathan's story

“I first became ill when I was 12, having had a difficult first year at secondary school with several nasty viral infections which never cleared up. My doctor then thought I might have glandular fever but the tests were negative. This just made me feel worse as school were giving me a hard time as officially there was nothing wrong with me. I finally got a diagnosis of Post Viral Fatigue but by this time I felt so ill I was hardly ever at school. It took all of my energy to just get there.

“Eventually I saw a specialist paediatrician who said I needed to just do half days, for half a term. After this I felt much stronger and we built up very slowly from there. If I hadn't had the support of that specialist I think I would have ended up really ill and missing much more school. I wish more people knew about and understood this condition.”

Jonathan, aged 16

What is M.E./CFS?

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

Symptoms vary but may include persistent exhaustion ('fatigue'), muscle and/or joint pain, sleep disturbance, 'flu-like symptoms such as headache, sore throat, painful lymph nodes, dizziness and/or nausea and problems with memory and concentration. A more complete list is given on pp 7-9.

Different types of M.E./CFS

In 2009/10 Dr Margaret May, Dr Esther Crawley and Dr Alan Emond published research on M.E./CFS in children which showed that there appear to be three different types (or phenotypes) of M.E./CFS in children and young people:

- musculoskeletal (where the main symptoms were muscle and joint pain)
- migraine
- sore throat.

The researchers found that the migraine phenotype was associated with the worst pain, disability and school attendance, whilst those with the musculoskeletal phenotype appeared to have the worst fatigue.

None of the phenotypes were associated with age or length of illness (suggesting that they did not reflect loss of physical fitness due to prolonged inactivity, known as 'deconditioning.')

The lack of association with symptoms of depression or anxiety (with the exception of the migraine phenotype) suggests that they are unlikely to reflect mood disorders.

The study concluded that paediatricians who see children with M.E./CFS need to appreciate that it is a condition with different phenotypes that affects children differently and this means that different treatment approaches would be likely needed for the different types.

What causes M.E.?

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

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

In adults, M.E./CFS is more common in women than in men, however in young people, the illness seems to affect girls and boys in similar numbers, certainly up to puberty.

Triggers

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

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

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

It is not clear why some children or adults get M.E./CFS following a virus or infection while others recover normally. They may be vulnerable genetically, or their recovery after an infection could be affected by, for example, trying to return to school too soon, doing vigorous exercise, or experiencing major stresses.

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

One big outstanding question is whether emotional stressors can be a trigger. Studies are not clear, some suggesting a link and others not. It is unlikely that stressful life events, such as bereavement or starting a new school, can trigger M.E./CFS on their own. It may be a combination of factors.

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

What are the symptoms?

Young people experience most of the same symptoms as adults with M.E./CFS, but they can be particularly prone to tummy ache, pain in their limbs, feeling sick, losing their appetite or gaining weight. Feeling completely exhausted most, if not all of the time, is one of the main symptoms of M.E./CFS.

Often, children with M.E./CFS 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./CFS 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 a few or several of the symptoms listed below. You may find that these symptoms fluctuate, or your child goes on to develop new symptoms at different stages of the illness. Most children report having had all of the symptoms at some time during their M.E./CFS journey.

Cognitive impairment is significant in children and young people and has been especially noted in boys.

Fatigue

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

Pain

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

Feeling generally unwell

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

Recurrent sore throat

- with or without swollen glands

Sleep disturbance

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

Concentration, thinking and memory

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

Mood

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

Problems with the nervous system

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

Digestive problems (which can also be Irritable Bowel Syndrome)

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

Intolerance, eg.

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

M.E./CFS fatigue is very different from ordinary tiredness

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

Girls may find that symptoms worsen at different times in their menstrual cycle.

How is M.E./CFS diagnosed?

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./CFS.

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

A useful document to bring to your GP's attention, if they haven't met the condition before, was produced by the Department for Education and Skills in 2004. It is called *Change for children – every child matters. Chronic Fatigue Syndrome/Myalgic Encephalopathy (CFS/M.E.)*. Also known as Megan's Journey, it is available on our websites, www.actionforme.org.uk and www.ayme.org.uk

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. According to the NICE guideline, "a child should be referred to a paediatrician for assessment within six weeks of presentation" and "a diagnosis should be made after other possible diagnoses have been excluded and the symptoms have persisted for three months in a child or young person*; the diagnosis should be made or confirmed by a paediatrician." (*four months for an adult)

All children should be referred to a paediatrician if their symptoms persist for more than three months. After three to four months they should be referred to a CFS/M.E. specialist service if moderately affected and six months if mildly affected. They should be **referred immediately** if they are severely affected.

However, NHS services vary greatly across the UK. The availability of both specialist services and paediatricians with experience of M.E./CFS depends on where you live. Contact AYME for details on 0845 123 2389.

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./CFS can sometimes come as a relief to parents whose children have been told by teachers or doctors to 'pull themselves together.'

Keeping a record of symptoms

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. If you aren't able to see a paediatrician with knowledge of the condition, please contact the AYME helpline for advice and support.

Keeping brief notes will help you to keep a check on the progress of your child's 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.

Will my child need to go into hospital?

Most children don't need to be admitted to hospital for their M.E./CFS, 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 rooms can be noisy, so if your child is sensitive to noise, earplugs may be useful. If you can take a beanbag to sit/lie on, this can make it more comfortable and you can try to find a quiet corner to settle yourselves in.

