THE ME ASSOCIATION

LEAVING A LEGACY

Changing people's lives in the future

Including:

How to leave a legacy

How the ME Association helps people with ME/CFS

Research, information, support and other matters

An ongoing commitment from the ME Association

Making a Will

MAY 2024

Leaving a Legacy was written by Neil Riley, Previously Chairman of The ME Association.

Thank you for thinking of ME

LEAVING A LEGACY

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LEAVE A LEGACY

It is never too early to write a will, and including a legacy to the ME Association means that we can continue with our work, helping others, and investing in biomedical research to pursue effective treatments and a cure.

Your decision to leave a legacy could make the most wonderful difference to the lives of people with ME in the future

Death isn't a subject any of us like to think about. It means that we must face up to the idea that we won't be around forever: that one day we won't be here anymore.

But thinking about what happens afterwards, about the legacy you want to leave, and about the difference you could still make, can be a very positive experience.

At the ME Association we work hard to support people with ME/CFS, but the disease remains little known and understood. We fund research and provide information through our leaflets that help people with the illness to cope with life.

HOW THE ME ASSOCIATION HELPS PEOPLE WITH ME/CFS

RESEARCH

The ME Association funds biomedical research through our dedicated Ramsay Research Fund, which has invested over £1m in recent years. We support the UK ME/CFS Biobank and we are funding post-mortem tissue research at the Manchester Brain Bank.

Leaving a legacy would help us to continue funding much-needed research which, in turn, will help to find better treatments for patients and eventually, we hope, a cure.

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.

Leaving a legacy helps us to continue researching, writing and producing the best possible information and keep it completely up to date and all available to download for free.

> *"I cannot praise the ME Association enough. Without their helpline, literature and sensitivity I would be experiencing a much more difficult existence. As it is, I am managing my ME and coping so much better now. It's why I've decided to leave a legacy, so that the MEA can continue working to help people like me and invest in more research"*
>
> JILL B

Picture donated to our ***Real ME*** *photo library*

SUPPORT

The ME Association provides support to people struggling with ME/CFS. This is available from ME Connect, our telephone helpline, email, and social media private messaging service. It can be very helpful to speak with a trained member of the team at a time when you need it most and we can find the most relevant information for your situation. Opening hours and contact information for ME Connect is on the last page of this booklet.

Leaving a legacy helps us to keep our vital service running, helping those who need it most.

HOW THE ME ASSOCIATION HELPS PEOPLE WITH ME/CFS

You or a family member or friend may have been affected by ME/CFS, or you may have cared for a loved one affected by an ME/CFS diagnosis.

Whatever your connection, you'll know how much it can affect quality of life and turn someone's world upside down.

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 from the 2021 NICE Clinical Guideline on ME/CFS – the successful result of 14 years lobbying and hard work.

HEALTH AND 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.

Picture donated to our ***Real ME*** *photo library*

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.

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. Knowing that you are not alone can be a great comfort and we are happy to answer your questions and share helpful tips.

THE RAMSAY RESEARCH FUND

We invest only in biomedical research studies and infrastructure projects that will help lead to:

- a better understanding of underlying disease mechanisms
- the development of reliable diagnostic tests for use in clinics
- safe and effective forms of treatment

ME/CFS is a complex illness with symptoms that cut across several medical boundaries – genetics, endocrinology, immunology, muscle pathology, and neurology in particular – so research into the underlying cause of ME/CFS. is rather like piecing together a complex medical jigsaw puzzle.

We actively seek researchers who will examine these disease mechanisms. This must be our top priority if we are to obtain a better understanding of this disease and discover effective forms of treatment.

Research must be our top priority if we are to obtain a better understanding of this disease and discover effective forms of treatment

Medical research is very expensive – and finding the underlying cause and effective treatment isn't going to be easy. But that is not going to stop us trying.

Legacies give us greater freedom to seize opportunities as they arise – and you can be assured that all donations to the Ramsay Research Fund are spent on research – with no deductions for administration or other charity expenses.

OUR ONGOING COMMITMENT

We work hard to support people with ME/CFS., but the disease remains little known and understood.

Legacy income gives us the ability to extend our activities and improve recognition and acceptance. For example:

It helps us provide support to those affected by the disease when they need it most. ME Connect, our telephone helpline, has been established for over ten years, and has received more then 35,000 calls. Callers can speak to a fully-trained volunteer, in confidence, about anything that might be troubling them. This disease can be very isolating, and ME Connect serves as a vital lifeline for many.

