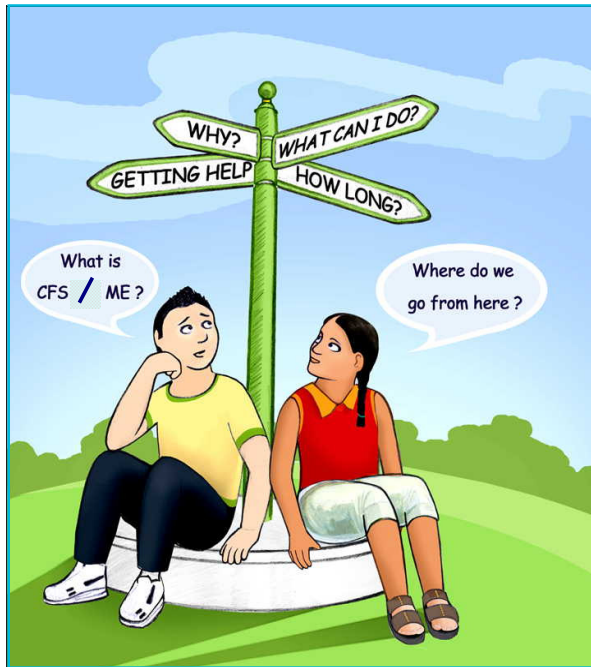


# Young Person's Guide to CFS/ME



The Royal College of Paediatrics and Child Health

This leaflet has been developed as part of the 'Evidence based guideline for management of CFS/ME (Chronic Fatigue Syndrome / Myalgic Encephalopathy) in children and young people' produced by the Royal College of Paediatrics and Child Health.

## • What have I got?

Your doctor has said you have Chronic Fatigue Syndrome (CFS), or they may have called it Myalgic Encephalopathy (ME). These terms mean the same thing so we've called it CFS/ME in this leaflet.

## • What is it?

CFS/ME is an illness, which makes you feel very tired and unwell. This 'poorly' tiredness is quite different from the 'sleepy' tiredness that everyone feels at times. People of all ages can get CFS/ME; although you may not know anyone else with CFS/ME, other young people do get it, mostly when they are teenagers - it is more rare in young children.



## • Why did I get it and when will I get better?

Doctors are still unsure about what causes CFS/ME. Scientists are working on it but they haven't found the answer yet.

Some people get better in a few months, but in others it can take quite a bit longer than that. It is important to try to be patient and understand that it may take a while. We do know that children get better faster than grown-ups with CFS/ME.

## • Why all these tests?

Because we don't know what causes it there are no tests that can tell your doctor that you definitely have CFS/ME. Your doctor will need to make sure that it isn't something else causing your symptoms. To do this they will examine you thoroughly and take some blood (it shouldn't hurt!) and test your urine. Telling your doctor about *all* your symptoms, how severe they are and when they started will also help him/her to make the diagnosis.

## • How will CFS/ME affect me?

CFS/ME can cause many different symptoms, although you are unlikely to get them all. The most common ones are in the table on the middle pages of this leaflet.

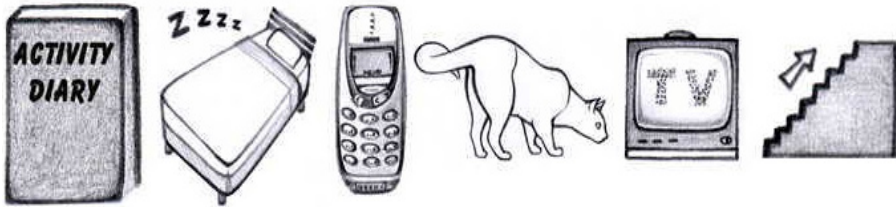
As with any illness, some people have worse symptoms than others. You might have 'bad days' when your symptoms are worse but you will also have 'good days'. Your symptoms might also be better or worse at particular times of the day. Remember that your illness may be very different from other children with CFS/ME. Some stay fairly well all the time and can attend school most days, whilst others get very poorly.

- **What is an activity diary?**

Your doctor will probably suggest you keep an activity diary. This is somewhere you can record how much you can do and how you are feeling and will help you talk with your doctor about how you feel.