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 and magazines can make the experience less stressful for your child (although some tests or investigations may require your child not to eat or drink beforehand).

For advice on hospital stays, see p 21.

Treatment: how can our GP and others help?

Your GP should be your best contact in terms of managing your child's illness on a regular basis. You may be lucky and find a GP who has a special interest in M.E./CFS, but sadly many GPs lack experience in dealing with this complex illness, particularly in children. If this is the case you could ask if there is another GP within the practice, or a nurse or other healthcare professional, who has an interest in M.E./CFS.

Depending on where you live, your GP may refer you to a specialist. A visit to a specialist is known as 'secondary' care and can only be arranged through your GP.

All children should be under the care of a paediatrician, even if this has to be someone at a distance, to whom your GP can refer for advice and guidance. They can also confirm the diagnosis, co-ordinate care and help with any educational and social issues that 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 meet, to explain anything you don't understand. It can be difficult to take everything in at once, particularly if you knew nothing about M.E./CFS before.

Where possible, take a partner or friend with you to appointments for support. Always ask your child in advance whether they have any questions about their illness. Remember, with M.E./CFS it can be difficult for your child to think on the spot, so allow them time to respond.

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.

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./CFS. Setting realistic short term goals with your GP, paediatrician or other professionals is an important aspect of managing the condition.

What if we want to see a private practitioner?

Many people try different approaches to help them manage their illness and their symptoms. Most private practitioners and complementary therapists are competent, ethical and caring.

Unfortunately, we also sometimes hear of practitioners who promise 'miracle cures,' charge excessively for treatments and even harm their patients. If you are considering treatment with a private doctor who operates outside the NHS or a complementary therapist, we recommend that you:

- talk to your GP or specialist and ask for their advice, especially if your child's treatment involves taking pills or medicines
- always use a qualified therapist who belongs to a professional body
- find out about their experience. How many children with M.E./CFS have they treated recently? What have their outcomes been? What evidence can they produce to verify these outcome measures?
- beware of any practitioner who tells you that their approach will cure your child – there are no miracle cures.

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

Management of symptoms

There are a number of approaches available to help your son or daughter as they get better over time – but there is no magic pill that can cure M.E./CFS. There are differing medical opinions about treatment. Here we try to present a balanced review of what may be offered.

All of the approaches described in this booklet may take time to work, so don't expect results immediately.

Always involve your child with their treatment, as they will be the best judge of what makes them feel better – but at the same time, remember that you are the parent and that might mean being firm about issues. Discipline and boundaries make children feel safe and being treated in the same way as their siblings is important.

Medication, lifestyle changes and therapies

If left untreated, symptoms such as pain, sleep difficulties and mood problems can take over your child's life and get in the way of recovery. Your doctor and other healthcare professionals can sometimes help to treat these symptoms by prescribing medication and perhaps suggesting changes in their lifestyle.

If medication is prescribed, it is recommended that children are started on a lower dose than normal and build up slowly, as some people with M.E./CFS do report sensitivity to medication.

Sometimes it can take quite a long time to find the most effective medication and some people with M.E./CFS are thought to be more prone to side effects. It is important to work closely with your GP and/or paediatrician and feedback regularly on how the medication is affecting your child. After the recommended period of time, a review should be undertaken.

Under national service frameworks, children in some parts of the UK are entitled to a health management plan, designed with their input and regularly reviewed by all concerned.

Anxiety, depression and other mood problems

Understandably children with long-term conditions can develop anxiety and depression. It is vital that they feel supported in talking about their fears and concerns and are referred to a professional who can help them.

Find out more about helping your child cope with anxiety and depression on p 28.

Sleep

It is important that your child establishes a good sleep routine. Encourage them to go to bed at the same time every night and to get up at the same time each morning. This will be easier if your child avoids sleep in the daytime, having regular rest periods instead.

If they are having problems with sleep, medication may help in some cases. Small doses of anti-depressants and other medication may help sleep disturbance, even if your child is not depressed. 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. See AYME's factsheet on sleep management.

Pain

Low doses of some drugs normally used as antidepressants can help control pain, eg. nerve pain, that is not easily controlled by regular painkillers. Muscle pain with twitching or cramps can sometimes be helped by muscle relaxants. If your child has severe headaches this should be discussed with your paediatrician or GP, who will prescribe safe and appropriate medication after ruling out other causes and may refer your child to a pain clinic.

Irritable Bowel Syndrome (IBS)

Symptoms can be helped by anti-spasmodic medication and changes to your child's diet (see p 25).

Dizziness or balance problems

These can in some cases be helped by medication. Trying relaxation techniques may help with the anxiety these symptoms cause.

“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, setting short realistic goals which allow him to succeed not fail. Life is much better for us all now.”
Shian (mother)

Activity management

Paediatricians and therapists with experience of working in this field have devised a programme which has proved to be effective for many in managing the condition and aiding recovery, especially for those with an early diagnosis.

Each child is supported in identifying his/her 'baseline' of activity, with activity split into physical, intellectual, emotional and social. Baselines are a level of activity they can sustain for three to four weeks, for seven days, without symptoms being exacerbated.

After this, for those mild to moderately affected, increases of around 10-25% in activity are advised.

