



ME CONNECT

We're here to help

August 2019

Explaining M.E. to other people

A LETTER FROM ME CONNECT

It is difficult when people don't understand M.E. They don't understand how you are feeling. How can you explain to them how ill you really are?

Begin by telling people how your illness started and how you feel. Short explanations are best; just tell people the three or four main symptoms you have.

Your family and friends may like to read a little about M.E. so we enclose a short leaflet – **So what is ME/CFS?** The ME Association has 90 leaflets and booklets – have a look at our Order Form at www.meassociation.org.uk or ask any ME Connect volunteer for an Order Form. Some people just don't want to read leaflets about your illness but they may be persuaded to watch a short video. Look on The ME Association website. The video **If Only** just lasts for three minutes but describes how people with ME feel and lists many of the symptoms of ME.

Would you like your GP to understand more about M.E.? Here we recommend our clinical guidance book **ME/CFS/PVFS: An Exploration of the Key Clinical Issues**, which was written by Dr Charles Shepherd and Dr Abhijit Chaudhuri.

It can be helpful for the medical profession and indeed your family to read about your particular symptoms so we enclose a chart for you to complete by noting your own symptoms and the severity of these. A disability rating scale can also help and is enclosed with this leaflet.

There may, however, be one or two people in your life who just don't understand M.E. or don't believe in the illness. This is hard so we have some more ideas to help you explain M.E. to people. Let's look at some of the comments or questions you may get. These can be upsetting so we'd like to help by suggesting some responses for you. Just keep them simple!

■ **I don't believe in M.E., it's just a psychological illness.**

M.E. is actually a physical illness, listed as such by the World Health Organisation. It makes me feel really unwell. Perhaps I could tell you a little about it?

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■ **You looked alright when you were out yesterday.**

Most people with M.E. often look well but I feel ill for much of the time. When you see me out and about, it means I am having a better day! Most of the time you won't see me, I'll be too exhausted to get out.

■ **You were well enough to do emails this morning so why can't you cook the tea now?**

Because I've got no energy left, I am exhausted. M.E. is a fluctuating condition, I can have good mornings and bad ones. If I do too much then I have to rest or collapse.

■ **You would feel better if you did more exercise/you are too scared to exercise.**

I love doing things, always have but people with M.E. suffer from what is called post-exertional malaise. It means I feel shattered the day after I've used too much energy. It works better for me to pace myself and to manage my energy levels.

■ **I get tired as well but I don't make so much fuss about it.**

ME tiredness is different. Unlike most people, I can still feel tired after a good night's rest.

■ **You just don't want to work.**

I love working and going out for a meal and meeting friends. It would be a joy to be well enough to work. Don't forget, it is hard to manage without the money from work and I miss my job very much.

Try to use an image where you can. If, for example, you are asked:

■ **Why are your legs weak and wobbly, you haven't done very much today?**

Because I'm ill my legs have no strength in them. There are 250,000 people like me with ME and they feel weak and wobbly when they have used up their limited amount of energy. People with M.E., especially when they are tired all the time, feel weak and wobbly. At the moment, my legs feel as if I have cycled 10 miles.

Another example of using an 'image' is to ask people how they felt when they had flu or another debilitating illness

Do you remember how you felt when you had the flu and how horrible it was? People with M.E. feel like that for much of the time.

There will be some people who will never understand M.E. but that is OK!

Just tell them you are not well or that you have a debilitating illness. Explain to them, briefly, what you can and can't do together with what help and support you need.

Please do call us if you need more help to explain your illness to your GP, family and friends, we are here to help.

With our best wishes

ME Connect

Our telephone helpline, ME Connect, is available every day of the year

10-12noon, 2-4pm and 7-9pm

Telephone: 0344 576 5326

Email: meconnect@meassociation.org.uk

Calls cost the same as other standard landline numbers (starting 01 or 02). If you have a call package for your landline or mobile phone, then calls will normally come out of your inclusive minutes.



So what is ME/CFS?

