



# THE ME ASSOCIATION

## What we do and why we do it

*Changing Attitudes, Improving Lives*

SUPPORT



INFORMATION



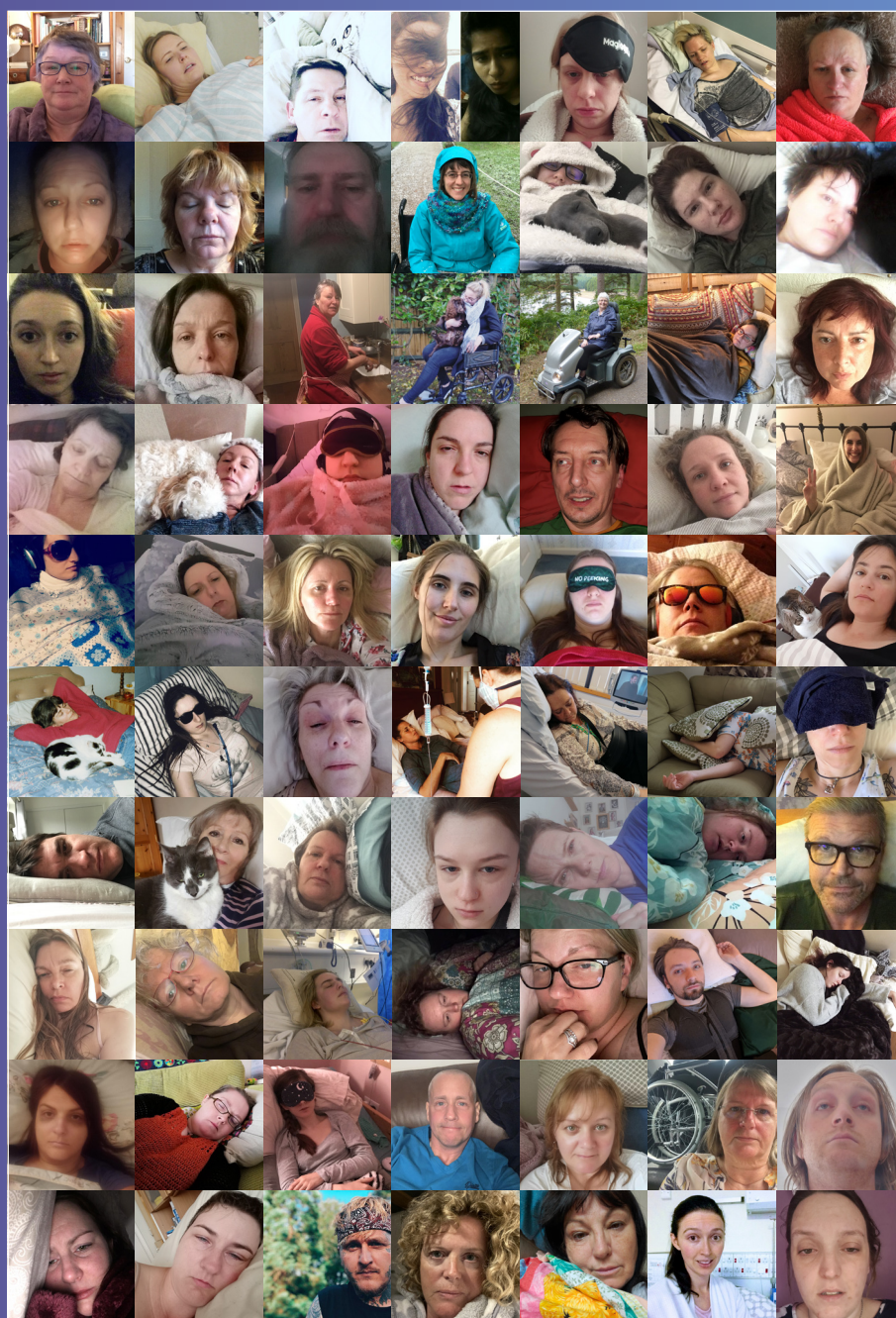
CAMPAIGNS



EDUCATION



RESEARCH



We support, inform, campaign, and invest in medical research for people affected by ME/CFS, PVFS and Long Covid.

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## INTRODUCTION

The ME Association has been providing expert help since 1980. We understand the challenges faced by people who live with ME/CFS, PVFS, and Long Covid, and believe that nobody should struggle alone.

We have established an excellent reputation over the last 43 years and consistently deliver high standards of support, provide reliable and timely information, welcome medical training, lobby effectively, and we make prudent research investments.

More than 1.25 million people in the UK live with ME/CFS and Long Covid which represents a real health crisis. Around 5-10% of people who catch an infection can develop a post-viral fatigue syndrome like ME/CFS and Long Covid. Half of those with Long Covid are believed to meet the diagnostic criteria for ME/CFS. These are life-changing and indiscriminate medical conditions that affect both adults and children regardless of socio-economic or ethnic background.

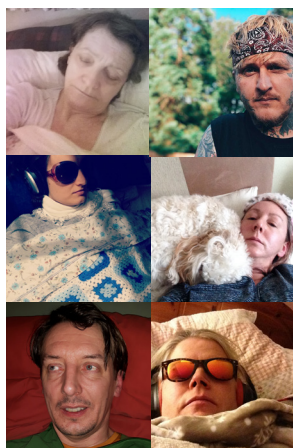
■ We believe that everyone with these medical conditions should be entitled to the best and most accessible health and social care as well as easy access to welfare benefits when they need them.

■ In making medical research a key priority through the Ramsay Research Fund, we are learning more about what causes and perpetuates Post-Viral Fatigue Syndrome and ME/CFS. We hope this knowledge will result in an accurate diagnostic test, more effective treatments and even a cure.