NB. 'Screen time' ie. watching television and using computers, is a high energy activity and needs careful monitoring, especially before bedtime. See sleep hygiene advice at www.ayme.org.uk

An activity management programme needs to be individually tailored and managed by an experienced professional with appropriate skills and expertise in M.E./CFS. If you live in an area which does not have easy access to M.E./CFS specialists, contact AYME for advice.

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.

If not, ask to be referred to a paediatrician as sound management advice, especially in the early stages, is widely believed to affect prognosis.

Depending on where you live, your GP may or may not know which is the closest paediatrician with experience of M.E./CFS, so do contact AYME for advice.

Pacing, CBT and GET/GAT

There are three other management strategies which involve or include an element of activity management:

- pacing
- cognitive behavioural therapy (CBT)
- graded exercise therapy/graded activity therapy (GET/GAT)

A form of pacing known as adaptive pacing therapy (APT), together with CBT and GET, were studied in a trial of adult patients known as the PACE trial.

All participants received specialised medical care (SMC). Patients receiving one of the therapies were compared with others who had SMC alone. All saw mild to moderate improvement over a 52 week period.

The APT used in the trial was less likely to be effective than CBT or GET. However, both CBT and GET included elements of incremental pacing, gradually increasing baseline activity. Surveys by M.E./CFS charities have consistently shown that the majority of adults with M.E./CFS find pacing helps them to manage their illness. At the moment there is no research evidence for any of these strategies in children.

More information about the approaches is given below.

Pacing

The concept underpinning 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./CFS 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./CFS commonly tend to attempt too much activity rather than too little, resulting in a 'boom and bust' cycle.

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./CFS 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. Remember they have the rest of their lives to catch up with education, health comes first!

It can be very difficult for parents to have to manage their child's activity. Getting your GP or health professional involved, to negotiate activity levels, may cause less stress for all involved.

Make time for rest and relaxation. Resting means just that: doing nothing. Reading and watching TV can be relaxing for us, but they still require the brain to be active and are classed as high energy activities for those with M.E./CFS. 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.

Detailed advice on pacing may be found in Action for M.E.'s booklet, *Pacing for people with M.E.* (this has been written with adults in mind).

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 eg. a tendency to overdo it, or being unable to say 'no.' Its use does not imply that the cause of the illness is psychological.

CBT can help your child to find ways to cope with issues such as frustration, anxiety, panic and depression, to help them feel more in control of the illness rather than controlled by it.

It can also help with practical issues such as:

- managing energy and activity
- setting up a sleep routine
- dealing with reactions or attitudes to M.E./CFS that can slow recovery
- goal setting
- psychological support.

CBT can be used one to one, in a group or in a family setting. For CBT to be effective the therapist should have a sound knowledge of M.E./CFS, be appropriately trained and be able to work with you in a collaborative and flexible way.

Graded exercise therapy

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

It says: “The first step is to set a sustainable baseline of physical activity, then the duration of the activity is gradually increased in a planned way that is tailored to the person.

“This is followed by an increase in intensity, when the person is able, taking into account their preferences and objectives, current activity and sleep patterns, setbacks/relapses and emotional factors.

“The objective is to improve the person’s CFS/M.E. symptoms and functioning, aiming towards recovery.”

Some researchers and clinicians believe that inactivity and the resulting loss of physical strength and fitness (deconditioning) may be a factor for some people with M.E./CFS. GET seeks to reverse this effect, by focusing on gradual but progressive increases in aerobic exercise.

Often, for those mildly affected, walking is the chosen exercise, maybe starting at a few paces or five minutes. For those who are well enough, more traditional types of exercise such as cycling or swimming can be incorporated.

For children who are severely restricted, GET may involve lifting their heads from the pillow for a few seconds, progressing slowly over weeks or months to a longer term goal of supported sitting. Stretching and strengthening stiffened and weakened muscles may also play a part where appropriate.

When it works, GET can have 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./CFS to an activity or exercise that has been avoided, helping to improve confidence.

Graded activity therapy

GAT is a person-centred approach to managing a person's symptoms by using activity. Activities are selected, adapted and graded for therapeutic purposes to promote health and well-being. Therapy is goal-directed and uses activity analysis and graded activity to enable people to improve, evaluate, restore and/or maintain their function and well-being in self-care, work/education and leisure.

Are CBT and GET/GAT safe?

There has been little research into any of these strategies in children.

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

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

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

There have been no published randomised controlled trials of GAT. In Action for M.E.'s 2010 survey of adults who have tried physical rehabilitation therapies, 39% reported an improvement after GAT, while 26% said that they were worse.

People with M.E./CFS who wish to try GET/GAT should ask to be referred to a specialist CFS/M.E. clinic, where this expertise exists, if at all possible. Details of clinics are available in Action for M.E.'s online services directory, or by calling Action for M.E. or AYME (see p 44) for children and young people's services.

If a stay in hospital is necessary

Most children with M.E./CFS don't need to be admitted to hospital but some do.

If an inpatient stay is recommended, AYME can provide information to give to the hospital pre-admission. Find out if the hospital has a specialist who knows about and understands the condition. Ask if there are clear goals for the admission.

AYME has a list of hospitals with experience of treating patients with M.E./CFS which have been used and recommended by its members. In some cases they can put you in touch with parents whose children have been treated there. Hospital stays are however very personal and what suits one family may not suit another. If possible we would always recommend a visit beforehand to enable you to discuss and plan the admission.

