

MANAGING YOUR EMOTIONS

WHEN YOU HAVE ME/CFS

APRIL 2022



MANAGING YOUR EMOTIONS

INTRODUCTION

While ME/CFS is a physical illness with a wide range of disabling physical symptoms, taking time to be aware of the emotional and psychological impact that can sometimes occur is also important.

In this booklet, we explore some of the emotions that people with ME/CFS may experience and consider general coping strategies to help manage mental health.

Experiencing emotions of a new, more intense, or even negative nature is normal for anyone trying to cope with an often devastating and long-term neurological condition.

ME/CFS is a complex condition and its effect on mental health can differ between individuals. Emotional responses are long and varied and often overlap - so we discuss just some of those that are most frequently expressed.

COMMON EMOTIONS

Low mood

With any significant life change, we can experience feelings of low mood. Anything from a lack of sleep to a change in diet can also have an impact on our mood. Reflecting on how we are unable to do things any more can sometimes lead to feelings of sadness, a sense of withdrawal and tearfulness.

Some common thinking patterns that contribute to low mood include:

- Catastrophising (always thinking of the worst case scenario)
- Focusing on the negatives ("Nothing is going right")
- Dwelling on the past ("I used to be able to do this, why can't I now?")
- All-or-nothing
- Negative labelling of self ("I'm useless!")
- 'Should' statements ("I should be able to do more!")

It is important to remember that these are just thoughts. If you change the way you think to something less judgemental, more flexible and a little more accepting, it can have a positive impact on your mood.



Managing Your Emotions was written by Dr Lisa Dvorjetz, Advisory Psychologist to the ME Association.

Dr Lisa Dvorjetz is an accredited counselling psychologist with both the British Psychological Society and the Health and Care Professions Council.

Lisa is currently working within the NHS and private practice with people who have long-term health conditions.

We know her well. She has been volunteering as an ME Connect helpline supervisor since 2013.

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Depression

Feeling low in mood or unhappy is a very different experience from feeling depressed. If you consistently, over a period of weeks or months, struggle to get out of bed in the morning because of your mood, constantly feel hopeless, worthless and lose interest in the things that you usually enjoy, then you should consult your GP for support.

It is equally as important to seek more immediate help from your GP, the Samaritans or people close to you if you are starting to have thoughts of hurting yourself in any way or are thinking about taking your own life.

Anxious feelings

Having ME/CFS can bring up all kinds of worries such as the physical, financial and practical impact it can have on one's life.

People with ME/CFS are unable to predict how badly the condition will affect them on a daily basis. Living with this unpredictability can be difficult and add to feelings of not having control over your state of health - which can contribute to symptoms of anxiety.

Some of the most common psychological and physical symptoms of anxiety include feeling worried a lot of the time, having difficulty falling or staying asleep, being hyper-alert or on edge, feeling irritable and having trouble concentrating.

A good strategy here is to ask: "What am I worrying about and can I do anything about it?"

If not, then the worry is around a hypothetical situation and there is nothing that can be done but you might benefit from writing it down or talking it out with someone else to help get it out of your head.

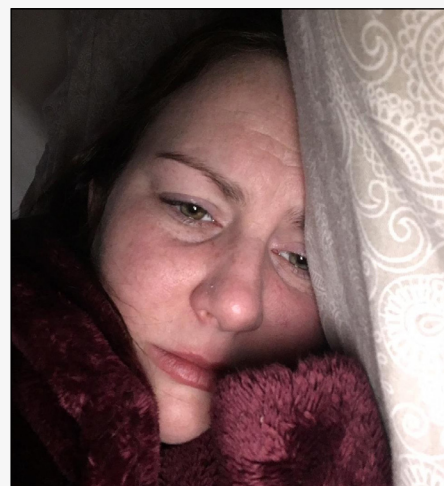
If there is something that can be done, then a structured action plan is needed.

Focusing on a plan and identifying the change required is a way of regaining some control. Try a step-by-step approach using small manageable goals until the problem has been resolved.

