

THE ME ASSOCIATION

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MORTALITY IN ME/CFS

Research Review



NOVEMBER
2023



Mortality in ME/CFS was written by **Dr Katrina Pears**, Research Correspondent for the ME Association.

Katrina became the charity's Research Correspondent in 2021 and produces the weekly research update, research reviews, conference reports, and other related content.



INTRODUCTION

In May 2023, the ME Association requested the latest mortality data from the Office for National Statistics (ONS) and discovered that between 2001 and 2021, 150 deaths in England and Wales were partly or fully attributable to ME/CFS.

ONS Data: <https://tinyurl.com/mtpuxzxa>

It's a sobering topic, but it is important that we review and consider the latest data and consider what might be the leading causes of death for people with this long-term disability.

ME/CFS is rarely cited when compared to other causes of death in the UK. However, some aspects of ME/CFS can potentially make it become a life shortening illness.

- McManimen *et al.*, 2016: <https://tinyurl.com/mwcrpstu>
- Kingdon *et al.*, 2020: <https://tinyurl.com/ms8yerdj>

ONS data has revealed that 88 deaths between 2001 and 2016, and 62 deaths between 2017 and 2021, were partly or fully attributable to ME/CFS. This is a significant increase in the rate of deaths (an increase from 5.5 deaths per year to 12.4 deaths per year) in the 2 respective periods. Across the 20 year period, there were 7.5 deaths per year on average.

We don't have any evidence that the mortality rate – the number of people dying from ME/ CFS per year – has increased between the time periods, but the data may well reflect a greater awareness of ME/CFS in recent years and of its potentially life-threatening complications.

However, there is a need for better data before we can reach any firm conclusions.

It is often reported that the first official recorded death from ME/CFS was that of 32-year old, Sophia Mirza in 2005. However, these data record 9 deaths partly or fully attributed to ME/CFS between 2001 and 2004.

Malnutrition is the most serious life-threatening complication in those with ME/CFS, especially in very severe cases. Individuals can become unable to swallow or digest food and don't get adequate nutrition or hydration. In these instances, tube-feeding, and IV fluids are required, although unfortunately these measures may not prevent death.



Along with the recent call we have made to the Department for Health and Social Care for better epidemiological studies into ME/CFS, there is also a need for more reliable studies into mortality.



MORTALITY RESEARCH

The few studies exploring mortality in ME/CFS reveal conflicting information.

Although a study in 2006 reported that ME/CFS was not associated with an increase in mortality from any cause, including suicide, a more recent study reported that although the overall risk of death in ME/CFS was no different from that in the general population, there was a substantial (seven-fold) increase in the risk of suicide.

■ Smith *et al.*, 2006: <https://tinyurl.com/549bdr4r>

■ Roberts *et al.*, 2016: <https://tinyurl.com/bdh3a7bp>

Other studies have claimed a higher risk of death from heart failure, cancer, and suicide in ME/CFS, and similar findings were reported by **Jason *et al.*** in 2007 who said that heart failure, suicide and cancer accounted for 59.6% of all deaths in ME/CFS.

■ McManimen *et al.*, 2016: <https://tinyurl.com/mwcrpptu>

■ Jason *et al.*, 2007: <https://tinyurl.com/5aczs2b8>

Caution needs to be applied here, as these studies only involved small cohorts of people with ME/CFS which reduces the reliability of the conclusions – especially when trying to apply them to larger populations.

Along with the recent call we have made to the Department for Health and Social Care for better epidemiological studies into ME/CFS, there is also a need for more reliable studies into mortality. Only then will we better understand the possible risks that people with ME/CFS might face and determine the best approach to clinical care to prevent premature death.

POST-MORTEM RESEARCH

As well as helping us understand more about the cause of ME/CFS, post-mortem research could help to shed further light on mortality.

■ Donovan *et al.*, 2010: <https://tinyurl.com/aafac73e>

In 2010, it was determined that a post-mortem tissue bank was feasible in the UK, but plans were put on indefinite hold because of the significant costs involved.

■ Lacerda *et al.*, 2010: <https://tinyurl.com/y4exmbp3>

The ME Association and UK ME/CFS Biobank team were involved in these developments, and the charity has just announced a post-mortem arrangement with the Manchester Brain Bank.

We have initially funded post-mortem examinations on 5 consenting individuals with ME/CFS and will consider extending this project in the future. There is certainly a case for post-mortem research extending across Europe.