*PVFS = Post-Viral Fatigue Syndrome. ME = Myalgic Encephalopathy, Myalgic Encephalomyelitis. CFS = Chronic Fatigue Syndrome. Long Covid = Post-Acute Sequelae of Covid-19 (PASC), Post-Covid Syndrome.*





**Front Cover:**

*Images kindly provided  
in response to the  
Real M.E. Campaign.  
We welcome further  
images and stories.*

[https://  
meassociation.org.uk/  
real-people-real-me](https://meassociation.org.uk/real-people-real-me)



## INTRODUCTION

There is research evidence that ME/CFS can lead to long-term disability and a lower quality of life than Multiple Sclerosis or Cancer. It most often presents as a complex post-viral fatigue syndrome (PVFS) triggered by an infection that dramatically impacts a person's ability to complete everyday tasks and to get about normally. Long Covid affects people in a similar way.

There are no effective drug treatments at this time, but convalescence and appropriate self-management can help stabilise and improve functional ability. While complete recovery from ME/CFS is rare, we don't yet know enough about the prognosis for people with Long Covid.

- We provide a safe and welcoming community for people affected by these conditions who come together and benefit from sharing their experiences.
- Support is available from ME Connect: our telephone helpline, email, and social media private messaging service. We offer membership, a magazine, an e-newsletter and free information on the website including 'Medical Matters'. We respond quickly to the many requests for help that we receive daily.
- We offer reliable and timely information using the knowledge of specialist advisers and experts and have the largest range of literature covering all aspects of life with ME/CFS and Long Covid. We also campaign to raise awareness and bring about positive change, particularly in health and social care services.
- We arrange training for healthcare professionals, offer a medical magazine, and are working with the Department of Health and Social Care and the NHS to implement the recommendations from the 2021 NICE Clinical Guideline on ME/CFS – the successful result of 14 years lobbying and hard work.
- We fund biomedical research through our dedicated Ramsay Research Fund, which has supported the UK ME/CFS Biobank since it started in 2011. We are also investigating the possibility of setting up a Post-Mortem Tissue Bank. One key feature of our scheme is that we make no deductions whatsoever for administrative costs when we award research grants. Admin costs are paid for out of the general running costs of the charity.
- We believe in collaboration and support Forward-ME, the ME Research Collaborative, DecodeME, The All-Party Parliamentary Group on ME, Physios4ME, the Chronic Illness Inclusion project and various Long Covid initiatives.

6 Full Trustees

2 Associate  
Trustees

12 Employees

6 Self-employed  
contractors

25 Volunteers

## TRUSTEES

We have a terrific team of trustees who provide direction and strategy on a voluntary basis, including several who contribute to day-to-day management oversight.

They are supported by dedicated full and part-time members of staff at head office near Buckingham and others who work from home, together with several self-employed contractors. A large number of fully-trained volunteers help ensure the ME Connect Telephone Helpline is available 365 days a year.

Most people working for the charity have personal experience of PVFS/ME/CFS or Long Covid, have loved ones who are affected, are medical or research experts, or have developed a deep understanding after a long period of service. This knowledge and experience is what helps us to be who we are – delivering quality service when and where it's needed.



Row 1, L-R: Neil Riley, Chairman; Dr Charles Shepherd, Trustee & Hon. Medical Adviser; David Allen, Trustee; Martine Ainsworth-Wells, Trustee

Row 2, L-R: Nicola Anson, Trustee; Ewan Dale, Trustee; Nicky Strong, Associate Trustee; Tilly Robinson-Miles, Associate Trustee



## PEOPLE

Row 1, L-R: Vicky Smith, Head of Finance and Operations; Hilary Briars, ME Connect Manager; Russell Fleming, Head of Communications; Caroline Cavey, Magazine Editor, Literature Designer; Tony Britton, Fundraising and PR Manager

Row 2, L-R: Emma Jefferies, Social Media Specialist; Dr Katrina Pears, Research Correspondent; Ian Baker, Website Manager; Juan Corlett, Engagement Lead; Clare Bain, Communications Officer

Row 3, L-R: Gill Briody, Membership Coordinator; Helen Darling, Administrative Officer; Theresa Holmes, Debbie White, Angie Bedborough, Administrative Assistants

Row 4, L-R: Sarah Swan, Finance Assistant; David Biggs, Merchandise and Post; Sue Mayes, ME Connect Volunteer; Glenys Robbins, ME Connect Volunteer; Ella Smith, Welfare Rights Adviser

Row 5, L-R: David Walton, Hon. Employment Adviser;; Dr Lisa Dvorjetz, Emotional Health and Wellbeing Adviser; Dr Nigel Speight, Hon. Paediatric Medical Adviser; Dr Richard Cantillon, Hon. Dental Adviser; Sue Luscombe, Hon. Dietetics Adviser



## SUPPORT AND INFORMATION



**ME CONNECT**  
The support and information service for people affected by ME/CFS/PVFS and Long Covid

0344 576 5326  
10am-12 noon, 2pm-4pm, 7pm-9pm every day of the year

Contact ME Connect by phone, email or social media/private message

**HERE TO LISTEN**  
We are here to listen, empathise and support you with any issues you might be facing.

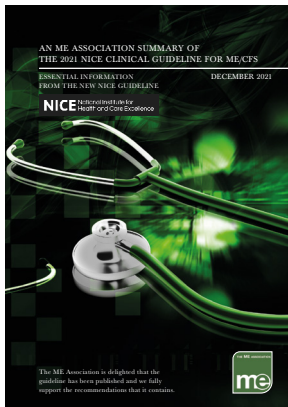
**VITAL SUPPORT**  
We are here to help you reach an informed decision.

**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 | twitter.com/meassociation  
facebook.com/meassociation | instagram.com/meassociation

Call out the name on other standard landline numbers (charging 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.