Having a child admitted to hospital as an emergency is traumatic for any parent. With M.E./CFS, it can be especially worrying, as you may not know how long your child will have to stay. Hospital staff may or may not know about M.E./CFS, its symptoms and how they affect your child. As soon as possible put the hospital team in touch with your GP, paediatrician or whoever is taking the lead on managing your child's M.E./CFS. If in doubt, contact AYME who will link them to a specialist consultant for further information and support. This is especially important if an anesthetic is required.

Whatever the circumstances, try to make the hospital experience seem as normal as you can. Bring books and/or toys from home – but monitor visits very carefully. Being in the hospital with M.E./CFS will be exhausting and visits from friends and family will need to be carefully regulated.

Your child will need support in a strange environment but they also need space. Encourage your son or daughter to tell you if 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.”
Lesley (mother)

Complementary approaches

There is no miracle cure for M.E./CFS, so watch out for any therapy or other approach 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, relaxation and meditation, gentle yoga exercises and breathing techniques, to name but a few.

Various 'processes,' 'programmes' or 'techniques' are offered by private practitioners. Like other approaches, they seem to work for some people but not for everyone. Where they don't, it has been reported that this can leave your child feeling let down and guilty: it's important to let them know it's not their fault.

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

There is little research into the use of complementary therapies in M.E./CFS, 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 or costly with little result at the end.

Some remedies should not be taken together or are unsuitable for young children so always consult your GP or paediatrician first.

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

When will my child get better?

M.E./CFS 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 and to remain realistic yet positive. Just because your child has mild symptoms now, doesn't mean that they will become worse. Even if your child 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 those who are unfortunate enough to have a long period of ill health.

What holds back recovery?

M.E./CFS can be an extremely frustrating illness, particularly as the intensity of the different symptoms can fluctuate. It is much easier to exacerbate the symptoms than to relieve them.

Managing M.E./CFS requires patience and self control. Understanding what makes the condition worse is important for you and your child.

Many factors can hold back recovery:

- **Sleep difficulties**

Poor quality sleep and sleep reversal are common in children and are major factors to be addressed before anything else can be effectively implemented.

- **Overactivity**

Doing too much can trigger setbacks and result in the illness persisting. On good days, your child will naturally want to do more – but do too much and 24 hours or more later, they may find themselves in a relapse from which recovery will seem painfully slow. This pattern is called 'boom and bust.' If it becomes the norm it can be very distressing and there are strong indications that this pattern can prolong the illness.

It is important that you and your child get to know their limits and to set small, incremental, realistic goals for getting better. This may mean that initially they have to reduce their overall activity levels so that they can achieve a routine they can sustain. They will achieve more by working within their limits and increasing activities very gradually, than by pushing the boundaries all the time.

- **Mood problems**

Depression and anxiety reduce a person's mental and physical ability to cope with any long-term condition, so it is vital these are addressed. See p 28.

- **Inactivity**

In the early stages of the illness in particular, or during a relapse, adequate rest is necessary and helpful. It is important to think about the quality of your child's rest, not just the quantity. See the information on pacing on p 17.

However, while rest is very important, doing too little or being totally inactive can be harmful. Prolonged inactivity can cause muscle wasting and weakness. Some gentle activity is important.

Set-backs and relapses

The fluctuating nature of M.E./CFS 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 the onset of an infection or trying to do too much. If your child is doing more than their body can cope with, their symptoms may become worse. This can happen gradually, so you may not be aware initially that anything is wrong.

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

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./CFS. Your GP or specialist should put a relapse plan in place, in case this should happen; if they don't then ask for guidance before it happens.

"My husband and I found our son's relapse very demoralising 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." Heather (mother)

Diet and nutrition

It is very important that young people with M.E./CFS have a balanced diet and drink plenty of fluids (about six to eight glasses per day). In addition to the energy required to cope with their illness, your child is still growing.

But catering for a son or daughter's dietary needs can be a source of conflict, even with a healthy child. It can be especially difficult if your child has developed stomach or bowel problems or is suffering from nausea. They 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.

Some children experience stomach problems because they have become intolerant of certain foods but this isn't common. True food allergies do not seem to be a cause of, or more common in, people with M.E./CFS. Allergy tests are rarely helpful and intolerance tests are difficult to interpret.

The most common tolerance problems are experienced with wheat, higher fibre diets (cereals, brown bread, etc) 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, seek professional advice first, as it is really important to make sure your child is still getting all the essential nutrients. Exclusion diets can lead to other problems if not carefully managed.

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. Again the use of supplements in children with M.E./CFS should be undertaken only under medical advice. Some parents also favour using organic foods to maximise available vitamins and minerals and reduce the possible effect of pesticides. AYME and the British Dietetic Association (Tel: 0121 200 8080. www.bda.uk.com) produce factsheets on healthy eating for people with M.E./CFS.

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, leading to a reluctance to eat. Try to use common sense and neither force or withdraw food. Eating disorders can develop in young people as a way to control an aspect of their lives when they are in a situation that makes them feel powerless. Eating disorders charity Beat (Tel: 0845 364 1414. www.b-eat.co.uk) offers advice to parents and children.

Emotional wellbeing

M.E./CFS 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./CFS, as they are going through a time in their lives when there are naturally a lot of changes.

