

My friend, please understand

Chris McCormack found she was often asked by sufferers for tips on how to explain their illness simply to friends. She put together an information sheet for Action for ME. This extract from it is for you to give to a friend to help them understand your condition.

ME is a much misunderstood illness. If a person with ME has given you this article to read, it is because they want you to understand the impact their illness has on them. In terms of symptoms, they may experience overwhelming physical fatigue (usually mental and emotional fatigue too). They may feel very weak and ill, like having flu, all the time, and may have a lot of pain and headaches.

Your friend could have problems with communication (finding words etc.), memory, concentration, thinking and speech. They may have digestive problems and despite being exhausted, might have problems with sleep. They may look OK (just the same as they used to) even though they may feel very ill.

Anybody diagnosed with 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”.

Overwhelming exhaustion

Someone with ME can often find activities exhausting – not just physical activities like shopping, ironing, walking, going up/down stairs etc. but even things like making a phone call, sending an e-mail, 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, 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. 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 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 a 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 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.

Allow yourselves a period of adjustment to the new situation – however strange you might find the situation with your friend now having ME, 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.

Little things

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. e-mailing 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 ME if you are interested.

The spoon theory 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. You can download it at: http://www.butyoudontlooksick.com/the_spoon_theory

For further details about Interaction magazine please visit <http://www.afme.org.uk>

Chris McCormack is patient rep for the Leeds NHS CFS/ME Service. This summary was taken from Interaction 68 and can be reproduced as long as the above credits are intact.