- **What should I write in my diary?**

Agree with your doctor how often and what you should record in your diary. But you could write about what you do in the day including time with friends, physical activity such as walking, mental activity like reading and something that feels good, like caring for a pet. You can also use it to record your symptoms. If writing is too much, then try drawing what you do, a bit like the picture on this page. Note activity in your diary, then you and your doctor will see the progress you're making or if anything changes.



- **What is an ability scale?**

To measure how severe your illness is you can use an 'Ability Scale', which will help you work out what you're able to do and monitor how your illness is progressing (available through AYME, see back page). You can record your level on a scale in your diary but remember that progress may be slow and you may actually be making progress even while staying at the same level on the scale.

## Some common symptoms of CFS/ME

SYMPTOM	DO'S/DON'TS	WHAT/WHO MIGHT HELP
<p><b>Sleeping problems such as difficulty getting to sleep</b> or waking at night or feeling sleepy during the day and then not sleeping at night.</p>	<p><b>DO</b></p> <ul style="list-style-type: none"> <li>▪ try to get up at the same time each day.</li> <li>▪ try relaxation techniques or warm baths and milky drinks before bed.</li> </ul> <p><b>DON'T</b></p> <ul style="list-style-type: none"> <li>▪ get up at different times each day.</li> <li>▪ sleep during the day if possible.</li> <li>▪ use the computer or watch TV at night as flickering screens keep the brain alert.</li> <li>▪ lie in bed worrying about not getting to sleep if possible.</li> </ul>	<p>If the simple things don't help tell your doctor about your problems sleeping. Keeping a record of your sleep problems in your diary will help your doctor to understand.</p> <p>There are some medicines which might help or they might suggest a psychologist who can teach you relaxation techniques to use to help you get to sleep.</p>
<p><b>Problems Eating</b> You might feel too tired to eat, or feel sick and have a tummy ache. You may not feel hungry or thirsty, or find your food does not taste nice.</p>	<p><b>DO</b></p> <ul style="list-style-type: none"> <li>▪ try to eat healthily. If you can't eat three big meals, try eating little and often.</li> </ul> <p><b>DON'T</b></p> <ul style="list-style-type: none"> <li>▪ stop eating. Your body needs good food to make energy and rebuild your body.</li> <li>▪ try any extreme diets which exclude certain foods unless you have been advised to because of an allergy.</li> </ul>	<p>Tell your doctor – they may suggest you talk a dietician who can give you advice, and check that what you are eating provides you with everything you need.</p> <p>You could keep a diary of what you eat which helps to see if your diet is healthy.</p>
<p><b>Problems Walking</b> Some people find walking extremely exhausting and have problems with balancing. Dizziness can be a problem when standing.</p>	<p><b>DO</b></p> <ul style="list-style-type: none"> <li>▪ work out how far you can easily walk and increase very slowly.</li> <li>▪ if your walking is bad, consider using a wheelchair.</li> </ul> <p><b>DON'T</b></p> <ul style="list-style-type: none"> <li>▪ keep on walking until you're too tired to go further.</li> </ul>	<p>A physiotherapist might give you exercises to keep your muscles working properly. Write down what you can do in a diary.</p> <p>Your doctor may be able to help you borrow a wheelchair to use until you feel a little better.</p>
<p><b>Pain</b> Especially headaches and muscle pain.</p>	<p><b>DO</b></p> <ul style="list-style-type: none"> <li>▪ tell other people about the pain you are in– especially your doctor.</li> </ul> <p><b>DON'T</b></p> <ul style="list-style-type: none"> <li>▪ keep it to yourself, or be angry with others for not realising you are in pain.</li> </ul>	<p>Your doctor will be able to suggest some simple things that may help with pain, for example using ice or heat packs. There are also various medicines your doctor might suggest. If the medicine doesn't work, don't feel bad about going back and asking your doctor to try something else.</p>