DIAGNOSIS OF ME/CFS

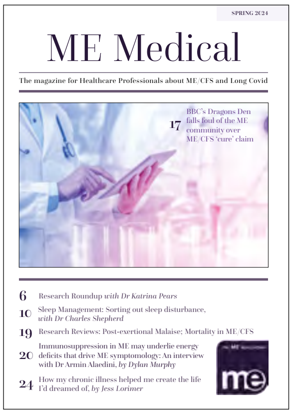
THE IMPORTANCE OF HAVING AN
EARLY AND ACCURATE DIAGNOSIS

APRIL 2022

TEN KEY ASPECTS

THE TEN MOST IMPORTANT
FACTORS OF MANAGING
YOUR ME/CFS

NOVEMBER 2023



SPRING 2024

ME Medical

The magazine for Healthcare Professionals about ME/CFS and Long Covid

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ME Essential

FOR PEOPLE AFFECTED BY ME/CFS AND LONG COVID

NEWS: The BBC's DRAGONS DEN falls foul of the ME community over ME 'cure' claim

CHARITY NEWS: Hilary Briars retires as manager of ME Connect and we welcome our new manager, Katharine Leat

MEDICAL: Sleep Management and sorting out sleep disturbance, plus Ask the Doctor Q&As, with Dr Charles Shepherd

RESEARCH: The latest research and new MEA research reviews with Dr Katrina Pears

SCIENCE: An interview with Dr Armin Alaedini, by Dylan Murphy

LIFESTYLE: House hunting with ME/CFS, with the help of Kirsty and Phil on Channel 4's Location, Location, Location

REAL ME: Jess Lorimer's illness helped create the life she dreamed of

OUR ONGOING COMMITMENT

We are able to send delegates to key conferences in the UK and, on occasion, overseas to ensure our voice is heard and people with M.E. are represented. We are better able then to pursue campaigns that more effectively inform and lobby for example, NICE, the medical profession, and politicians.

We make available the most extensive, and updated, library of information offered by any charity, covering medical management, benefits and social care, diet and nutrition, and much more. All of the leaflets and books we produce are written by Dr Charles Shepherd and other qualified and knowledgeable advisers on our team.

We are very proud of our magazine, ME Essential, which keeps our members updated about developments in our community, as well as providing exclusive interviews and understandable research reviews.

Visit the Research section of the website for more information:

https://meassociation.org.uk/research

MAKING A WILL

While it is possible to prepare a Will yourself, it is always advisable to seek legal representation. A solicitor can help you decide how you would like to leave things in order to make the greatest difference.

Which is why we've partnered with specialists for our will writing offer - giving you the chance to write or amend your will for free.

The ME Association will cover the cost of writing or amending a simple single or mirror will. You will have an expertly written will at no cost to you. Through this process you are under no obligation to include the charity in your will. However, once you have provided for those closest to you, we hope you will take the opportunity to consider the ME community.

MAKING A WILL

We always recommend seeking professional legal advice when writing or updating your Will. There is no obligation to use either service or to leave a gift to The ME Association.
We're pleased to offer two free Will-writing services through our trusted partners.

Option 1 – Octopus Legacy - online, by phone or in person

Octopus Legacy lets you create a simple Will online, by phone or in person (including at home or as an urgent 48hr service), completely free of charge. Their legal team at Octopus Legal Services (SRA No. 8007668), regulated by the Solicitors Regulation Authority, will review your Will before it's sent to you for signing. Update services are also available to keep your Will current.

Get started at our dedicated portal: **will.octopuslegacy.com/me**
You can save your progress and return at any time.
Prefer to talk? Call Octopus Legacy on **020 4525 3605**
and quote The ME Association.

Option 2 – National Free Wills Network *(with a local solicitor)*

Prefer to write your Will face to face? Through our membership of the National Free Wills Network (NFWN), you can have a Will written or updated free of charge with a local solicitor.

Simply complete the enquiry form at **https://myfreewillsportal.org/MEAssociation** and an information pack will be sent to you.

If you'd like to leave a gift to The ME Association, your Will writer may ask for our details:

Registered office: 7 Apollo Office Court, Radclive Road,
Gawcott, Buckingham MK18 4DF
Charity number: 801279 (England and Wales)

Have a question or want to let us know about a gift you've pledged? Contact our Trusts and Legacy Manager,
Sarah Harper, at **legacies@meassociation.org.uk**
or call directly on **07701 223722**.

> *Leaving a legacy to the ME Association means that we can continue with our work, helping others, and investing in biomedical research to pursue effective treatments and a cure*

THE ME ASSOCIATION

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

Freephone

0808 801 0484

For opening hours visit:
meassociation.org.uk/me-connect

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!

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meassociation.org.uk