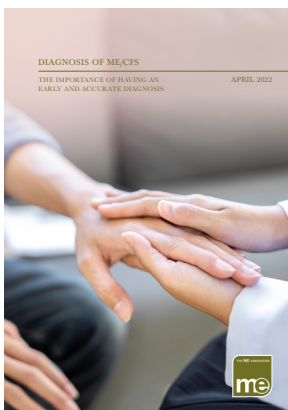
AN ME ASSOCIATION SUMMARY OF THE 2021 NICE CLINICAL GUIDELINE FOR ME/CFS

ESSENTIAL INFORMATION FROM THE NEW NICE GUIDELINE

DECEMBER 2021

**NICE** RECOMMENDATION BY NICE

The ME Association is delighted that the guideline has been published and we fully support the recommendations that it contains.



DIAGNOSIS OF ME/CFS

THE IMPORTANCE OF HAVING AN EARLY AND ACCURATE DIAGNOSIS

APRIL 2022

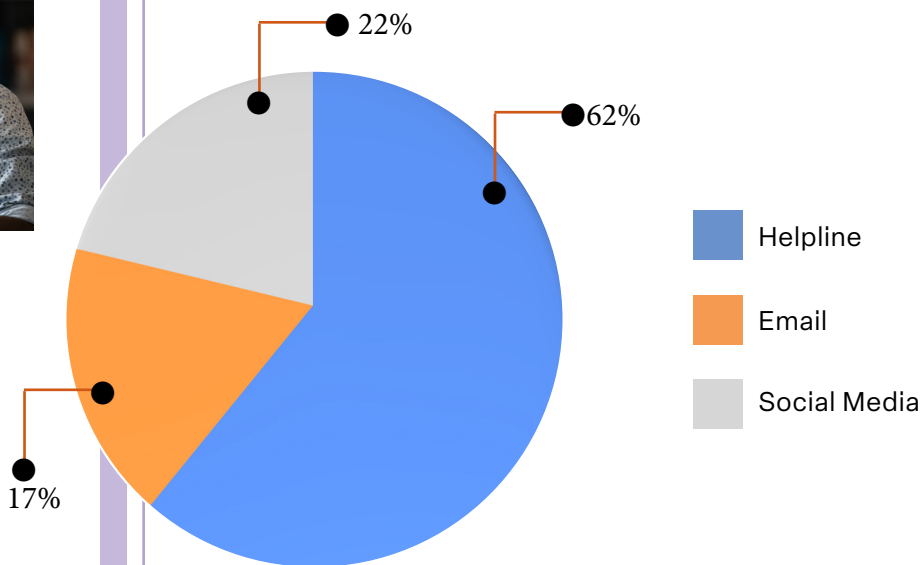
- ME Connect is available to everyone affected by PVFS/ME/CFS and Long Covid. It is the charity's flagship support service and is professionally delivered by a committed team of staff and volunteers:
- The Telephone Helpline is available 365 days a year. Help is also available by email and private social media messaging.
- We have seen a steep increase in requests for help via email and social media and have invested additional resource in these areas to ensure that we listen to everyone and reply to their concerns promptly.
- We provide the most extensive library of timely and reliable information anywhere on the internet. Literature is produced and updated in association with specialist advisers on relevant topics. We make a small charge for most downloads to help cover some of the production costs but include a lot of free information (in the shop and elsewhere on the website).
- In 2022 we introduced 'Medical Matters' as a free resource which has been widely welcomed and complements the more detailed literature that is available. It enables website visitors to review answers from specialist advisers to questions about life with PVFS/ME/CFS and Long Covid and on other related health topics.



## SUPPORT

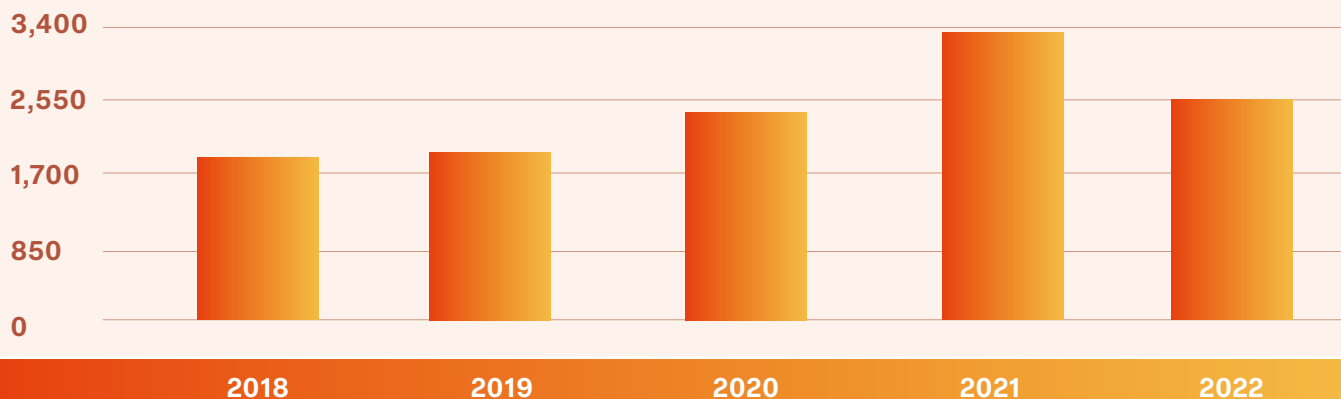


ME Connect: 4,144 people helped in 2022



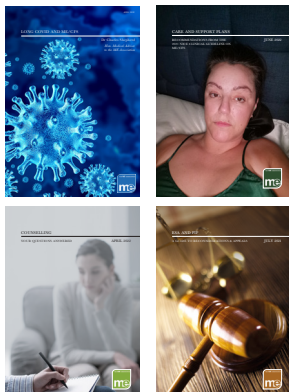
ME Connect Telephone Helpline:  
12,000 people helped in the last five years