SYMPTOM	DO'S/DON'TS	WHAT/WHO MIGHT HELP
<p><b>Difficulty doing mental activities</b></p> <p>You may have problems reading or your words come out in the wrong order when speaking or writing, or you can no longer do maths problems that used to be easy.</p>	<p><b>DO</b></p> <ul style="list-style-type: none"> <li>▪ try to do some mental work each day, in tiny chunks of time.</li> <li>▪ if you can't manage books, read magazines, or do simple puzzles rather than school work.</li> </ul> <p><b>DON'T</b></p> <ul style="list-style-type: none"> <li>▪ think you are going mad, or becoming stupid. This is part of the illness and will go away.</li> <li>▪ worry about school and exams – you can catch up when you are better.</li> </ul>	<p>Tell your teachers, parents and doctors how the illness is affecting you, so they can plan how to best help. A meeting between the school and your doctor can be helpful to plan your school work.</p> <p>They may suggest learning from home, cutting down on the number of subjects or even stopping studying for a while.</p> <p>If you want to take exams, special arrangements can be made and AYME can give you advice on this.</p>
<p><b>Anxiety and Worry-</b></p> <p>People with CFS/ME often worry about how long they will be ill and how they will catch up on missed schoolwork. But worrying can give you tummy ache, headaches, and make it difficult to get to sleep.</p>	<p><b>DO</b></p> <ul style="list-style-type: none"> <li>▪ try and help yourself stay relaxed—listen to nice music, soak in a warm bath, think of all the pleasant things you will do when you are better.</li> </ul> <p><b>DON'T</b></p> <ul style="list-style-type: none"> <li>▪ keep your worries to yourself- talking about them to someone else can make it feel less of a problem.</li> </ul>	<p>Talk to your doctor about any stresses you may be under e.g. schoolwork.</p> <p>If you find you are feeling really tense a lot of the time, then a counsellor might help – they can also teach you relaxation techniques that might help.</p>
<p><b>Depression</b></p> <p>It is quite natural to feel down in the dumps when you are ill. But if you feel <b>really sad, all of the time</b>, and can't imagine getting better, then you might be suffering from depression.</p>	<p><b>DO</b></p> <ul style="list-style-type: none"> <li>▪ remember you won't feel like this forever.</li> <li>▪ find someone to talk to and get help if you need it.</li> </ul> <p><b>DON'T</b></p> <ul style="list-style-type: none"> <li>▪ feel ashamed – feeling low could be a result of being ill or could also be how the illness affects your body.</li> </ul>	<p>Tell your doctor how you are feeling. Talking can help, so they might suggest you see a counsellor, psychologist or psychiatrist. This does not mean that your doctor doesn't believe you are ill – children with other illness such as diabetes are also helped by seeing a psychologist. Your doctor can also prescribe medicines that might help.</p>
<p><b>Other symptoms</b></p> <p>These are less common but might include feeling hot and cold, being sensitive to noise and light, or sore throat and painful glands.</p>	<p><b>DO</b></p> <ul style="list-style-type: none"> <li>▪ remember that CFS/ME can cause different symptoms in different people.</li> </ul> <p><b>DON'T</b></p> <ul style="list-style-type: none"> <li>▪ panic and think new symptoms mean you are getting worse.</li> </ul>	<p>Tell your doctor about any new symptom or any symptom that is getting worse. They may want to do a few more tests or refer you to a specialist who can help treat your symptom.</p>