■ The ME Association announces new post-mortem research partnership with Manchester Brain Bank | 19 October 2023:

<https://tinyurl.com/yc2yb2ww>

ME ASSOCIATION COMMENT



In our current state of knowledge, it's impossible to draw any firm conclusions as to whether people with ME/CFS have a reduced life expectancy.

There are a small

number of very specific circumstances where life expectancy is reduced

as a result of having ME/CFS – suicide and malnutrition being 2 important examples.

There are also components of the underlying disease process, and the way that ME/CFS affects everyday life, that could be having a negative impact on life expectancy. Examples being low level inflammation, inability to carry out regular aerobic exercise, and weight-gain.

On the other hand, there are aspects of ME/CFS that could actually help to increase life expectancy. Examples here include low blood pressure, not smoking or drinking alcohol, and having a healthier diet.

Overall, life expectancy is going to be a complex puzzle to unravel, and we won't be able to reach any decisions without further high quality epidemiological research and better information from death certificates on people with ME/CFS who have sadly died.

In response to questions that arise about life insurance policies, the current MEA position is that there is no sound evidence to indicate that the underlying disease process in ME/CFS, and the consequences it may have on lifestyle, reduces overall life expectancy.

Dr Charles Shepherd, *Trustee & Hon. Medical Adviser, to the ME Association*





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THE DATA

■ Between 2001 and 2021, 150 deaths in England and Wales were partly or fully attributed to ME/CFS. This can be broken down into 88 deaths between 2001 and 2016, and 62 deaths between 2017 and 2021.

YEAR	Office for National Statistics: Mentions of Post-viral Fatigue Syndrome (benign myalgic encephalomyelitis), deaths registered in England and Wales.
2001	2
2002	2
2003	3
2004	2
2005	1
2006	5
2007	2
2008	4
2009	4
2010	10
2011	6
2012	15
2013	8
2014	6
2015	7
2016	11
2017	7
2018	14
2019	15
2020	9
2021	17

■ ONS Mortality Data (2001-2016): <https://tinyurl.com/28rk22yx>

■ ONS Mortality Data (2017-2021): <https://tinyurl.com/mtpuxzxa>



“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.”



HOW WE CAN HELP

■ **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.

■ **MEMBERSHIP:** We put the interests of members at the heart of everything we do. We will provide you with a regular ME Essential magazine which is simply the best magazine available. It will keep you informed of developments, it shares personal stories and the latest medical information, with an Ask the Doctor feature in every issue.

To become a member, please click the following link:

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

■ **SUPPORT:** Support 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. We can find the most relevant information for your situation and we are available 365 days a year.

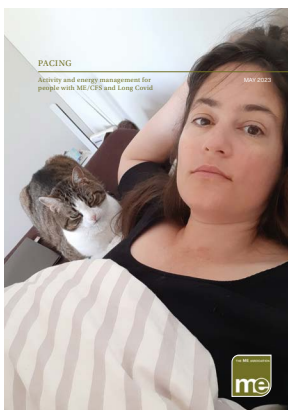
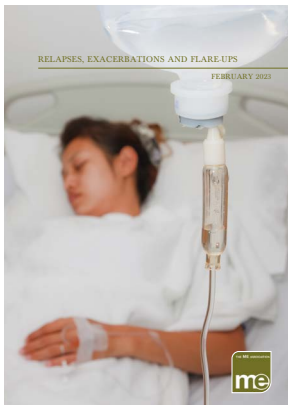
■ **INFORMATION:** We produce reliable and timely information written by topic experts and have the largest range of literature covering all aspects of life with ME/CFS and Long Covid. We can show you how to recognise and manage symptoms, to get an accurate diagnosis, a referral to specialists, and to 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 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 and the Manchester Brain Bank.

■ **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.

■ **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

“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.”



HOW WE CAN HELP

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.

THE ME ASSOCIATION LITERATURE

The ME Association has the largest selection of literature on ME/CFS and Long Covid in the UK. We cover:

- Awareness and Fundraising
- Benefits
- Carers and Social Care
- Diagnosis
- Diet and Nutrition
- Education and Employment
- Insurance and Travel
- Medical Management
- Mental Health
- Symptoms
- Template letters
- Vitamins and Supplements

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



ME CONNECT

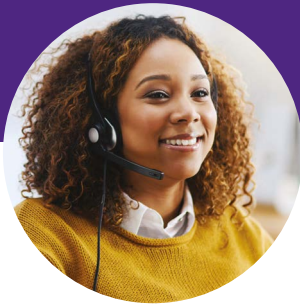
The Support and
Information Service for
people affected by
ME/CFS/PVFS
and Long Covid



Freephone 0808 801 0484

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

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!



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