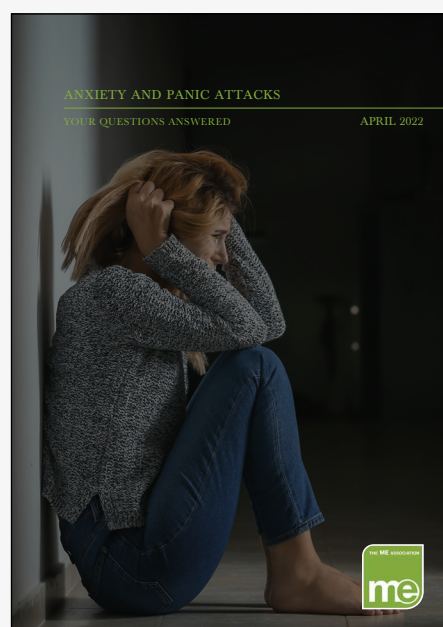
When the worry starts to become constant throughout the day and begins to negatively impact your ability to function or creates panic attacks, you must seek support and help from your GP.

The MEA has a leaflet, **Anxiety and Panic Attacks**, explaining what causes anxiety and panic attacks, why we feel anxious, and what we can do to help ourselves. You can download the leaflet here:

<https://tinyurl.com/42crb68f>



You might feel a deep sense of loss when future dreams and hopes appear unachievable. But it is normal to experience fear and worry about the future and to wonder if you will ever get better.



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If you need to talk to someone, the MEA's telephone helpline **ME CONNECT** is open for six hours a day, every day of the year, on **0344 576 5326**. Hours are: 10am – 12noon; 2pm – 4pm; 7pm – 9pm.

Loss and grief

The unremitting physical and mental exhaustion and other symptoms that occur in ME/CFS means that there will be certain things you are unable to do, can only do occasionally, or may not be able to do as well as you did before.

You will have suffered the loss of previous good health, which might have caused a breakdown in a relationship, a loss of employment and financial security, and it will most likely have resulted in a loss of independence.

The loss of identity, of who you were, can cause isolation from family and friends while you wrestle with uncertainty and worry about the future.

It is natural to experience a form of grief as these changes occur and during the struggle to adapt to new circumstances.

- You might feel a deep sense of loss when future dreams and hopes appear unachievable. But it is normal to experience fear and worry about the future and to wonder if you will ever get better.

- You might find yourself making comparisons between your 'old life' and the one you have now and experiencing feelings of despair.

Losses can be hard to think about and manage, but it is important to acknowledge them. You need to allow time for the grieving process to happen. It is a necessary part of building up your inner resilience so that you can move forward.

Frustration, irritability and anger

Just as feelings of sadness and worry are acceptable, so are feelings of frustration, irritation and anger.

It is perfectly understandable why you might feel frustrated by your inability to do the things you used to do or if you express anger that this has happened to you in the first place. Feelings such as these might be directed inwardly or towards others, and you can learn how to manage them.

The best way to learn to cope with these emotions, is to first recognise if there are certain situations or triggers when they occur and to consider your reactions to them.



The MEA has produced a helpful leaflet, **Counselling - your questions answered**. It can be found on our website here:

<https://tinyurl.com/2p8vd9u2>



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Then consider if there are alternative ways you can react to them. Is there a better way to communicate your feelings? Can assertive communication be achieved without aggression or anger? Can you express these feelings without becoming upset or it leading to a setback in your health?

Shame and guilt

ME/CFS is not an easy diagnosis to have and not just because of how it affects a person physically.

In the medical field, in the media and society as a whole, recognition and acceptance has generally improved, but there remains a degree of disbelief attached to anyone who has the condition.

The National Institute of Health and Care Excellence (NICE)

The National Institute for Health and Care Excellence (NICE) has now published a new clinical guideline for ME/CFS and it is one that we support.