### ME CONNECT Telephone Helpline



*“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.”*

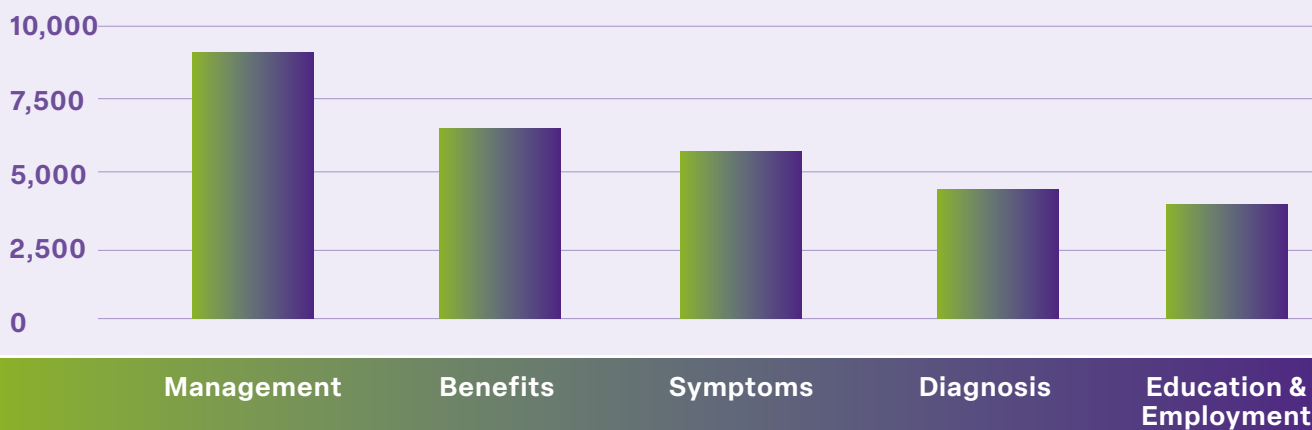
## INFORMATION



### Literature topics include:

- benefits,
- carers and social care,
- Covid-19 and Long Covid,
- education and employment,
- diagnosis,
- diet and nutrition,
- management,
- mental health,
- symptoms,
- vaccinations,
- vitamins and supplements.

### TOP 5 LITERATURE CATEGORIES: 2022 Sales/Downloads



*“The ME Association makes me feel less isolated. I believe that ME is real and physical and I like that the MEA is wholeheartedly behind research to prove this.”*



## Make a donation. *Help change lives.*

### Your help will mean that we can:

- support more people with ME/CFS
- increase awareness and understanding
- keep healthcare professionals informed
  - invest in biomedical research
- improve health & social care provision
- provide reliable and timely information
- campaign more effectively.



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





*“Thanks for producing such a helpful magazine about ME. The standard is consistently high and each edition is interesting and varied. I am married to a long-term ME sufferer and I am still learning a lot about the illness and how to be a carer. I need all the help I can get and this magazine is consistently encouraging, realistic and helpful.”*



## MEMBERSHIP

### About Membership

- We are very lucky to have terrific support from members. Everything we do is based on an assessment of their needs. We wouldn't be here today if it wasn't for their loyalty and we are very grateful.
- Every member receives 'ME Essential' magazine 4 times a year delivered by post to their home address. It features exclusive articles, scientific developments, 'Ask the Doctor', stories and opinions and helps members feel connected. It is a source of comfort and, quite simply we believe, the best charity magazine - anywhere!
- We have attracted many more digital memberships and renewals during and after the pandemic from people with PVFS/ME/CFS and Long Covid.
- We recognise that traditional membership is not for everyone, and continue to offer a range of options to non-members. Strong growth in this area has been recorded in recent years and we continue to offer help and information with ME Connect, the website, and across social media which has shown an especially strong performance.

### Become a Member

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

To become a member, please click the following link:

<https://meassociation.org.uk/product/new-membership-application/>



*“I would like to thank Dr Shepherd and the Association for all they are doing to support ME sufferers. I have benefitted so much from my membership to the Association, I appreciate all that you do.”*

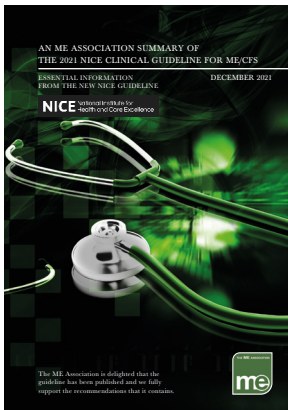
## MEMBERSHIP

### New and renewed memberships

- The total number of members can fluctuate during the year, and we recognise that people will choose to renew or join for a variety of reasons. Traditional charity membership and the payment of even a very reasonable subscription – which hasn’t changed in more than 10 years – is not for everyone.
- In the last 5 years total membership has increased 23% as we continue to improve its value and attract new members and retain existing members in good numbers. Ideally, we’d like a more representative number of members as we put their interests at the heart of everything we do.
- Future campaigns will aim to bring more new members onboard, but we are a charity for everyone and do not overlook the importance of serving the needs of the majority of non-members.



## CAMPAIGNS



### NICE Guideline on ME/CFS: An ME Association Summary

This free booklet is recommended reading. It lets you know what to expect from the NHS and social care services with regard to symptom recognition, diagnosis, management, referral, and ongoing care and support:

<https://meassociation.org.uk/9d0l>

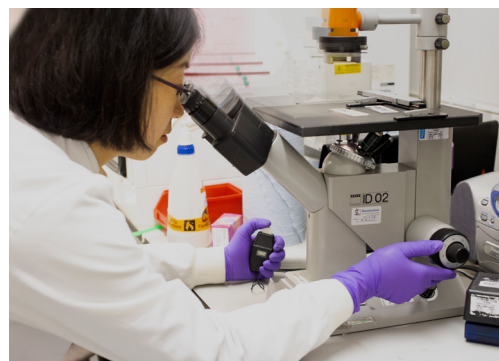
From ME to You  
The campaign ran from November 2022

In 2022, Martine Ainsworth-Wells was appointed Campaigns Director. She remains a Trustee, but has and will continue to use her professional experience to create appropriate campaigns that aim to drive forward the charity's strategy and its action plans in the years ahead.

