



ME Connect

The Support and Information Service



**FREEPHONE NUMBER
AND INCREASING
HOURS**

- We are here to listen
- We provide vital support
- It's a safe environment
- All communications are treated in the strictest of confidence

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.

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**Freephone
0808 801 0484**

To view the ME Connect telephone helpline opening hours please visit:

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

Alternatively you can email meconnect@meassociation.org.uk or connect via private message on one of our social media platforms.

See page 3.



INTRODUCTION



Neil Riley, Chairman of the ME Association, comments:

“When you are ill with a chronic condition like PVFS, ME/CFS or Long Covid, there are many things you want to know. What treatments work, where can I find a doctor who understands me, where can I get reliable information to complete my benefits claim?

“It can be even more important to make contact with another person, someone who understands how these medical conditions affect everyday life and the many challenges they bring. Someone who will listen without judgment.

“The purpose of ME Connect is simple. It is here to support people affected by PVFS, ME/CFS, and Long Covid to help them make informed choices. It is here to listen, to validate, and empathise with any issues they might be facing.

“Every year, ME Connect does this for thousands of people. Of all the services the charity provides, it is ME Connect of which I am most proud. It is what I feel a charity should be all about; giving help to those who need it at a difficult time in their lives.

“Staff and volunteers provide this service every day. Why? Because they want to help. They want to give something back to people who are in a worse situation than they are. They want to make a contribution, and it can be a very rewarding experience.”

WE ARE MEMBERS OF THE HELPLINES PARTNERSHIP

The Partnership is committed to supporting organisations that provide non-face-to-face advice, support and information to improve general wellbeing and has been doing so for over 20 years.

They champion the interests of their members and help them to build sustainability and deliver the best service they can for their users.



HOW WE CAN HELP



“Thank you so much for giving up your time to work on this Helpline. It is just so nice to speak to someone who really understands what I am going through.”

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.

All communications are treated in the strictest of confidence.

ME Connect, under the capable management of Katharine Leat, has launched a new, updated service to better help those who use it.

Katharine has hugely increased the ME Connect volunteer team to make it possible to answer more calls, more quickly. Alongside this the hours have been greatly increased.

To view the ME Connect telephone helpline opening hours please visit: <https://www.meassociation.org.uk/me-connect>

There are three ways to contact ME Connect. Firstly you can make contact by telephone to the **new Freephone number, 0808 801 0484**. Alternatively you can email meconnect@meassociation.org.uk or connect via private message on one of our social media platforms:



facebook.com/meassociation



X.com/meassociation

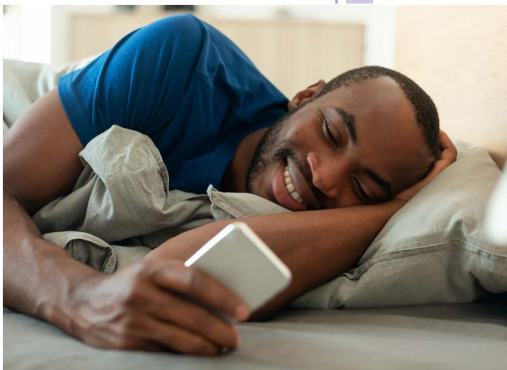


instagram.com/meassociation



ME CONNECT'S MANAGER

"I understand"... two of the most powerful words anyone living with ME can hear and so rarely do. The ME Connect team of staff and volunteers provide desperately needed understanding, empathy and information to those who contact ME Connect.



"I have worried about this problem for weeks but within five minutes you have given me the answer, thank you very much indeed."

Living with ME is challenging in so many ways, our service aims to make those challenges more manageable and alleviate the feelings of isolation and desperation that so often occur.

The information shared by ME Connect is produced by the MEA and can therefore be trusted. Similarly, we use a carefully compiled signposting list in order to direct people to other individual experts or organisations for further, or more specific, support as necessary.

Sometimes all that's needed is someone to listen. Our team provide a safe space, where there is time to talk and truly be heard.

I am proud to work with the ME Connect team who consistently demonstrate their compassion, empathy and knowledge with total commitment to those who need our help.

If you, or anyone you know, need support/information regarding living with ME, please do not hesitate to get in touch.

Katharine Leat

ABOUT KATHARINE:

Katharine was delighted to be appointed ME Connect Manager in January 2024. She believes it is a wonderful opportunity to support an amazing team of volunteers as they provide support and information to anyone whose life has been affected by ME/CFS or Long Covid.

Katharine has had ME since 2011 and is all too aware of the impact the illness has, including ending her teaching career and marathon running. By working for the ME Association, she wants to help lessen that impact for others.

She lives with her husband and their beautiful rescue animals in rural Norfolk. She loves all animals, being outdoors whenever possible, vegan cookery, writing stories and Liverpool FC!





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

DISCLAIMER

ME Connect 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 or Long Covid.



SENIOR VOLUNTEER



Sue Mayes, Senior Volunteer at ME Connect, said:

“We might hear from people who want general information, or who are anxious about their symptoms. They might already have a diagnosis and want more information about their illness.

“Callers may be in a muddle with claiming benefits or they may be worrying about their child and the effect on schooling. They may just need someone they can talk to, who can listen and who understands.

“We sometimes find that an empathetic understanding after months of worry can bring tears of gratitude. Often a call will end with a gentle joke and some laughter, something that can be missing from their lives.”

WE’RE HERE FOR YOU



Russell Fleming, Head of Project Development, comments:

“ME Connect is about delivering an accessible, professional and personalised service to people in need. I think we do this very well. Indeed, throughout the pandemic and ever since, we have seen much growth in the number of people seeking support and information. This has led to the charity investing additional resource in the service.

Email and social media private messaging provide a different but similar service to the helpline. We want to offer ME Connect to as many as we can and people have responded positively. We now receive almost as many emails and messages as the helpline receives phone calls. And, like the helpline, all replies are tailored to the individual, are confidential, and we all receive the same level of training.

It is a great honour to help people who are often in desperate situations and, from the responses we receive, I know the service is appreciated. We’re here for you!”



“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. We provide a personalised service and we're here when you need us most. Most of us have personal experience of these medical conditions, or care for a loved one who does. To view the ME Connect telephone helpline 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 literature covering all aspects of life with ME/CFS and Long Covid**. We can show you how to recognise and manage symptoms, to 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.”



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 Guidelines 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**.

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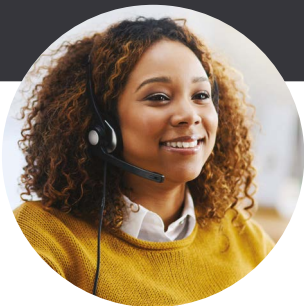
ME CONNECT

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

Contact ME Connect

3 WAYS TO GET IN TOUCH:

by phone, email or
social media private message



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with any issues you might
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