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./CFS is a real illness
- you don't think they're faking it
- they are not dying (some children have reported having these thoughts)
- you don't always understand what they're going through but will always try
- it's ok to feel angry about M.E./CFS, it isn't fair
- their family and friends are supporting them to get better
- most children do get better in time but they have to try to be patient.

Provide them with age-appropriate literature from AYME, to help them understand what is happening.

What's it like being a child with M.E./CFS?

Here are some of the things children with M.E./CFS have told AYME:

- "It's like a giant hoover has come out of the sky and sucked out all my energy."
- "All my senses are hypersensitive. And noise is painful and bright lights hurt my eyes."
- "My legs ache continuously; the muscles twitch and jump. I start off walking quite well but soon my legs grow heavier until they can't straighten."
- "Words come out all wrong and you forget what you're saying in the middle of a sentence."
- "Even on the hottest day I feel cold, especially my hands and feet. They tingle and sometimes I can't feel my fingers."
- "I can't concentrate on any kind of reading, writing or watching television for more than ten minutes."
- "I sleep all day and am awake all night. I try to sleep, but the inside of my head just goes round and round."
- "I can't walk straight and my balance is dreadful."
- "On bad days it can be hard work just lifting a spoon to your mouth."
- "My energy is used up so quickly, even on simple things like sitting up or getting dressed."

Children with M.E./CFS 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. Remember to respect their space and privacy and try to ensure they spend some time with their peer group if at all possible, even if it's just through safe online forums.

What can you do to help?

As well as looking after their health and doing what is necessary for their education (see p 29), maintaining as normal a routine as possible will help your son or daughter 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. Short visits are always better than no visits – but schedule them into their management plan.

You can also encourage your child to express their feelings creatively through activities such as art, poetry, music or story telling. Perhaps AYME could publish their work in its magazine.

Your child will probably want to find out more about their illness, or share their experiences with other young people with M.E./CFS. A great way to do this is via the internet. AYME is free to join for anyone under 26 and has a special secure members only area within its site, www.ayme.org.uk, with a secure and moderated message board to chat to other young people going through the same experience.

For parents, AYME has a group called AYME LINK which has its own message board and magazine. Action for M.E.'s Online M.E. Centre at www.actionforme.org.uk has a young people's section and, for students, an online forum and useful factsheets.

Dealing with anxiety and depression

Children can become depressed after developing M.E./CFS. 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./CFS makes them different, often at a time when they want to be the same as their peer group. They may experience bullying (see p 32) or unhelpful comments from other children or adults. Young people with M.E./CFS 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, psychologist or other professional, even if they are not very depressed or anxious. They can flag up any potential problems before they become serious. Family sessions may also be beneficial, as the whole family can be affected by your child's illness.

For some people, there is still a stigma associated with mental health. This can be especially so with depression or anxiety that comes from having to cope with M.E./CFS, 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.'

If your child experiences depression and anxiety, these are symptoms or consequences of M.E./CFS, not the cause of the illness.

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

Education

Although your child has M.E./CFS, they are still entitled to an education. All pupils should continue to have access to a suitable education as recommended by the Government's *Ensuring a good education for children who cannot attend school because of health needs*, published in January 2013.

This guidance is for local authorities though it may also be of interest to all those supporting the educational attainment of a child with health needs, including all types of schools, providers of alternative provision, parents and providers of health services. This document can be downloaded from www.education.gov.uk

Tell the school as soon as your child is ill, get medical certificates (sick notes) when they are needed and ask their teacher what he or she can do to help. Ensure you keep school fully informed about all medical appointments.

If your child is off school for a long-time, you should arrange to meet regularly with their teacher. Book a meeting through the school office, in advance, saying what the meeting is about.

It is good practice for children with a long term medical condition such as M.E./CFS, to have an individual education programme (IEP) drawn up in collaboration with their school, local education authority, the child themselves and their parents. Again, your first point of contact for discussion about an IEP should be the school.

Children with M.E./CFS 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. Your GP, paediatrician or specialist will usually need to write to the school and offer guidance on what is a suitable level of attendance for your child/young person or if they feel a home tutor would be better at this stage in your child's condition.

Maintaining good communications with the school is essential. Most schools are supportive. If yours isn't, contact AYME.

Parent Partnership (Tel: 0207 843 6058. www.parentpartnership.org.uk) offers free impartial advice about your child's education, the law and the rights of the child and parents. In Scotland, independent advice and information on additional support for learning (special educational needs) is available from Enquire (Tel: 0845 123 2303. www.enquire.org.uk).

Missing out

It is not only their education that your child will be losing out on 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 help your child keep in touch with friends throughout their absence by email, post, Skype, texts or phone calls if visits aren't possible as this will make reintegration far easier when the time comes. This communication does need overseeing by a parent or carer.

Don't push

Try to avoid pushing your child to keep up with their studies when they first become ill. This is a vulnerable time and too much pressure may result in your child having a setback. Sometimes a fresh start is more beneficial than struggling and failing to keep up with their current studies.

Help them to maintain some link with school perhaps via supervised email or web cam. When your child is ready, give them gentle encouragement and support to help them return.

“We realised the stress of worrying about letting us down, falling behind and failing was really damaging his health. When we backed off and set realistic and achievable targets his condition stabilised and he was much happier.” Caroline (mother)

Take it slowly

When your child is well enough, it is recommended that they try to attend school for very short periods to begin with in a quiet area – often just at lunch or break initially – before returning part-time. This will help them to maintain relationships with their friends, classmates and teachers.