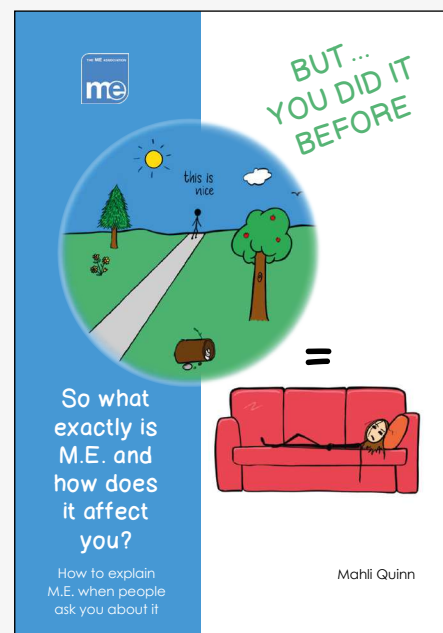
We hope that as the recommendations are implemented across the NHS and social care, it will lead to better understanding and to improvements in current healthcare services (see below for more information).

While we have a much-improved NICE guideline providing a good framework of recommendations to the NHS and social care, we really need advances in medical research to help remove any remaining disbelief.

Until such time as research can demonstrate an acceptable explanation for why certain people get ME/CFS, what perpetuates the symptoms and causes such profound disability, there will be an ongoing debate about the involvement of psychological factors and the best way to treat the condition.

We are getting closer to answers and hopefully one day soon there will be widespread belief in the physical nature of the condition. Until that time, some people will continue to express opinions that can affect how someone with ME/CFS feels.

These uncertainties can lead to feelings of shame and self-doubt. Some people describe being marginalised by family, friends, and healthcare professionals who do not understand or who do not believe that their symptoms are real. This can leave them feeling unworthy, unaccepted and dismissed.



MEA Information and Support

We have a large range of literature available to download from the website shop, including a section about the understandable effect of ME/CFS on Mental Health:

<https://meassociation.org.uk/me-association-shop>

■ **But... You Did It Before**, by Mahli Quinn, provides a great explanation of the impact of ME/CFS. It is available to order from the website shop:

<https://tinyurl.com/uvhv2af3>

■ If you need to talk to someone please contact the **ME Connect** telephone helpline on **0344 576 5326**.

Lines are open 365 days a year, 10am-12noon, 2pm-4pm and 7pm-9pm.

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Additionally, people have described feeling guilty for not being able to continue with their previous roles in the family, or for being a burden to someone else who has had to take on their responsibilities and become their carer, or for having to depend on welfare benefits.

You are unlikely to be in a position to do anything about the stigma attached to ME/CFS - it is best to leave those efforts to the ME Association and others. You need to focus on what you can do, not what you can't. Express your feelings to family and friends or, if you are able, then phone the ME Connect helpline and talk to someone who is ready and willing to listen.

If you are feeling overwhelmed, or you think your mood is affecting your ability to function, then reach out to your GP for help, or ask someone to do it for you.

If you are able, then consider joining the ME Association on its social media. We are always willing to ask questions of the community and you could benefit from reading the experiences of others.

Remember: You are not alone. Your feelings will have been experienced by others in the same or a similar situation to you. Don't keep things bottled-up. Talk to someone - it will help.

Hope

Understanding that symptom severity and the level of functional ability will often fluctuate or can even stabilise and improve, and that you can experience relatively 'good days', should provide a realistic sense of hope. Hope that perhaps the more severe symptoms and degree of disability are not going to be present forever.

Having a long-term or chronic illness can make you re-evaluate your life and your priorities. This increased awareness can lead to a greater sense of purpose and a better understanding of who you are and what you want to achieve.

Realistic hope should provide a good reason to carry on in life and to face the uncertainties, disappointments, and the disability that comes with ME/CFS. Hope that tomorrow will be better than today, is what helps us to survive.



You are not alone. Your feelings will have been experienced by others in the same or a similar situation to you. Don't keep things bottled up. Talk to someone - it will help.

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GENERAL WAYS TO COPE WITH YOUR EMOTIONS

Acknowledgement of feelings

Emotions are transient and sometimes cyclical; they can change a lot and are unlikely to be permanent so the first step in coping with your emotions is to try to identify what you are feeling and what may have triggered this feeling.

It is alright to feel afraid, show fear and allow yourself to be vulnerable. Imagine a pressure cooker; when our feelings build up without an escape they can often erupt out of nowhere or we can be emotional about the smallest of things. The way to defuse the build-up of emotions is by talking about them so there is some form of release.

