Prevalence

ME/CFS in the UK

Including:

Latest research and historic estimates

Establishing how many people have ME/CFS in the UK

Determining how many people have Covid-19 ME/CFS in the UK

SEPTEMBER
2025

PREVALENCE

PREVALENCE was written by **Russell Fleming**, Head of Project Development at The ME Association.

Latest research suggests a 62% increase on historic estimates for ME/CFS in the UK.

The ME Association has reached agreement with Action for ME that we will each adopt the latest research evidence from Professor Chris Ponting and Gemma Samms at the University of Edinburgh.

This suggests that 403,922 or 0.6% of adults and children in the UK would have a lifetime prevalence of ME/CFS (a 62% increase from historic estimates of 250,000), if there were minimal social and healthcare barriers to a diagnosis.

We have also agreed that we will use a figure of 950,000 (or 1.4%) as an estimate of adults and children in the UK who experienced an infectious trigger of Covid-19 and could meet the diagnostic criteria for ME/CFS (NICE Guideline NG206). This is based on 2023 estimates from the Office for National Statistics (ONS) and will be updated when more evidence becomes available.

Therefore, we feel the estimated prevalence of people with a potential diagnosis of ME/CFS could be as high as 1.35million in the UK (1.14million in England, 38,000 in Northern Ireland, 109,000 in Scotland, and 63,000 in Wales), representing a considerable health burden on the NHS and social care services and reinforcing the need for good quality care and support.

GEOGRAPHIC BREAKDOWN

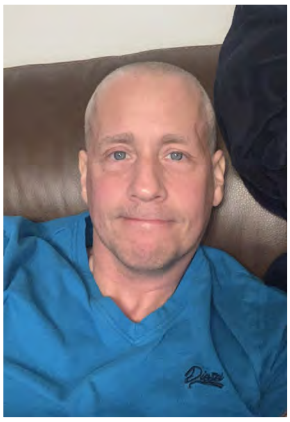
	ME/CFS	Covid-19 ME/CFS	Combined Total
England	341,354	802,845	1,144,199
Northern Ireland	11,350	26,695	38,045
Scotland	32,475	76,380	108,855
Wales	18,742	44,080	62,822
United Kingdom	**403,922**	**950,000**	**1,353,922**

1. ME/CFS: Using the 403,922 UK prevalence for ME/CFS (see Ponting and Samms research below)

2. Covid-19 ME/CFS: ONS Data (March 2023 below) and assuming 50% of 1.9M (950,000) meet criteria

3. Population: ONS UK Population estimates by country (Mid-2023), Table 1 from **ons.gov.uk**: **https://tinyurl.com/mr3ajvzh**

ESTABLISHING AN ESTIMATE OF PEOPLE WITH ME/CFS



Historically, making an accurate diagnosis has been hampered by the lack of a diagnostic test and varying degrees of medical uncertainty which has led to uneven rates of diagnosis across the country.

We don't know precisely how many people are affected by ME/CFS in the UK today.

Not everyone receives the correct diagnostic code on their medical records for example and, despite many parliamentary questions over the years to the Department of Health and Social Care, NHS England and other health authorities have failed to have failed to inject any notes of precision into this exercise.

Historically, making an accurate diagnosis has been hampered by the lack of a diagnostic test and varying degrees of medical uncertainty which has led to uneven rates of diagnosis across the country.

It is very likely that there are more people who are symptomatic but have not received a diagnosis, particularly in respect of other-than-white populations, people who live in deprived areas of the country, those who are misdiagnosed, and those who are missed altogether.

We can only make an estimate of the likely numbers affected based on good-quality epidemiological research. This was provided in April 2025 by **Professor Chris Ponting and Gemma Samms (DecodeME)**[1] from the **University of Edinburgh**[2], in a study that was funded by **ME Research UK**[3].

The new study was titled: **Unequal access to diagnosis of myalgic encephalomyelitis in England**, BMC Public Health, 2025[4]:

The research examined hospital admission and outpatient appointments in England from April 1989 to October 2023. The total dataset was for 62,782,175 individuals.