■ From November 2022 we ran a very successful campaign that recognised the unsung heroes in the community - the people who care for members when they are in most need. Instead of asking for donations during the festive season, we wanted to give something back. We asked for nominations and received over 330! Randomly selected nominees received a lovely hamper acknowledging their contribution and we shared many of their stories on-line and in ME Essential magazine.

■ In 2022, we worked with members of the UK ME/CFS Biobank team to consider ways that we could help promote this vital resource to more scientists in the world, helping it become financially independent. In February 2023, the Biobank will employ a Marketing Manager and we will provide assistance as the team work on a promotional campaign over the next 12 months. The ME Association provides financial support to the Biobank that covers its operational costs.

■ In May 2023, we hope to initiate a 12-month campaign that will aim to reach more people with symptoms or a diagnosis of PVFS, ME/CFS, and Long Covid. We believe that there are many more people affected by these medical conditions than are currently part of the community, and we are determining the best ways to reach them. We want to offer help to those who may not be aware that support is available, and let them know they are not alone.



### UK ME/CFS Biobank

Photo by Yas Crawford



## The ME Association website shop

We have the largest selection of relevant literature and other items of interest:

**Awareness & Fundraising**

**Benefits**

**Books & Reports**

**Carers and Social Care**

**Covid-19, Long Covid & ME/CFS**

**Education & Employment**

**Goods & Clothing**

**Insurance & Travel**

**Medical and Management**

**Children and Young People**

**Diagnosis**

**Diet & Nutrition**

**Management**

**Mental Health**

**Symptoms**

**Vaccinations**

**Vitamins & Supplements**

**Membership**

**Template Letters**

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

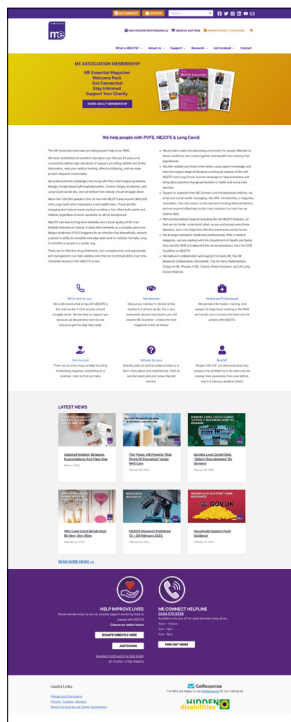


## WEBSITE AND SOCIAL MEDIA

- The ME Association's website and social media continue to attract good numbers of visitors, delivering strong reach and effective engagement; showing that we are being more effective than other charities in the sector.
- However, we recognise that despite the impressive growth on social media we have yet to attract the number of people believed to be affected by PVFS, ME/CFS, and Long Covid, so we will be doubling efforts in this area helped by the proposed campaign in 2023 (see page 7).
- The website and social media platforms help us share the news and research developments. They initiate very popular discussions about life with PVFS/ME/CFS and Long Covid. We attract people with a diagnosis, and those currently undiagnosed, as well as carers, family and friends, and healthcare professionals.
- The website shop contains our full range of literature. It continues to demonstrate that what we produce is very much in demand, and from the comments we receive, it's all very welcome.
- The website shop enables new members to join the charity and existing members to renew their subscriptions. Memberships and renewals grew strongly during the pandemic and we have received some incredible support for ME Essential magazine from a recent Members Survey. We will be reviewing members' benefits and the magazine in 2023/24, hoping to provide an even better service to those whose support we value the most.
- We carry a lot of free information on our website which we constantly strive to make as easy to use as possible. Popular free landing zones include our 'Medical Matters' information resource, our listings of local ME/CFS groups and other relevant groups around the UK and contact details for all the specialist ME/CFS services run by the NHS. We're proud to offer these services free of charge and invite readers to email us if they spot a mistake or something that needs to be updated. Email: [meconnect@meassociation.org.uk](mailto:meconnect@meassociation.org.uk)



## WEBSITE

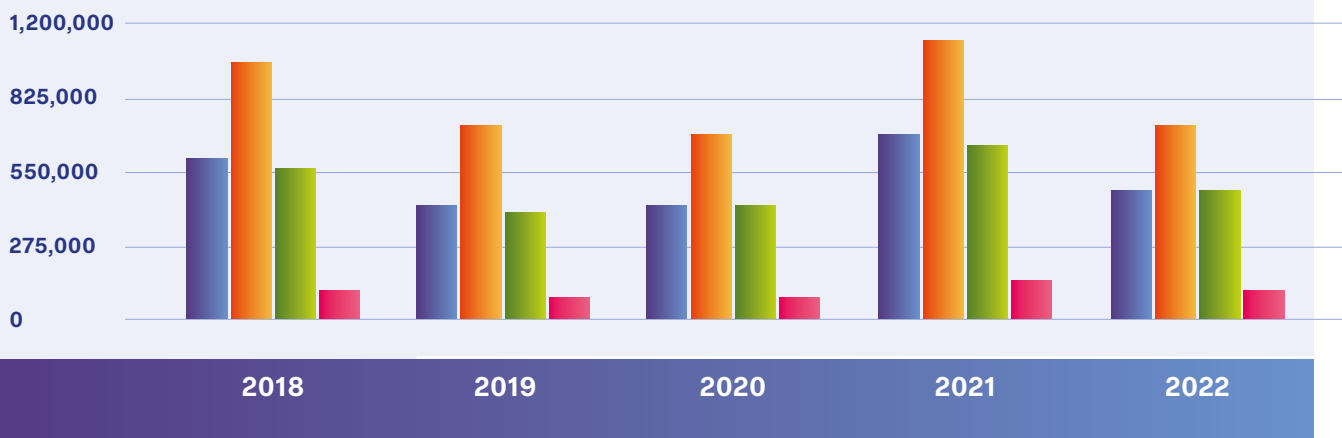


[meassociation.org.uk](http://meassociation.org.uk)

We have a very busy and popular website and are continuing efforts to make it more appealing and accessible. Despite the general trend in the last decade towards social media, people are still visiting the website in large numbers and clearly find the support and information that it offers to be worthwhile.