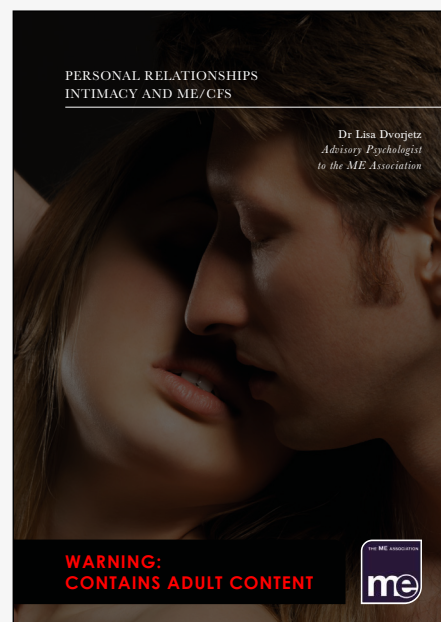
Communication

One of the best ways of dealing with your emotions is by talking to others about them, whether that be with family members, friends, support groups, professionals or spiritual leaders. Bottling up your emotions can take up more energy than it's worth!

- It is important to tell others how you are feeling, and to ask for help when you need it.
- Sharing your feelings can help and it will let someone else know if they need to provide more support or request it from a professional.
- Don't feel you are burdening someone else with your problems, as open communication is a key part of any relationship.
- Asking for help can be hard, but you shouldn't struggle alone and there are people who can help.
- Speak to a GP about any emotional issues you are having trouble managing. They can refer you to specialists who can help you learn how to cope with ME/CFS and the understandable impact on mental health.

If you don't have family or a friend to talk to or, if you prefer to speak with someone who is at a distance from your support network, then you can:

- reach out to the ME Connect telephone helpline on 0344 576 5326.
- join the ME Association as a member and benefit from ME Essential magazine
- read and take part in the discussions we hold on social media about life with ME/CFS.



If you have ME/CFS and are experiencing problems with a relationship, then you might like to read the MEA's booklet: **Personal Relationships - Intimacy and ME/CFS**. It can be downloaded from the website shop:

<https://tinyurl.com/faxbfxcx>



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When speaking to someone else in your life, it can be helpful if you are clear about your needs. It makes for more effective communication and means that some things can be planned for in advance.

For example, "You'll need to order the groceries online, because I can't do the shopping this week," or, "I have a doctor's appointment next week, and I need your help to get to the surgery".

Seeking help is not a sign of weakness. You are not a burden, or useless, and you shouldn't feel guilty. There is no benefit in trying to force yourself to do something that will leave you suffering even more the following day. Asking for help is a healthy way of coping in difficult situations.

It's also worth learning how to say "No" to people in your life - and to yourself - especially if you were the sort of person who was always willing to lend a hand when asked and put others first or applied yourself fully to any given situation.

You will need to learn to put your needs ahead of other people's or to compromise in ways that do not exacerbate your symptoms.

There are always things that need doing or that we want to do. But having ME/CFS means you will need to reevaluate your role and responsibilities. Activities that were once deemed important may not be as important any longer. Your priorities will have changed and you will need more help and support.

All too often, we can end up doing things we don't really want to do or we find ourselves in situations that are making us unhappy or might make our health worse. This can be because we didn't feel able to say 'no' for fear of offending someone or appearing selfish.

In order to use the word 'no', you have to be polite but firm. Learn where your boundaries are – what you can do, what you can't do and sometimes what you don't want to do. It can be hard to say 'No' and there will be times when you don't want to. But you might be able to reach a compromise, by saying, "I can't manage all of that today, but this is what I can do now, and what I hope I can do tomorrow."



Doing things that we enjoy and being kind to ourselves can help reduce the stressful feelings we have as well as make us feel as if we have more control in our lives. It can also give us a sense of purpose and help to distract from the symptoms we might be feeling.



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Self-care and self-compassion

For people with ME/CFS, the range and severity of physical and emotional symptoms can vary from day-to-day. This can make any management strategy difficult, but there are a variety available and they should be tailored to your personal needs.

It is important to find an approach that takes into account your abilities and your need for support from other people. A management plan should include taking time to properly rest and relax and to enjoy more pleasurable activities.

