THE ME ASSOCIATION

Explaining ME/CFS

How to talk to other people about ME/CFS

Introduction by ME Connect

Helping your GP to understand ME/CFS

What exactly is ME/CFS?

Disability Rating Scale

Meeting people in more formal situations

ME/CFS and your symptoms

SEPTEMBER 2024

Katharine Leat, ME Connect Manager, heads an amazing team of volunteers who provide support and information to anyone whose life has been affected by ME/CFS or Long Covid.

INTRODUCTION FROM ME CONNECT

It is difficult when people don't understand ME/CFS. They don't know how you are feeling, so how can you explain to them how unwell 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 ME/CFS so we have included a description of the condition and its severities to help them to understand it more clearly. Our disability rating scale is also included. This begins on page 7: So what is ME/CFS?

The ME Association has an extensive range of reliable literature about PVFS, ME/CFS, and Long Covid, written by Dr Charles Shepherd, other advisers, and topic experts. This literature is all free to download from the ME Association website here:

https://meassociation.org.uk/free-literature-downloads/

Unfortunately there may be people in your life who just don't understand ME/CFS or don't believe the illness exists. This can be hard to accept, so let's look at some of the comments or questions you may receive and the ways you could respond to them.

- **I don't believe in ME/CFS. It's just a psychological illness.**

ME/CFS 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?

- **You looked ok when you were out yesterday.**

People with ME/CFS 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! When you don't see me, it is usually because I am too exhausted or unwell to go out.

INTRODUCTION FROM ME CONNECT

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.

- **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. ME/CFS is a fluctuating condition, I can have good mornings and bad ones. If I do too much then I have to rest or I'll 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 ME/CFS 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 to normal tiredness. Sometimes I don't even have the energy to stand. And I can still feel tired after a good night's rest.

- **You just don't want to work.**

I actually love working. It would be a joy to be well enough to work. 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:

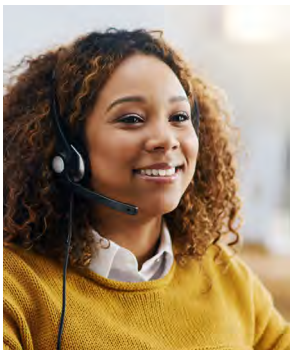
- Why are your legs weak and wobbly, you haven't done very much today?

Because I'm ill, my legs have no strength in them. There are more than 402,000 people like me with ME/CFS and we feel weak and wobbly when we have used up our limited amount of energy. People with ME/CFS, 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 awful you felt? People with ME feel like that for much of the time.

INTRODUCTION FROM ME CONNECT



"Realising that you can, in some small way, make a difference to someone's life is very humbling and rewarding."

ME Connect Volunteer

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

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

ME CONNECT HELPLINE

If you need to talk in confidence about anything to do with ME/CFS, please call our ME Connect support line.

CALL

FREEPHONE 0808 801 0484

For up-to-date opening hours please visit:

https://www.meassociation.org.uk/me-connect

HELPING YOUR GP TO UNDERSTAND ME/CFS

"Before I started with ME Connect, I was given training which taught me to listen, really listen, to the people who call. I found these skills transferred automatically to non-helpline contexts. As a result, I learned to connect better with others."

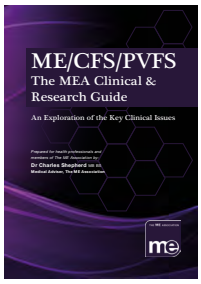
ME Connect Volunteer

Do you want your GP to understand more about ME/CFS? The ME Association is working positively with colleagues in the NHS and social care to implement the recommendations set out in the 2021 NICE Clinical Guideline on ME/CFS.

We are also part of the 2022-25 Government initiative to improve healthcare provision, understanding, awareness and biomedical research investment, working with the Department of Health and Social Care and the established working groups.

