

My Friend Has M.E. - What Do I Need To Know & How Can I Help?

What is M.E.?

M.E. (Myalgic Encephalomyelitis) - also known as Chronic Fatigue Syndrome (CFS) - is a chronic, fluctuating illness. It is also sometimes diagnosed as Post Viral Fatigue Syndrome (PVFS). The condition affects many parts of the body such as the nervous and immune systems. The most common symptoms are severe fatigue or exhaustion, problems with memory and concentration, and muscle pain. The WHO (World Health Organisation) classifies it as a neurological condition; it is a long-term condition which can last weeks, months or even - in some people - years. Everyone is different.

How is your friend likely to feel?

- Overwhelming physical fatigue - usually mental & emotional fatigue too.
- May also feel very weak and ill - like having 'flu' all the time
- May have a lot of pain and headaches
- May have problems with communication (finding words etc), memory, concentration, thinking and speech
- May have digestive problems and, despite being exhausted, might have problems with sleep.
- May **look** OK (just the same as they used to) even though they may feel very ill.

Anybody diagnosed with CFS/ME is on a steep learning curve as they find out about the condition and how best to manage it for themselves (and all the various different symptoms that they may have). This may involve a combination of resting, pacing and 'grading'.

- Someone with ME can often find activities exhausting - not just physical activities, like shopping, ironing, walking, going up/downstairs etc. but even things like making a phone call, sending an email, having visitors, dealing with paperwork, reading a book, watching TV or eating a meal. Because of this, your friend may have to alter their lifestyle considerably while they recover their health e.g. giving up work/going part-time, not driving far, taking an extended break out of school or university, being unable to socialise, do sport, or drink alcohol - it is different for everyone. Some people describe the fatigue as like 'a plug being pulled' or 'a battery running out'.
- The condition can vary from day to day and also fluctuate within the day. So what someone can do one day, they can't necessarily do the next day. And to make matters even more complicated, the fatigue is sometimes delayed i.e. it may not necessarily follow on immediately after a given activity but may appear a day or so later.
- Your friend may seem unreliable until they get to grips with the condition and it stabilises - it can take time getting used to living with such very low amounts of energy and feeling ill all the time. They can often over-estimate what they can do and then get payback fatigue etc.

for days afterwards. To avoid this, they may sometimes have to cancel arrangements.

- As well as learning how to deal with the condition itself, your friend may also be struggling emotionally to get to grips with all the unwelcome changes of lifestyle they are faced with. This may include living on much reduced income/benefits etc. if they are no longer able to work

How can you help?

- Your friend is still the **same** person but **what** and **how much** they are able to do may now be very different
- Where you may have done a lot of activities together previously e.g. shopping, going for a drink, playing sport, this may well have to change now that your friend is unwell
- You may now have to rethink what you are able to do together e.g. short visits or phone calls to keep in touch, going to the pub for one drink instead of spending all evening there, or watching a film on TV instead of going out to the cinema
- **Ask** your friend how best to organise things with their very limited reserves of energy, as even short phone calls can be exhausting. You need to be guided by your friend e.g. **ask** if they are up to a chat or not and be flexible - your friend may be too tired to talk now, but they may have enough energy for a quick call or a visit later on, after they have had chance to rest. Encourage your friend to explain what their needs are and how they feel etc.
- Allow yourselves a period of adjustment to the new situation - however strange **you** might find the situation with your friend now having M.E., it is far harder and stranger for **them** having to deal with all these unwanted changes.
- Make it clear that your friend is still your friend even if you now do things differently. Perhaps you can offer to help with practical things like housework, driving, shopping or paperwork. Your friend may not be used to asking for or accepting help - make it easy for them to say 'yes, please' or 'no, thank you'.
- Accept your friend as they are now. Please understand that they can't just 'pull themselves together'.
- Allow your friend to talk about their condition, feelings etc. **if** and **when** they want to. Be a good, active listener - try to understand how it feels for your friend. Be supportive - no-one wants to be ill and good friends can be hard to come by. Show willing to listen to your friend and learn from them. Believe them when they talk about how they feel and what they can or can't do.
- Accept that your friend may sometimes have to cancel arrangements or shorten a visit if feeling unwell - don't take it personally. Look for areas where you can still be friends and maintain your relationship e.g. emailing or texting **may** be less tiring than making a phone call - **ask**

your friend the best way to keep in touch.

- Remember even small things can be greatly appreciated e.g.
 - Send a card or a letter when they are too unwell to see people
 - Organise treats or plan something nice that you can both enjoy together
 - Ask how to find out more about M.E. if you are interested.

Some useful websites with other more detailed leaflets/booklets on the condition are:

www.afme.org.uk	Action for ME
www.meassociation.org.uk	The ME Association

and for younger people with ME:

www.ayme.org.uk	Action for Youth with ME
www.tymestrust.org	The Tymes Trust

The Leeds CFS/ME Service provides a series of booklets for their patients on how to manage different aspects of the condition; in addition there is a booklet for Carers of people with CFS/ME.

'The Spoon Theory' or 'What it feels like to be sick' is a short article which has proved very popular because of its ability to convey just what it can **feel like** to live with limited reserves of energy. (It was actually written by someone with a condition called Lupus, but it is equally relevant to ME.) You can read it for yourself at:

www.butyoudontlooksick.com/the_spoon_theory