Ponting and Samms then reviewed entries for people with the G93.3 (Postviral Fatigue Syndrome (PVFS) International Classification of Diseases (ICD-10) diagnostic code on their hospital records. They concluded that there was a prevalence of 0.16%.

https://tinyurl.com/mvrxtxdm

References:

(1.) https://www.decodeme.org.uk
(2) https://tinyurl.com/7hfdee5m
(3) https://www.meresearch.org.uk
(4) https://tinyurl.com/2m6r3kp2

ESTABLISHING AN ESTIMATE OF PEOPLE WITH ME/CFS

This code was used because it was the most relevant ICD-10 code for ME/CFS, and research conducted using data from the UK Biobank had suggested that 72% of those with a G93.3 code on their records had further evidence of ME/CFS.

> ■ The ICD provides coding for every known disease and the NHS bases in its own diagnostic coding system – SNOMED-CT – on it. PVFS was listed in ICD-10 as a parent term under 'other disorders of the brain' i.e., a neurological disease, and featured 'benign myalgic encephalomyelitis' as the only entry.
>
> **https://meassociation.org.uk/efnn**

It is important to note that if an individual was diagnosed in primary care by a GP and the same code was not used or reported at a hospital outpatient appointment or admission, then they would not have been picked up by this research.

When examining UK Biobank data, the researchers found that only 28% of those with a GP code on their medical records also had a code for ICD-10 G93.3. It is hard to quantify how much this might affect the results, but it could mean a significant underestimate.

Ponting and Samms tried to adjust for this likelihood, while accounting for the significant variation in diagnoses across different groups (ethnicity, location, and age). They estimated the number of people in the UK who would have a diagnosis and a recorded code (i.e., G93.3) if there was minimal social and healthcare barriers to a diagnosis, and for this they used the data from the Cornwall and Isles of Scilly Integrated Care Board.

Cornwall and the Isles of Scilly had recorded the oldest population of people with ME/CFS, the highest recorded number with a diagnosis, the highest female-to-male ratio and the lowest other-than-white population. The maximal prevalence for white females and males was 0.92% and 0.25% respectively.

Ponting and Samms commented that, even if some of the 403,922 people did not meet a strict case definition for ME/CFS, this would likely be offset by those diagnosed by GPs in the NHS or privately who did not have the G93.3 coding, and those who did not have a likely infectious onset to ME/CFS.

Cornwall and the Isles of Scilly had recorded the oldest population of people with ME/CFS, the highest recorded number with a diagnosis, the highest female-to-male ratio and the lowest other-than-white population.

ESTABLISHING AN ESTIMATE OF PEOPLE WITH COVID-19 ME/CFS

Attempts to determine how many people have ME/CFS became more complicated during and after the pandemic and through the predictable emergence of Long Covid.

A significant proportion of those unable to recover from a Covid-19 infection are likely to meet the diagnostic criteria for ME/CFS. Indeed, more people are now likely to be receiving an ME/CFS diagnosis than Long Covid.

Since testing for Covid-19 was terminated, we have seen referrals to Long Covid clinics fall quite dramatically in some areas while referrals to ME/CFS services have risen, leading to longer wait times.

Long Covid clinics have also been closed which has left ME/CFS services as the only viable specialist referral option, although in some areas of England, and especially in Wales, new 'Post-Viral' specialist services have or are being commissioned that will accept referrals for both.

The research from Ponting and Samms did not consider the impact of Covid-19 on the number of people diagnosed with ME/CFS. Their estimates were based on those with a recorded code of G93.3 (Postviral Fatigue Syndrome) recorded at hospital admission or in their outpatient records up to October 2023. It may well also have picked up some people whose trigger was Covid-19, but we don't really know.

We have agreed to use a figure of 950,000 to account for the research from America (below) that has suggested between 40-60% of people with 'Long Covid' could meet the diagnostic criteria for ME/CFS i.e., they have all the relevant symptoms including post-exertional malaise and no organ damage that has resulted from a Covid-19 infection.

A significant proportion of those unable to recover from a Covid-19 infection are likely to meet the diagnostic criteria for ME/CFS. Indeed, more people are now likely to be receiving an ME/CFS diagnosis than Long Covid.

- Bonilla *et al*. ME/CFS is common in post-acute sequelae of SARS-CoV-2 infection (PASC): Results from a post-COVID-19 multidisciplinary clinic | February 2023

  https://tinyurl.com/mu55d3r5

- Jason *et al*. ME/CFS and Post-Exertional Malaise among Patients with Long COVID | December 2022

  https://tinyurl.com/3msbxbec

ESTABLISHING AN ESTIMATE OF PEOPLE WITH COVID-19 ME/CFS

Prevalence estimates for Long Covid in the UK come from data published by the Office for National Statistics (ONS), although these estimates were based on self-reported Long Covid and not a clinical diagnosis and so we have treated them with caution.