There is a section on our website specifically for healthcare professionals:

https://meassociation.org.uk/health-care-professionals/



We recommend our clinical guidance book **ME/CFS/PVFS: An Exploration of the Key Clinical Issues**, written by Dr Charles Shepherd. This is the most comprehensive, evidence-based summary of ME/CFS/PVFS currently available. It contains everything that health professionals, patients, and the people who care for them need to know about ME/CFS/PVFS.

Use this QR code to link to the MEA's Clinical and Research Guide ME/CFS/PVFS: An Exploration of the Key Clinical Issues (The Purple Book).

Free Copies for Healthcare Professionals

Using funding from the ME Association medical education budget, we send free hard copies of the Clinical & Research Guide (The 'Purple Book') to healthcare professionals and medical students via our mailing list or on an individual basis. We also send **ME Medical** magazine to them on a quarterly basis. This can be done by direct request from professionals or by people with ME/CFS making a nomination.

ME Medical magazine is our quarterly magazine specifically produced for healthcare professionals. It features topical news and developments, healthcare recommendations, research publications and information regarding implementing the 2021 NICE Guideline on ME/CFS. The magazine also includes "Ask the Doctor" questions, with Dr Charles Shepherd, and personal stories from people with ME/CFS.

HELPING YOUR GP TO UNDERSTAND ME/CFS

Healthcare professionals can register themselves and people with ME/CFS, or their friends or family members can visit the Healthcare Professional website page and complete the sign-up form to nominate one:

https://meassociation.org.uk/me-medical-magazine/

The Clinical & Research Guide will be sent each time it is updated, and ME Medical Magazine will be sent on a quarterly basis, by post.

Healthcare professionals can opt-out of these mailings at any time.

The 2022 edition of the Clinical & Research Guide is also available in Kindle format on Amazon:

https://meassociation.org.uk/4nop

WHAT EXACTLY IS ME/CFS?

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.

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.

The ME Association has produced a new booklet, MEA Disability Rating Scale on ME/CFS, that expands on the illness severity definitions recommended in the NICE Guideline on ME/CFS. It is more detailed and relevant, can be used to explain your current situation to others, in medical or benefit discussions, and as an aid to monitoring progress.

You can download a free PDF file of this booklet here:

https://meassociation.org.uk/f7fq

DISABILITY RATING SCALE

The NICE Guideline on ME/CFS publishes the following disability rating scale:

MILD ME/CFS

People with mild ME/CFS care for themselves and do some light domestic tasks (sometimes needing support) but may have difficulties with mobility. Most are still working or in education, but to do this they have probably stopped all leisure and social pursuits. They often have reduced hours, take days off and use the weekend to cope with the rest of the week.

MODERATE ME/CFS

People with moderate ME/CFS have reduced mobility and are restricted in all activities of daily living, although they may have peaks and troughs in their level of symptoms and ability to do activities. They have usually stopped work or education, and need rest periods, often resting in the afternoon for 1 or 2 hours. Their sleep at night is generally poor quality and disturbed.

SEVERE ME/CFS

People with severe ME/CFS are unable to do any activity for themselves or can carry out minimal daily tasks only (such as face washing or cleaning teeth). They have severe cognitive difficulties and may depend on a wheelchair for mobility. They are often unable to leave the house or have a severe and prolonged after-effect if they do so. They may also spend most of their time in bed and are often extremely sensitive to light and sound.

VERY SEVERE ME/CFS

People with very severe ME/CFS are in bed all day and dependent on care. They need help with personal hygiene and eating, and are very sensitive to sensory stimuli. Some people may not be able to swallow and may need to be tube-fed.

DOWNLOAD THE NICE GUIDELINE HERE

MEETING PEOPLE IN MORE FORMAL SITUATIONS

If you are going back to work, going into hospital, off to college or going anywhere where you will meet people who will need to know about ME/CFS but may not have a full understanding of this illness, it may be helpful to take with you something to give to them to help explain your symptoms.