Attendance should only be built up gradually, to a level they can sustain. Contact AYME for advice.

If your child attends 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 son or daughter 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 and it is essential to choose subjects and teachers they enjoy rather than sticking to core subjects initially.

Maintaining their education

Pupils should not be at home without access to education for more than 15 working days.

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./CFS. This can be done by providing literature or putting them in touch with AYME (see p 44).

Pacing their studies

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.

You should be able to arrange home tuition through your child's school, who will refer your child to your local education authority. One-to-one work with a home tutor can be taxing for your child, so be careful not to overload them and if you have access to an M.E./CFS health specialist, liaise closely with them throughout.

"If only we had realised his health is far more important he wouldn't have become so ill. Children can always catch up with their education but getting your health back isn't so easy. He now has a home tutor and is doing half of the GCSEs he had planned to do. We are beginning to see improvements in his health so it is worth it to get our son back."
David (father)

What do parents say?

- "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. Why did you bring her to school?' Sarah was made worse by the muddle and it frightened her. Once she was diagnosed, we all started pulling in the same direction in a positive way. We gave the school information from AYME and we had a meeting with her teachers. Everything changed from then on."
Jonathan (father of Sarah, aged 13)

- “The most difficult thing for us was reducing activity when we felt our child was already missing out on so much. When it was explained to us how this would help in the longer term it made it easier. Also without the support of our Occupational Therapist I doubt he would have stuck to it with just his parents on at him.” Brenda (mother of Tom, aged 15)
- “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 she was asked the wrong question. She collapsed after five minutes and needed a week off school to recover. Close liaison between teachers, parents and medical professionals is vital if therapy is to work.” Carrie (mother)
- “We found things started to improve for our daughter when we took bold decisions. Following a relapse we stuck to the plan agreed with her paediatrician and she recovered more quickly than ever before. We took it slowly and didn’t expect her to return to her previous level of functioning immediately.” Shannon (mother)

What if my child is bullied?

Bullying, whether physical or verbal, is a serious matter and needs to be resolved. Useful information and helplines may be found at www.direct.gov.uk – just type ‘bullying’ into the search box. Kidscape (Tel: 0845 120 5204. www.kidscape.org.uk) offers advice to concerned parents/guardians of bullied children.

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./CFS, 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.

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.

Make sure your child knows where he or she can get help as they may not always feel able to tell you. Childline (Tel: 0800 1111. www.childline.org.uk) offers free, confidential support to children and young people.

Finding out that your child is being bullied is a stressful and distressing experience for any parent. Support is available from Parentlineplus (Tel: 0808 800 2222. www.parentlineplus.org.uk). If you are worried about your child’s safety contact the NSPCC helpline (Tel: 0808 800 5000. www.nspcc.org.uk) or talk to the staff on the AYME helpline on 0845 123 2389.

Higher education

Most universities and colleges are well briefed on the needs of students with M.E and their student support services will offer a range of advice and practical support. Contact their disability or learning support advisers before applying to find out what different institutions offer.

Your child should speak to a careers adviser from a national agency such as:

- National Careers Service for England
(Tel: 0800 100 900. <https://nationalcareersservice.direct.gov.uk>)
- Careers Wales (Tel: 0800 100 900. www.careerswales.com)
- Careers Service Northern Ireland
(Tel: 0300 200 7820. www.nidirect.gov.uk/careers)
- Skills Development Scotland
(Tel: 0141 285 6000. www.skillsdevelopmentscotland.co.uk).

Action for M.E. has a Student Hub at www.actionforme.org.uk/students, which includes a student forum, information to consider before and at university and factsheets about the impact of M.E./CFS on studying. AYME has a special service for university students and an area on the message board for them to share information.

“My daughter found it helpful to describe her energy levels like a battery level or mobile phone. It helped her to see why she shouldn’t let her battery run completely down but always keep something in reserve. This gave her a feeling of control and responsibility.” Carrie (mother)

You, your family and M.E.

You may find that your relationship with your child changes because of their M.E./CFS. You are now a carer as well as a parent. This can be difficult for you and your child because M.E./CFS 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.

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! Read Action for M.E.'s frank and helpful booklet for carers, by carers. You can download it free from www.actionforme.org.uk or order a printed copy by phone (see p 44).

It is important that you take some time for yourself, however little, to rest and socialise. You won't be able to give your child your full support if you are constantly exhausted, frustrated or depressed. Even just a cup of tea at the bottom of the garden will give you a break.

You may be entitled to benefits (see p 38) to help you with care so don't disregard this without thinking it through.

If you provide a regular and substantial amount of care for someone aged 18 or over, you can ask the social services department in your local council for a carer's assessment which may entitle you to receive help with care.

"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. We learnt that it was better to stick to the plan and avoid these 'boom and bust' times. That is when he began to really improve." Caroline (mother to James)

How much attention does my sick 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 and/or 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?

This is a situation that needs careful handling. If you have other children, they may well 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 understand 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 AYME and Action for M.E.'s publications and websites (see p 44).

There are no easy answers. 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.