These might include things like meditation, creative arts, listening to music, taking a warm bath, healthy eating, cooking, talking to a friend, keeping a journal, observing nature, reading, writing, going for a gentle walk.

Each would depend on your ability and the help and support you have available.

Doing things that we enjoy and being kind to ourselves can help reduce the stressful feelings we have as well as make us feel as if we have more control in our lives. It can also give us a sense of purpose and help to distract from the symptoms we might be feeling.

Another way of coping is to not be too self-critical. We can often be our harshest critics and this might be because we are comparing our performance now against how we performed before ME/CFS. If you make a mistake, or things don't work out the way you wanted, imagine what you'd say to a friend who came to you with the same problem. You might try to help them see that it wasn't the end of the world, that they did their best and encourage them not to blame themselves.

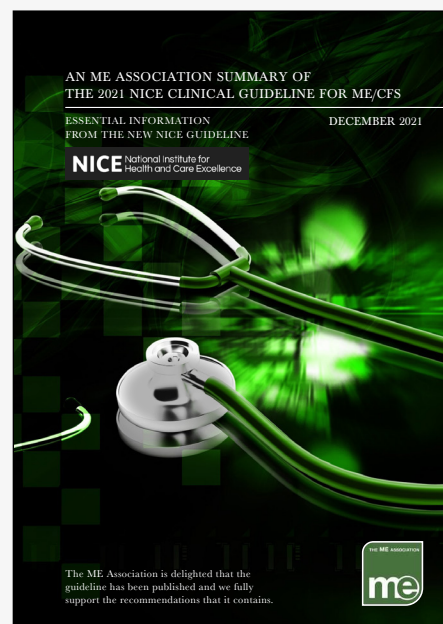
WHERE CAN I FIND SOMEONE WHO CAN HELP?

1. NHS Primary & Secondary Care

Ask your GP: For most people this will be their first port of call. GPs should provide ongoing care and support to people with ME/CFS and be capable of following the recommendations in the 2021 NICE clinical guideline.

The NICE clinical guideline provides detailed recommendations to the NHS and social care services and is a recommended read for all patients, families and carers.

You and your GP can determine if a referral to an NHS counsellor or an ME/CFS specialist service is required, or if there is more your GP can do to support your needs.



The ME Association has produced a free booklet summarising the NICE clinical guideline that can be downloaded from the website shop:

<https://meassociation.org.uk/ek50>

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Should you decide on a referral, it might be preferable if one is made to a local ME/CFS specialist service that includes a clinical psychologist who will have the necessary experience and a professional interest in helping people with the condition.

Everyone with ME/CFS is entitled to a referral to a specialist service even if one is not available in your area. Often the service will provide a fixed number of outpatient appointments that are aimed at confirming a diagnosis, helping you learn how to best manage your condition, and providing help with mental health.

More information about ME/CFS specialist services and the help they can offer can be found in the NICE guideline, or you can visit the service's website (see below).

A clinical psychologist can help with the emotional or mental health issues that often occur as a result of ME/CFS and will work to improve your wellbeing. Counselling or therapy will be provided over a number of sessions that might be delivered face-to-face or remotely via video or telephone. If you are unable to access the service in person, it might also be possible to arrange home visits.

You can find out if there is an ME/CFS specialist service in your area, and what they currently offer, by visiting the MEA website and entering your postcode:

<https://meassociation.org.uk/nhs-me-cfs-specialist-services/>

2. Private counselling services

■ **British Association of Counselling and Psychotherapy (BACP):**

<https://tinyurl.com/bh6ncdux>

■ **Counselling Directory:** Enter your postcode for a therapist near you, click on What's worrying you and then scroll down to find CFS/ME: <http://www.counselling-directory.org.uk>

■ Look on the **UK Council for Psychotherapy** website for a therapist in your area: <https://www.psychotherapy.org.uk/>

■ It is also possible that both the **BACP** and the **Counselling Directory** will have details of counsellors who will work with you by telephone or online.

3. Telephone helplines

Telephone helplines are not a replacement for one-to-one counselling, but can provide an essential service if you need to talk to someone who is trained to listen without judgement or pressure.



BECOME A MEMBER OF THE MEA

For a small subscription you can receive quarterly issues of **ME Essential** magazine, keep updated with the latest information on ME/CFS and with stories from other members of the charity.