In 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.

In 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.

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

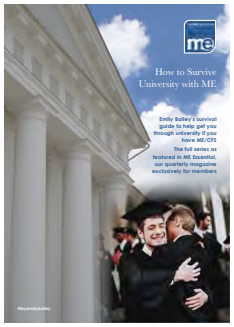
Tick those symptoms that apply to you and, at the end, add anything that you feel may be relevant to your ME/CFS.

It may be a good idea to take few copies of this leaflet with you (without necessarily filling in your name and address) and have them available to hand out when necessary. It will help you to avoid getting over-tired by having to explain the same things many times.

Leaflets that you may find helpful:

Going into hospital:
https://meassociation.org.uk/m83s

A short-form summary on anaesthetics and ME/CFS:
https://meassociation.org.uk/229f



University & How to Survive by Emily Bailey:
https://meassociation.org.uk/pavk

Employment issues:
https://meassociation.org.uk/vo36

MY PERSONAL DETAILS

Name

Address

Post code

Date of birth

How long I have had ME/CFS

Years:

Months:

Emergency contact

ME/CFS AND YOUR SYMPTOMS

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.

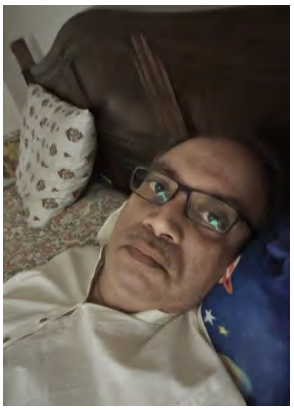
The severity and symptoms of ME/CFS varies from person to person.

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

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

These are the symptoms that I have all, most, or some of the time:

All	Most	Some	
			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 - e.g. to perfume



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.

WHAT EXACTLY IS ME/CFS?

All	Most	Some	
			Sensory problems:
			Sensitivity to temperature change
			Numbness
			Pins & needles
			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)

ME CONNECT HELPLINE

If you need to talk in confidence about anything to do with ME/CFS, please call our ME Connect support line.

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FREEPHONE
0808 801 0484

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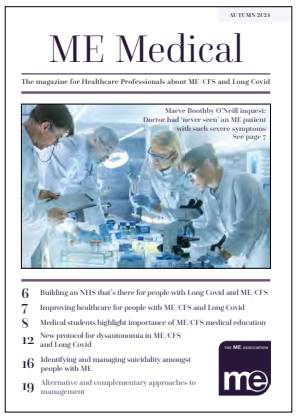
https://www.meassociation.org.uk/me-connect

WHAT EXACTLY IS ME/CFS?

I need to take rests (add details)_____

Add anything that relates to your ME/CFS and is not included in the list

"Thank you for producing such a helpful magazine. The standard is consistently high and each edition is interesting and varied. I need all the help I can get and this magazine is consistently encouraging, realistic, and helpful."



THE ME ASSOCIATION

Changing attitudes and improving lives...

■ **COMMUNITY:** We provide a safe and welcoming community for people affected by ME/CFS and Long Covid who come together and benefit from sharing their experiences. We provide membership, an essential support service, excellent website resources and we host engaging discussions on the most popular social media channels. Knowing that you are not alone can be a great comfort and we are happy to answer your questions and share helpful tips.

■ **MEMBERSHIP:** We put the interests of members at the heart of everything we do. Your subscription means that we can support more people, campaign more effectively and fund more medical research. Members receive the exclusive ME Essential magazine which carries the latest news, medical information, personal stories, and feature articles. **Join us today**.