Your family and M.E./CFS

As M.E./CFS is difficult to diagnose, some families experience conflict if a parent, grandparent, sibling, uncle, aunt or other relative is reluctant to accept M.E./CFS as the cause of your child's ill health. This can be a difficult situation, but it is important that your child feels believed and that the immediate family is supportive.

AYME provides age-appropriate literature to help siblings understand what is happening.

Action for M.E.'s Online M.E. Centre www.actionforme.org.uk has a section for family and friends, which tries to see things from their point of view.

In practical terms, as a family you may find that your whole pattern of living changes. It can be hard finding time for the rest of the family. Plans can change at the last minute. Holidays together may have to be postponed and long-term planning becomes difficult. This is hard on everyone and your child may feel guilty about it. Reassure them by making everyone understand that having M.E./CFS is not their fault.

Try to spend time with your other children when your partner, a family friend or other family member is around to provide the care. Do you know or can you find someone you trust, who would be happy to be a regular, part-time or occasional carer?

Take time out with your partner if at all possible. Even if you can only go for a half hour walk, supporting one another and maintaining your relationship is even more important when you have a child with a long-term condition.

If it all gets too much, family therapy sessions with a professional such as a counsellor or psychologist may provide practical support and address some of the emotional issues surrounding your child's illness.

“My wife and I felt quite angry. We asked why M.E. – and why us? It was important to acknowledge and understand our anger. Being in touch with other AYME parents helped a lot.” Stephen (father)

Don't forget your friends

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 can be a lifeline to help you get through difficult times – and there are new friends out there, as many other carers are in a similar position. To find them contact Carers UK (Tel: 0808 808 7777. www.carersuk.org) or AYME LINK (www.ayme.org.uk) for parents and carers.

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.

Lone parents

Caring for a child with M.E./CFS 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.

Gingerbread (Tel: 0808 802 0925. www.gingerbread.org.uk) is a charity which provides advice and practical support for single parents.

You may be entitled to benefits (see p 38).

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

When your child becomes an adult

Unfortunately a small number of young people with M.E./CFS continue to experience symptoms into adulthood. This has implications for their 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 them (and you) to see their friends going away to college or starting their first job, but they may find they too can live independently with support.

If your child is under 26, the staff on AYME's helpline (see p 44) can help whatever the issue and ensure you have all of the information you need to access the right services for you and your child. If you find yourself under pressure from education, health or social services contact us for confidential information, guidance and support.

If your child is 26 or over, AYME's Grads group offers social networking, friendship and support, while Action for M.E. can provide a wide range of resources at www.actionforme.org.uk including the M.E. Friends Online Forum. It also offers a membership magazine, Welfare Rights Line (see p 44) and social networking via www.facebook.com/actionforme

Claiming benefits

Benefit rules are very complex and subject to change so please use the following as a general guide and seek advice about anything you are unsure of.

Your child may be entitled to benefits in the more severe stages of their illness.

Disability Living Allowance

The main benefit currently available (May 2013) is Disability Living Allowance (DLA), which helps towards mobility and personal care needs.

DLA is being replaced by a new benefit called the Personal Independence Payment (PIP) and this process began in April 2013. At first this will only affect new claimants but eventually it will affect all working-age DLA claimants. All existing DLA claimants of working age will be invited to claim PIP when it is introduced.

Children up to the age of 16 will remain on DLA and not be reassessed for PIP. When your child reaches 16 they will need to claim PIP instead. Five months before a young person claiming DLA turns 16, their parent or guardian will be contacted to tell them about the change in benefit from DLA to PIP. They will also be asked whether the young person will require an appointee to act on their behalf in benefit matters.

When the young person reaches 16 they will be contacted themselves and told that they need to apply for PIP. Provided the young person makes a claim for PIP, their DLA award will continue beyond their 16th birthday until a decision has been made on their entitlement to PIP.

DLA is made up of two components, mobility and care:

- mobility consists of two levels, higher and lower. Those claiming the higher rate are automatically entitled to (but still have to apply for) a Blue Badge and vehicle tax exemption.
- 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 Carer's Allowance.

Following their 16th birthday, your child may be able to claim benefits as an adult.

Carer's Allowance

Carer's Allowance is the main state benefit for carers. To qualify you must not earn more than the earnings limit and be caring for someone for at least 35 hours per week, plus the person you care for needs to be getting the middle or high rate care component of DLA, Attendance Allowance or Constant Attendance Allowance. In addition to Carer's Allowance you may also be eligible for other benefits, whether you are in or out of work.

Other benefits

- Child Tax Credit is a means-tested allowance for parents and carers of children or young people who are still in full-time education. You may get an extra amount if you are caring for a disabled child. For more information, call the Tax Credit helpline (Tel: 0345 300 3900. www.direct.gov/taxcredits). Please note that, due to the introduction of Universal Credit, it is planned that no new claims for Child Tax Credit can be made after October 2013.
- If you are bringing up a child as a lone parent you may be able to claim a range of benefits whether you are in or out of work. See p 37 for information for lone parents.
- Depending on your family circumstances, you may be able to claim low income benefits such as Income Support, Jobseekers Allowance, Housing Benefit and Council Tax Support.
- If you are working at least 16 hours per week you may be able to claim Working Tax Credit. All these benefits depend on your household income and savings, and different rules apply according to whether you are a lone parent, carer or part of a couple.