- **What can I do to get better?**

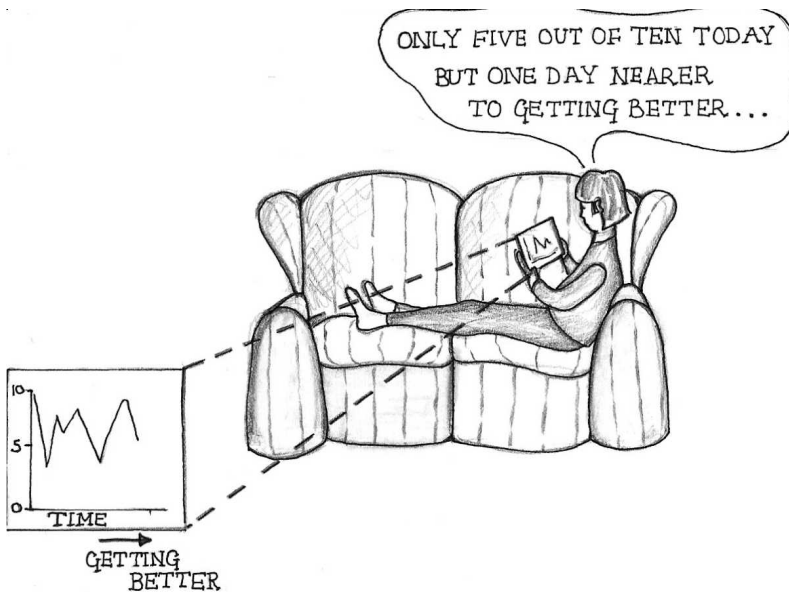
Unfortunately at the moment there are no pills or treatments that cure CFS/ME. Your doctor will advise you that balancing rest and activity will help you to get better, building up what you do very slowly and evenly.

- **Balancing rest and activity and finding a baseline**

Your doctor will probably talk about finding a baseline. This means finding your own balance of rest and activity that doesn't make you feel any worse.

It can be hard to get the balance right - If you are feeling very unwell you will need to get enough rest but spending all day in bed makes your muscles lazy and they won't be much good to you when you get better! So try to keep moving as much as you can. This may mean a little stretching, or walking a few steps. However doing too much on a day when you feel better can make you feel poorly for the next few days.

Everybody's baseline is different and will depend on how unwell they are. Your baseline may mean that you can go into school for a few hours or that you have to rest on the settee and can only manage a very short walk, Once you know what your baseline is talk to your doctor about building up your activity very slowly, doing the same amount for a while before increasing.

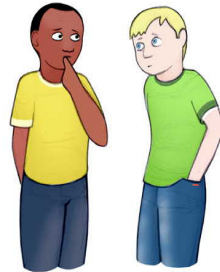


## • Will I have to see anyone else?

Your doctor will be able to prescribe medicines for any particularly troublesome symptoms, but they may suggest you see another specialist. This might be a physiotherapist or occupational therapist to help with balancing rest and activity, relaxation and specific exercises to help relieve muscle aches and stiffness, a dietician to advise on eating well, or a psychologist or psychiatrist to help you cope with feeling unwell. If they suggest this, ask your doctor how this other person will help you. If you feel someone else might be able to help, then do talk about it with your doctor.

## • What do I tell my friends?

It's difficult for friends to understand your illness and they don't know what to say. But it's important to keep in contact if you can. Write letters or phone/text/use MSN to keep in touch with them and the gossip. If you'd like them to visit, explain you get tired quickly so it may need to be a short visit. Other young people with CFS/ME may be able to give you some tips. If you don't know anyone you can make contact through young people's CFS/ME organisations such as AYME (see back page).



## • What about school?

You need to talk to your doctor about the best way to carry on with school, deciding between you what you can manage. AYME will be able to pass on advice from the Department for Education and Skills about children with medical needs.

## • Remember:

- \* Work out how much activity you can manage on a bad day, build up a little at a time and don't do too much on a good day.
- \* Take rests in between activities when necessary.
- \* Choose activities that you enjoy- and can still manage.
- \* Try to keep in touch with your friends – even if you can only see them for a little while.
- \* Don't worry about your education – you should be allowed to do what you can manage comfortably, and you can always catch up when you're better.

**Be patient – Getting better might take a while**



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**Supported by**



Many thanks to Jamie Hewitt for providing the artwork for this leaflet and to the Big Lottery Fund for their support.

**CFS/ME Further Information**

**Association of Young people with ME (AYME)** is a national charity supporting young people with CFS / ME.

They can be contacted at: PO Box 605, Milton Keynes, MK2 2XD

By phone at: (0845 1) 232389 or at [www.ayme.org.uk](http://www.ayme.org.uk)

Further copies of this leaflet can be downloaded from the RCPCH website at [www.rcpch.ac.uk](http://www.rcpch.ac.uk) or from the AYME website at [www.ayme.org.uk](http://www.ayme.org.uk).