- In the last 5 years, the website’s pages have been viewed over 7.5 million times in total.
- We saw a peak in 2021 because of the pandemic, but levels are now above what they were pre-pandemic.
- The majority of visitors remain on the website for between 1 and 30 minutes which is very encouraging.
- The general reduction in the number of people visiting the website reflects the continuing trend towards social media – although there was a notable increase during the pandemic and 2022 has held up well – with visitors spending more time on the website in general, which is to be welcomed.
- Around 85% of the people using the website are new visitors with the Homepage, free information about ME/CFS and Long Covid, the Literature we carry in the website shop, and the website blog, being among the most popular pages visited.

### WEBSITE USERS, SESSIONS, VISITORS



Users

New visitors

Sessions

Returning visitors



/meassociation



/meassociation



@meassociation



/me-association



/meassociation  
UKCharity



## SOCIAL MEDIA

Social media is often the quickest and most impactful way of keeping people informed. In 2022, we reached over 2.5 million people on the 3 main social media platforms with news, research developments and popular discussions about life with ME/CFS and Long Covid. We are very active on these platforms and regularly top the charts for any charity in this area both in the UK and internationally.

### Facebook:

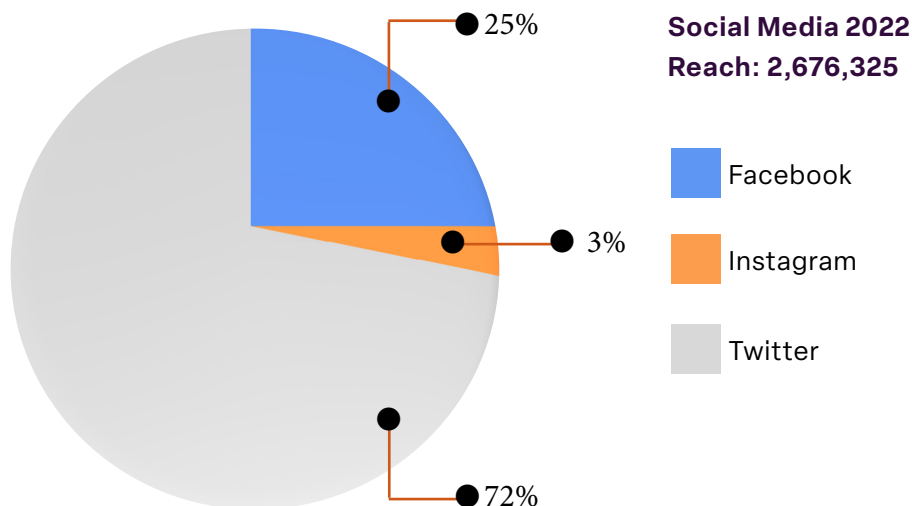
- We reached 673,691 people (+30%).
- We received 30,310 page likes (+1,725), and 80,464 page visits.
- Facebook audience = 87% Women, and 13% Men with a more mature demographic.

### Instagram:

- We reached 72,634 people (+21%).
- We had 9,182 followers (+1,603), and 26,041 profile page visits (the account was launched in 2021).
- Instagram audience = 90% Women and 10% Men with a younger demographic than Facebook.

### Twitter:

- We made 1,930,000 impressions.
- We had 19,049 followers (+988), and 238,000 profile page visits.



*“I like and trust that many people working for the ME Association have first-hand knowledge and experience of M.E.”*

## SOCIAL MEDIA

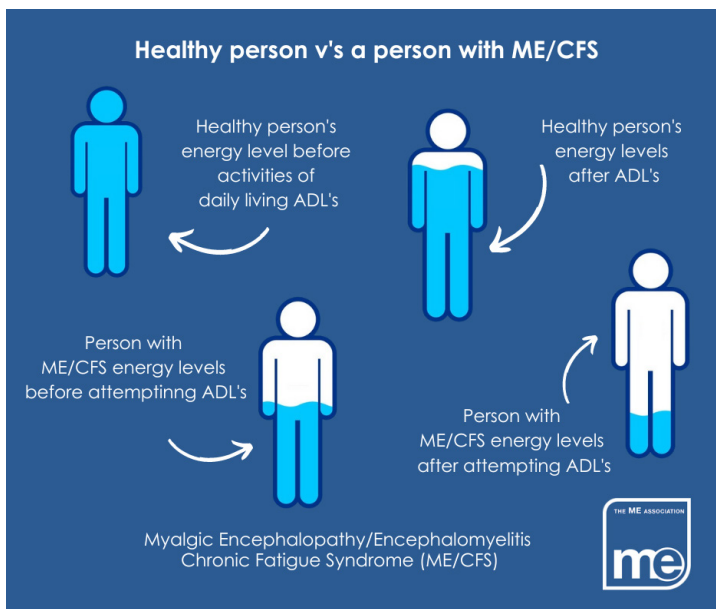
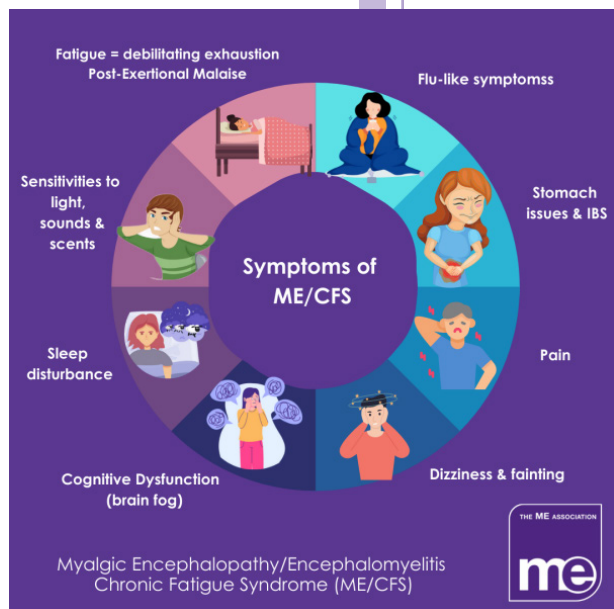
### May 2022

#### Symptom Post:

“All these symptoms dramatically affect a person’s quality of life and their ability to complete everyday tasks. Some people seem to underestimate how awful it is to have this neurological disease.”