You don't have to be personally affected by ME/CFS to join the ME Association. Membership is available to carers, family-members, and anyone with a professional interest in the condition.

Annual membership costs:

£18.00 (UK residents and BFPO)

£24.00 (Mainland Europe including Republic of Ireland)

£30.00 (Rest of the World)

Visit the website shop to find out more:

<https://tinyurl.com/yu89nuzx>



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ME Connect is the MEA's telephone helpline. If you need to talk to someone about any aspect of life with ME/CFS, please give us a call: 0344 576 5326. We are available 365 days a year and lines are open between: 10am-12noon, 2pm-4pm, 7pm-9pm. We're here to listen, here to help.

<https://meassociation.org.uk/MEConnect>

The Samaritans are available day or night, for anyone who's struggling to cope, who needs someone to listen. Whatever you're going through, you can call them at any time, from any phone for FREE: 116 123.

<https://www.samaritans.org/>

PLEASE REMEMBER

With any long-term illness it is understandable that you may feel a mixture of emotions. And sometimes you might feel nothing at all, a kind of emotional numbness or emptiness inside. Sometimes it can even be hard to know what you feel.

Talking about these difficulties and emotions with someone really can help, for example your GP, a therapist or our helpline – ME Connect.

Managing your emotions is just as important as managing your physical symptoms. Talking to others and sharing how you feel can improve your emotional wellbeing. Try to get all the help and support you possibly can and be kind to yourself.

ADDITIONAL SOURCES OF INFORMATION

The MEA has further information about mental health and ME/CFS:

- Anxiety and panic attacks
- Depression and antidepressants
- Cognitive behaviour therapy
- Counselling



THE ME ASSOCIATION WEBSITE SHOP

The ME Association has the UK's largest range of literature providing reliable information about all aspects of life with ME/CFS.

Leaflets, booklets, and guides can be downloaded from the website shop, and books and merchandise ordered online.

Categories include:

- Medical Management**
- Mental Health**
- ME Connect; Diet & Nutrition**
- General Information**
- Fundraising Leaflets**
- Benefits & Social Care**
- 'To Whom It May Concern' letters**

Visit the website shop:

<https://meassociation.org.uk/shop>



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FEEDBACK

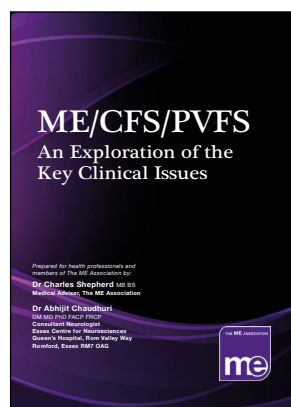
The ME Association welcomes feedback about this guide.

Please send any comments to:

The ME Association
7 Apollo Office Court, Radclive Road, Gawcott
Bucks MK18 4DF

or email: feedback@meassociation.org.uk

THE ME ASSOCIATION'S 'PURPLE BOOK'



The latest edition of **ME/CFS/PVFS - An Exploration of the Key Clinical Issues** is an authoritative publication representing the most comprehensive, evidence-based summary of PVFS/ME/CFS currently available. It contains everything that health professionals and patients need to know about this devastating neurological disease and comes highly recommended.

Price £10.00 (UK/BFPO)

Order from the ME Association website shop:

<https://tinyurl.com/4f55bhmc>

Alternatively, call our office on 01280 818963

or you can purchase a Kindle version from Amazon:

<https://tinyurl.com/y667ewcf>

DISCLAIMER

We recommend that the medical information in this leaflet is discussed with your doctor. It is not intended to be a substitute for personalised medical advice or treatment. You should consult your doctor whenever a new symptom arises, or an existing symptom worsens. It is important to obtain medical advice that considers other causes and possible treatments. Do not assume that new or worsened symptoms are solely because of ME/CFS.



ME CONNECT

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



Freephone
0800 538 5200

Monday to Friday 10am - 6pm
(Late night until 9pm on Thursdays)

Saturday & Sunday
10am - 12 noon & 7pm - 9pm

Contact ME Connect
3 WAYS TO GET IN TOUCH:
by phone, email
or social media private message



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



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