ME/CFS (myalgic encephalomyelitis/chronic fatigue syndrome) is a complex multisystem illness that affects the brain and muscle function and, in some cases, other body systems as well. It often causes prolonged ill health and disability.

Although many uncertainties remain about the cause of ME/CFS, research has demonstrated abnormalities involving the brain, muscle, immune and endocrine (hormone-producing) systems.

ME/CFS is classified by the World Health Organisation as a neurological disease.

The visible signs and restrictions that people normally associate with being ill or disabled may not always be obvious in someone with ME/CFS.

So a person with ME/CFS may look perfectly well and may have no obvious signs of problems relating to either how they can care for themselves or their ability to walk and get about.

ME/CFS is characterised by brain and muscle symptoms that are always made worse by minimal physical or mental exertion – something that is referred to as post-exertional malaise.

The severity and range of ME/CFS symptoms varies from person to person.

Symptoms and their severity can vary throughout the day, from day to day, from week to week and from month to month. ME/CFS is therefore known as a fluctuating medical condition – a medical term that is particularly important in relation to benefit and other assessments.

These symptoms can also, on occasion, vary quite suddenly – so a person's health can deteriorate quite rapidly, leading to complete exhaustion.

ME/CFS Disability Rating Scale

VERY SEVERE

100% disabled

Severe symptoms – often on a continual basis. Cognitive function (ie problems with short-term memory, concentration, attention span) is likely to be very poor. Bedridden and incapable of living independently. Requires a great deal of supervision and practical support – including disability aids, such as a hoist or stair lift – with all aspects of personal care (ie feeding, dressing, washing) on a 24-hour basis.

90% disabled

Severe symptoms, often including marked cognitive dysfunction, for much or all of the time. Bedridden and housebound for much or all of the time. Experiences considerable difficulties with all aspects of personal care. Unable to plan or prepare meals. Requires practical support and supervision on a 24-hour basis.

SEVERE

80% disabled

Moderate to severe symptoms for most or all of the time.

Only able to carry out a very limited range of physical activities relating to personal care without help. Requires help with meal planning and preparation. Frequently unable to leave the house and may be confined to a wheelchair when up, or spend much of the day in bed. Unable to concentrate for more than short periods of time. Usually requires daytime and night time supervision.

70% disabled

Moderate to severe symptoms for most or all of the time. Confined to the house for much or all of the time. Normally requires help with various aspects of personal care, meal planning and preparation – possibly on a 24-hour basis. Very limited mobility. May require wheelchair assistance.

MODERATE

60% disabled

Moderate symptoms for much or all of the time. Significant symptoms exacerbation follows mental or physical exertion. Not usually confined to the house but has significant restrictions on mobility when outside and may require wheelchair assistance. Likely

to require help with aspects of personal care and meal preparation – but not necessarily on a full-time basis. Requires regular rest periods during the day. Unable to resume any form of meaningful employment or education on a regular basis.

50% disabled

Moderate symptoms for much or all of the time. Symptom exacerbation follows mental or physical exertion. Not usually confined to the house but mobility restricted to walking up to a few hundred yards at best. May require help with some aspects of personal care. May require help with meal planning and preparation. Requires regular rest periods during the day. Able to carry out light activities (ie housework, desk work) associated with normal daily living for short periods but not able to resume regular employment or education.

40% disabled

Mild to moderate symptoms for some or much of the time. Normally able to carry out most activities associated with personal care and normal daily living but may require

Turn over

assistance with meal preparation. May be able to cope with some work-related tasks for short periods – provided they are not mentally and physically strenuous – but not able to resume employment on a regular basis.

MODERATE TO MILDLY AFFECTED

30% disabled

Mild to moderate symptoms for some of the time. Normally able to carry out all aspects of personal care and to plan and prepare meals. Able to walk short distances on a

regular basis. May be able to return to work on a flexible or part-time basis – provided adjustments are made to cope with cognitive and mobility problems. May have to stop leisure or social pursuits in order to return to work or education.