**Facebook Reach: 93,300**

**Twitter Impressions: 49,000**



### June 2022

#### Healthy Person vs. Person with ME/CFS

“A healthy person may find Activities of Daily Living (including personal hygiene, dressing, oral hygiene, eating, mobilising, etc.) second nature. A person with ME/CFS needs to pace to even attempt simple everyday tasks.”

**Facebook Reach: 37,600**

**Instagram: 7,500**





*“Brilliant PowerPoint presentation. It was so good. Easily understood everything. So happy I came!”*

*“PLEASE let Russell know how absolutely wonderful his presentation was - extremely informative, honest, and reassuring despite present travails (both ours and his)!”*

*“Thank you so much for again inviting Russell to speak to our Support Group!”*



## EDUCATING

■ The charity’s priority from 2022 onwards is working with the NHS and social care providers to successfully implement the recommendations made in the NICE Guideline on ME/CFS to ensure that everyone receives the very best health care available. To this end we are actively engaging with primary, secondary, and social care, and supporting local groups in their efforts to see improved and new services across the UK.

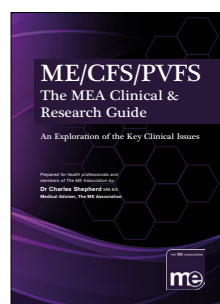
■ We deliver presentations to healthcare professionals about ME/CFS and Long Covid upon request and at medical conferences.

■ We provide educational materials to professionals and produce regular medical and research updates with ‘ME Medical’ magazine, which is produced 4 times every year and sent to the business address of any professional who has requested a copy or been nominated by a patient, and to every NHS ME/CFS Specialist Service in the country.

■ We produce ‘The PVFS/ME/CFS Clinical and Research Guide’ (AKA ‘The Purple Book’) which is written and regularly updated by Dr Charles Shepherd (Trustee and Hon. Medical Adviser). It contains everything that a professional needs to know about the condition – and is a useful reference tool for patients. The Guide is freely available for professionals, can be ordered via the website shop, available in hard copy format for professionals and can be ordered through the website shop. It is available in print format for professionals or in Kindle format or as an e-book on Amazon.

■ We have helped to develop online CPD training modules for ME/CFS and will create more to tie up with the training, together with webinars, as we contribute to the training that professionals receive as students, when they join the ME/CFS & Long Covid Specialist Services, and as GPs and allied health professionals in primary care.

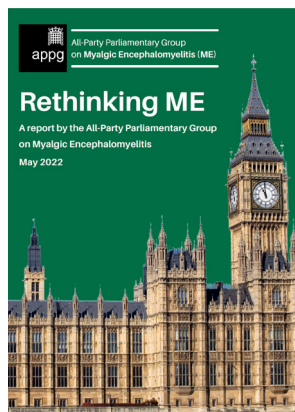
■ With recruitment and retention of professionals working in ME/CFS & Long Covid identified as a key priority, we are working with the DHSC\*, BACME\*\*, and existing local specialist services to try at the local level and determine how to attract and retain good applicants and provide an appealing career structure.



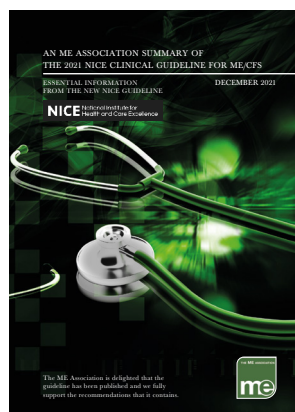
\*DHSC: Department of Health and Social Care

\*\*BACME: British Association of Clinicians in ME/CFS





*“I wanted to belong to a charity that provided support, lobbying and biomedical research.”*



NICE Guideline on ME/CFS: An ME Association Summary

<https://meassociation.org.uk/product/nice-guideline-mecfs-me-association-summary/>



## INFLUENCING

- We are part of the Secretariat that that supports and works with the All-Party Parliamentary Group on ME chaired by Carol Monaghan MP. This seeks to draw notice to required improvements in health, social care, education and employment opportunities for people with ME and encourage biomedical research into cause and treatment.
- We are active members of Forward-ME, which was formed to present one, unified voice on key ME/CFS issues of the day. A significant number of ME/CFS charities, organisations and other patient-support groups are represented there.
- We engage almost every day with the news-media to raise awareness and inform others about ME/CFS and Long Covid. Dr Shepherd is a recognised authority in the UK on these subjects and we use every opportunity we can to promote key messages and provide expert contributions to stories and research developments.

### The NICE Clinical Guideline on ME/CFS

- After many years of lobbying to remove the first (2007) NICE Guideline on ME/CFS because it contained unhelpful and unrealistic recommendations, the charity's efforts culminated in a 2017 petition to NICE that carried 15,000 signatures, and resulted in the decision to review and update the Guideline in 2018.
- From 2018 - 2021 we focused on developing a new NICE Guideline on ME/CFS that better reflected the patient experience and was fit for purpose.
- Dr Shepherd was a member of the NICE Guideline Committee. We are very happy to endorse its recommendations which we believe to be the most positive development to have occurred in recent years.
- We are working proactively with the Department of Health and Social Care (DHSC), the Royal Colleges of Medicine, The British Association of Clinicians on ME/CFS (BACME), local NHS Integrated Care Services, and ME/CFS & Long Covid Specialist Services.
- In order to ensure that patients obtain the most appropriate and safe care, we will continue to place our highest priority on full implementation of both the NICE Guideline on ME/CFS and the NICE Rapid Guideline on Long Covid. We are activelyengaging with support groups across the UK to help them mobilise and lobby for health and social care improvements at the local level.