■ **SUPPORT:** ME Connect is the charity's support and information service. We listen and we understand. All our staff and volunteers have knowledge and understanding of these medical conditions. We provide a personalised service and we're here when you need us most. You can contact us via our telephone support line (Freephone) or by email. Please see back page for more details. To view the ME Connect telephone support line opening hours, please visit: **https://www.meassociation.org.uk/me-connect**

■ **INFORMATION:** We produce reliable and timely information written by topic experts and have the **largest range of free literature covering all aspects of life with ME/CFS and Long Covid**. We can show you how to recognise and manage symptoms, get an accurate diagnosis, a referral to specialists, and to obtain the healthcare that you deserve. We also provide an **e-newsletter** and free access on the website to **Medical Matters** and other relevant information.

■ **RESEARCH:** We fund medical research via the **Ramsay Research Fund** and are especially interested in research that can find diagnostic markers, causes, and treatments. We support the UK ME/CFS Biobank and the Manchester Brain Bank, and have invested over £1m in medical research in the last 10 years.

■ **MEDICAL EDUCATION:** We arrange training for healthcare professionals, offer a medical magazine, ME Medical, and are working with the Government, NHS, Royal Colleges of Medicine, and Local Authorities to implement the recommendations of the 2021 NICE Clinical Guideline on ME/CFS – the successful result of 14 years lobbying and hard work.

"The MEA is doing exactly what it said it would by providing support, actively lobbying for recognition, improvements to health and social care, and funding biomedical research."

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Registered Charity Number 801279

THE ME ASSOCIATION

Changing attitudes and improving lives...

■ **LOBBYING:** We campaign to raise awareness and bring about positive change. We believe in collaboration and work with the NHS and social care services, the Department of Health and Social Care, the British Association of Clinicians in ME/CFS (BACME), Forward-ME, the ME Research Collaborative (MERC), DecodeME, the All-Party Parliamentary Group (APPG) on ME, Physios4ME, the Chronic Illness Inclusion project (CII), Hidden Disabilities Sunflower, and Long Covid initiatives.

■ **HEALTH & SOCIAL CARE:** The charity works with healthcare providers to successfully implement the NICE Guideline recommendations on ME/CFS and Long Covid to ensure that everyone receives the very best healthcare, wherever they live in the UK. We want well-trained healthcare professionals providing excellent services because timely intervention can lead to better health outcomes and improved quality of life.

■ **DONATIONS:** In order to help more people and invest in medical research we depend on your generosity. If you feel able to make a donation or want to raise funds in other ways, please get in touch with the fundraising team: fundraising@meassociation.org.uk or you can **make a direct donation via the website.**

WHAT ARE ME/CFS AND LONG COVID?

We answer key questions about these medical conditions and compare similarities and differences. You'll also find the NICE Guideline reproduced in full in an easy-to-use **database**.

MEDICAL MATTERS

Medical Matters is an easy to use online supplement to the more detailed literature. The same topic experts provide answers to commonly asked questions.

NHS REFERRAL SERVICES

If you need to locate an ME/CFS specialist service or Long Covid Clinic then we can help. We have listed all secondary care referral services in an easy-to-use **database**.

THE ME ASSOCIATION

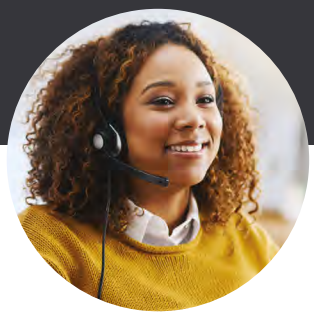
ME CONNECT

The Support and Information Service for people affected by ME/CFS/PVFS and Long Covid

HOW TO GET IN TOUCH:
by phone or email

Freephone 0808 801 0484

For opening hours visit:
meassociation.org.uk/mec



HERE TO LISTEN

We are here to listen, validate and empathise with any issues you might be facing.

VITAL SUPPORT

We are here to help you reach an informed decision.

SAFE ENVIRONMENT

We provide a safe, confidential and understanding environment where you can be heard and understood.

We're here for you!

meconnect@meassociation.org.uk

For all information relating to ME Connect visit: https://meassociation.org.uk/mec