Please note that changes to the benefits above began to take effect in April 2013. Housing Benefit, Tax Credits and Income Support will be replaced by Universal Credit. At first this change will only affect new claimants but eventually all claimants will move on to Universal Credit. You should receive notification about any changes to your benefits in advance. It may take several years before your benefits are affected. There is further information about Universal Credit in Action for M.E.'s *Guide to welfare benefits and other financial support* and Universal Credit factsheet.

Child Benefit is payable if you are responsible for a dependent child or young person. From 7 January 2013, a High Income Child Benefit tax charge applies to certain people on higher incomes. If a household receives child benefit, and either the person claiming child benefit or her/his partner has a taxable income over £50,000 for the tax year, s/he may be required to pay extra tax because the household receives child benefit. The child benefit itself is not cut or taxed. If her/his taxable income is over £60,000 for the tax year, the extra tax paid will be

equivalent to the whole amount of child benefit received, so will effectively cancel out the child benefit.

Most forms of child support maintenance are fully disregarded as income for means-tested benefits and Tax Credits.

Other help

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

If you are caring at home for a severely disabled child and you qualify for Tax Credits or certain other benefits, you may be eligible for help through the Family Fund (Tel: 0844 974 4099. www.familyfund.org.uk)

Each person's circumstances are different and so other benefits may be available to you that are not listed here. Eligibility for benefits also depends on your family circumstances, any savings you have and in some cases your National Insurance record as well as your status in the UK.

Health costs

In England, your child is entitled to free prescriptions if they are under 16 (or under 19 and in full-time education). If you live in Wales, Scotland or Northern Ireland, all prescriptions are free, whatever your age. If you are on certain benefits, you and the person you care for will be entitled to help with health costs. Help may also be available if you are on a low income.

For further information contact the Help with Health Costs advice line (Tel: 0845 850 1166. www.nhs.uk).

Further advice

Benefits factsheets are free to download from www.actionforme.org.uk

Members of Action for M.E. and AYME can contact the charities' helplines (see p 44) for expert advice on welfare benefits.

Other sources of information include:

- your local Citizen's Advice Bureau (www.citizensadvice.org.uk)
- Benefit Enquiry Line (Tel: 0800 882 200. www.direct.gov.uk)
- Contact a Family (Tel: 0808 808 3555. www.cafamily.org.uk)

Contact a carers organisation such as Carers UK (Tel: 0808 808 7777. www.carersuk.org) or Carers Trust (Tel: 0844 800 4361. www.carers.org) for more details.

When your child gets better

Most children with M.E./CFS 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.

Even so, children and young people who have had M.E./CFS frequently tell AYME that although being ill was challenging, they also feel grateful as they have learnt much about themselves and feel they will be more caring and empathic towards others after their experience. Several young people have even successfully changed career path as a result of having M.E./CFS.

Alexander's story

"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)

Parent's checklist

Try to stay positive yet realistic, as the majority of children with M.E./CFS do get better. Hold on to hope and:

- ask for help when you need it
- 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
- find out about welfare benefits
- keep reminding your child's school about their needs
- take each day at a time and enjoy the good days
- keep your own work or business going where possible but expect that you may need to be flexible
- contact AYME: there may be more help available that you aren't aware of
- read Action for M.E.'s booklet by carers, for carers or check out the carers' section at www.actionforme.org.uk

AYME is free to children and young people up to their 26th birthday, and all booklets, leaflets and factsheets are free to download at www.ayme.org.uk. It costs £20 to join LINK, AYME's parents and carers' group with its own bi-monthly news bulletin and private message board at www.ayme.org.uk (a percentage of this money goes to support your child's charity).

All of Action for M.E.'s booklets and factsheets are free to download at www.actionforme.org.uk and many parents become Supporting Members to receive our magazine and other benefits.

Paige's story

"Our daughter first became ill when she was nine years old. We became so concerned as no one could tell us what was wrong. After two years of negative tests, hospital visits and being faced by disbelief, a friend heard a programme about M.E. on the radio and raced round to tell us about it as she recognised all of Paige's symptoms.

"We contacted the AYME helpline and were advised how to get a diagnosis confirmed. Our GP referred us to an M.E./CFS specialist who confirmed the diagnosis and explained everything to us. I can't tell you what a relief it was.

"Paige is now 13 and thanks to the specialist we saw, she is doing really well. She is back at school full-time. She is not doing P.E. yet and hasn't re-joined her after-school clubs but otherwise is back to being a happy and active girl.

"Her symptoms at the beginning were terrifying for us all, especially the pain and nausea, and we can't believe that no one in the NHS recognised her condition. Without that radio programme we often wonder how things would have progressed. The rest of our journey hasn't been easy but knowing what was wrong and seeing the specialist was definitely the turning point for us."

Karen (mother of Paige, aged 13)

Useful contacts

Both charities cover the whole of the UK. Visit our websites for links to carers' support groups and other relevant agencies.



Action for M.E.

PO Box 2778, Bristol BS1 9DJ

General enquiries: 0845 123 2380 or 0117 927 9551 (Mon to Fri 9am to 5pm)

Enquiries email: admin@actionforme.org.uk

Welfare Rights Line: 0845 122 8648 (call for times)

www.actionforme.org.uk

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10 Vermont Place, Tongwell, Milton Keynes MK15 8JA

Helpline: 0845 123 2389 (Mon to Fri 10am to 2pm)

Email: info@ayme.org.uk

www.ayme.org.uk

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