20% disabled

Normally only mild symptoms at rest but exacerbation will follow activity. Able to carry out all aspects of personal care and to plan and prepare meals. Able to walk short to medium distances (up to half a mile) on a regular basis. Normally able to return to flexible or

part-time employment. May be able to resume full-time employment.

10% disabled

Generally well with only mild symptoms. No problems with personal care or daily living. Mobility may still be restricted but almost back to previous levels. May be able to return to full-time employment.

0% disabled

Fit and well for at least the past three months. No symptoms at rest or following exertion. Capable of full-time employment or education.



Our quarterly ME Essential magazine

To find out how to obtain it regularly, please phone 01280 818964 or email: admin@meassociation.org.uk

Explaining ME/CFS to other people

If you have been diagnosed as having ME/CFS, it may be of help to take with you something to give to them to help explain your symptoms.

This could apply if you are going back to work, going into hospital, off to college or anywhere where you will meet people who will need to know about ME/CFS but may not have a full understanding of this illness.

In a hospital you may well find that some of the staff already know and understand about ME/CFS but at college or work this may not be the case.


On the following pages there is a short explanation about ME/CFS and a list of symptoms.

On the first of these pages is a space for your name, address and date of birth – as it may be relevant to have the form put on a file.

Tick those symptoms that apply to you and, at the end, add anything that you feel may be relevant to your ME/CFS.

It may be a good idea to take few copies of this leaflet with you (without necessarily filling in your name and address) and hand them out when necessary – e.g. to more junior staff.

ME Connect Helpline

 ***If you need to talk in confidence about anything to do with ME/CFS, please try our ME Connect helpline. It's open every day of the year on 0344 576 5326. The lines are open 10am-12noon, 2-4pm, 7-9pm.***

Calls cost the same as other standard landline numbers (starting 01 or 02). If you have a call package for your landline or mobile phone, then calls will normally come out of your inclusive minutes.

JUST WHAT IS ME/CFS?

ME/CFS is a disabling illness although the visible signs and restrictions that people normally associate with being disabled may not always be obvious. Some people with ME/CFS often look well.

ME/CFS is characterised by severe symptoms that can be made worse by minimal physical or mental exertion.

The severity and symptoms of ME/CFS varies from person to person.

ME/CFS can vary from day to day and even throughout the day. It can, on occasion, vary quite suddenly – from being nearly normal to feeling very ill and exhausted. ME/CFS is therefore known as a fluctuating medical condition – a medical

MY PERSONAL DETAILS	
Name	_____
Address	_____ _____
Postcode	_____
Date of birth	_____
Number of months/years I have had ME/CFS	_____
<i>(please state which)</i>	

term that is particularly important in relation to benefit and other assessments.

The onset of other symptoms can come on just as suddenly.

On these pages are the symptoms that I have – all, most or some of the time.

SYMPTOMS	All the time	Most of the time	Some of the time
Activity induced fatigue			
Pain			
In my muscles			
In my joints			
In my nerves			
In my glands			
Muscle twitching or spasms			
Cognitive dysfunction = brain fog			
Dizziness or balance problems			
Headaches (tick if migraines)			
Sensory problems			
Sensitivity to loud noises			
Sensitivity to bright lights			
Sensitivity to smells - eg to perfumes			
Sensitivity to temperature change			
Numbness			
Pins & needles			

SYMPTOMS	All the time	Most of the time	Some of the time
Sleep disturbances			
Hypersomnia – excessive sleep			
Frequent night time wakening			
Unrefreshing sleep			
Palpitations			
Low blood pressure leading to faintness when standing up			
Orthostatic intolerance (unable to maintain upright posture)			
Cold hands and feet			
Sore throats			
Enlarged glands			
Allergies			
Drugs			
Chemicals			
Irritable bowel syndrome			
Nausea and sickness			
Eye Problems			
Dry eyes			
Hearing problems			
Tinnitus – strange noises in the ear			
<i>Add anything which you feel particularly relates to your ME/CFS and is not included in the list.</i>			

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