*“The MEA does an amazing job. Very little research has been achieved compared to other illnesses but this is due to a lack of government investment as your efforts on our behalf are outstanding!”*

## INFLUENCING

■ We are lobbying health and social care providers in Scotland, Wales, and Northern Ireland in the hope the NICE Guideline recommendations will be implemented in full and that healthcare provision for ME/CFS (and Long Covid) is made as much of a priority in these countries as it is in England.

■ Government-led initiatives in England are being driven forward by the Department of Health and Social Care. Three working groups were established in June 2022 and a Delivery Plan is expected to be released for stakeholder comment in Spring 2023.

The working groups are: Research, Attitudes and Education, and Living with ME/CFS. They include representatives from NICE, the NHS, BACME, social care, other experts, researchers, the DWP and other Government departments, and the patient and carer communities. They aim to, for example:

- a. Prioritise implementation of the NICE Guideline recommendations.
- b. Improve health and social care provision, access to services, and to benefits.
- c. Develop a renewed focus on research to better understand ME/CFS and develop effective treatments.
- d. Improve medical education, understanding, and awareness.
- e. Improve the training, recruitment, and retention of health and social care professionals.

*“I am announcing the Government’s intention to develop a cross-Government delivery plan on ME/CFS for England, aligning with other devolved nations as appropriate. In particular, we are engaging with the Scottish Government to explore areas of potential shared interest and learning, especially in terms of research into ME/CFS.*

*“At the heart of the delivery plan will be two core principles. Firstly, that we do not know enough about ME/CFS, which must change if we are to improve experiences and outcomes. Secondly, we must trust and listen to those with lived experience of ME/CFS.”*

The Rt Hon Sajid Javid, MP, Secretary of State for Health and Social Care, 12 May 2022





We provide vital support, reliable information, medical training, effective campaigning, and invest in much-needed medical research.

*We're here for you!*



## MEDICAL RESEARCH

■ We pay for research through our Ramsay Research Fund and welcome grant applications. We want to hear from scientists keen to advance our knowledge about the causes of the disease and what prolongs it - particularly if their work will help to develop diagnostic tests and effective treatments.

■ In the last five years to the end of 2021 we have invested over £700,000 in medical research studies and infrastructure projects. It is difficult to attract good-quality research applications. One advantage we can offer is that every pound we award to a successful applicant is spent on their actual research project. We make no deductions whatsoever to cover our own costs of setting up the grant or monitoring its progress. The charity itself picks up the bill for these. And, in the near future, we expect to be aligning ourselves to the research imperatives expected in the new DHSC Delivery Plan for ME/CFS.

■ We have built cash reserves for future research because we recognise the need to support studies and clinical trials of significant size that have the greatest potential to confirm or provide the answers that we all crave.

■ The UK ME/CFS Biobank, which we built up in 2011, has developed an excellent international reputation. We have provided more than £500,000 to support its operational costs and will continue to do so until it can achieve financial independence.

Blood samples and clinical data are collected locally - including from people severely affected - and samples are stored at the Royal Free Hospital in London. Researchers at the London School of Hygiene and Tropical Medicine conduct their own studies and make the samples and data available to others for a reasonable fee - which is often more economic and of better quality than if they had to recruit participants themselves.

■ Creating an ME/CFS Post-Mortem Tissue Bank is something we continue to consider. This will be an expensive project but one that we believe is necessary to collect, store, and make post-mortem tissue available for research. We believe it would allow a better understanding of what is happening in parts of the body that are involved in this disease - skeletal muscle, the brain and nervous system in particular.

We want a permanent facility that will expand on the work we have been doing over many years with the neuropathology team at Addenbrooke's. We have been the only charity in the world to be involved in the collection and study of post-mortem tissue and we do not want to abandon this important and promising area.



*We're here for you!*



## MEDICAL RESEARCH

- In 2021/22 we were part of the James Lind Alliance Priority Setting Partnership on ME/CFS that identified the Top 10 research priorities which are now being used by the DHSC in its work on developing ME/CFS research.
- We play an important part in the work of the ME Research Collaborative – chaired by Dr David Strain – which aims to promote research investment (the work of the MERC was halted in June 2022 to allow the recent DHSC initiative on research to come to fruition).
- We helped to set up and continue to support the DecodeME study which will examine the DNA of 20,000 people with ME/CFS and 5,000 people who developed ME/CFS following a Covid-19 infection. DecodeME remains the world's largest study of the genes of people with ME/CFS. It should provide valuable insights into the risks of developing PVFS, ME/CFS and Long Covid. Recruitment began in earnest in the autumn of 2022.

## FUNDRAISING AND FINANCE

We receive welcome donations, legacies and income from fundraising events, direct from members and an ever-increasing number of non-members. The income received has meant we weathered the pandemic relatively well compared to charities in this and other sectors. Support for us continues to grow, and we have harnessed our powerful social media resources to help make this happen.

We have received some large legacies that have added to cash reserves and we are carefully considering our future strategy and spending plans. Use of these reserves will allow us to help more people affected by PVFS, ME/CFS, and Long Covid. We want to increase investment in biomedical research that will help us to better understand the underlying disease process and move closer to a diagnostic test and effective treatments.

We are acutely aware that people with chronic long-term illnesses have been badly impacted by the Cost-of-Living Crisis, and may not be able to support us so generously if these conditions continue. To guard the charity against any downturn in income, we have built up some sensible cash reserves. If necessary, we shall use these so that the people who rely on us can expect us to deliver services of the same high quality and responsiveness in the future.

Report and Accounts: <https://tinyurl.com/bdf4zwha>