- In England and Scotland, an estimated 3.3% (2 million people) were experiencing self-reported Long Covid (symptoms persisting beyond 4 weeks after an infection). This is based on data released in April 2024. 1.5million people (75%) experienced symptoms that adversely affected daily activities, with 381,000 (19.2%) reporting their ability to undertake daily activities had been ‘limited a lot’.

An earlier data release in March 2023 revealed that 2.9% of the UK population (1.9million people) were self-reporting Long Covid, with symptoms adversely affecting the daily activities of 1.5million (79%) and 381,000 (20%) reporting activities had been ‘limited a lot’.

The estimate we are using is based on this earlier data. We have, therefore, concluded that around 50% of 1.9million people i.e., 950,000 with Long Covid could meet a clinical diagnosis (NICE) of ME/CFS.
We will revise these estimates when more reliable research evidence becomes available.

- ONS: Self-reported coronavirus (COVID-19) infections and associated symptoms, England and Scotland: November 2023 to March 2024.

  https://tinyurl.com/srk58yda

- ONS: Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: 30 March 2023.

  https://tinyurl.com/3cj8k7fa

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MORE INFORMATION

- We will be updating the MEA website and related MEA literature with these newly agreed estimates as soon as possible.

- We have published a booklet: Long Covid and ME/CFS: Are they the same condition? Available to download for free from the website:

https://meassociation.org.uk/vqei

- Our updated leaflet, Prognosis, Permanency and Quality of Life, is now available free from the website:

https://meassociation.org.uk/s9by

- The NICE Guideline on ME/CFS (NG206) is a comprehensive set of clinical recommendations that we would strongly suggest both carers and patients read to better understand what can be expected from the NHS and social care services. They also teach us more about the process of obtaining a diagnosis and how specialist services can provide help and support.

https://www.nice.org.uk/guidance/ng206

- The NICE Rapid Guideline on Long Covid (NG188) is available but is incomplete. Unlike their Guideline on ME/CFS, it hasn't yet been published as a full guideline because the evidence-base is still being established. It was last updated in January 2024.

https://www.nice.org.uk/guidance/ng188


LONG COVID AND ME/CFS

Are they the same condition?

MAY 2023

The NICE Guideline on ME/CFS (NG206) is a comprehensive set of clinical recommendations that we would strongly suggest both carers and patients read.


PROGNOSIS, PERMANENCY AND QUALITY OF LIFE IN ME/CFS

What to expect following a diagnosis of ME/CFS in terms of disability, improvement, recovery, and quality of life

Including:
Prevalence
Prognosis: Chance for improvement or recovery
Fluctuation and symptom severity
What factors can influence prognosis?
Research into prognosis
Quality of life
Mental health
Permanent ill-health

JULY 2025

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 free literature covering all aspects of life with ME/CFS and Long Covid**. We can show you how to recognise and manage symptoms, 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.


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ME Essential

FOR PEOPLE AFFECTED BY ME/CFS AND LONG COVID

LIVES WE CANNOT LIVE: A photographic exhibition by Jeremy Jeffs, presented by the MEA.

LIFESTYLE: How journalling can empower your path with ME.

FUNDRAISING: Marathon runs, concerts and more, all for the MEA.

THE LAST WORD: Poetry, prose and painting by Sarah Charters.

CHARITY NEWS: Neil Riley, Chairman of the MEA, resigns; MEA invests in Canadian drugs trial for ME/CFS and Long Covid.

NEWS & RESEARCH: The search for a blood-based biomarker for ME/CFS.

MANAGEMENT FILE: Orthostatic intolerance and orthostatic hypotension.

ASK THE DOCTOR: Dr Charles Shepherd answers your questions.

HEALTH: Cystoscopy experience.

"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."


SUMMER 2025

ME Medical

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

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30 Lives We Cannot Live: *A photographic exhibition by Jeremy Jeffs, presented by the ME Association*

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 Guideline 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**.

ME Connect

The Support and Information Service

FREEPHONE 0800 NUMBER AND FULL TIME HOURS... OPEN 365 DAYS A YEAR INCLUDING WEEKENDS AND BANK HOLIDAYS

- 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

> *"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."*

MEDICAL MATTERS WITH DR CHARLES SHEPHERD

2025 NCVO MEMBER

Registered with FUNDRAISING REGULATOR

THE **ME** ASSOCIATION

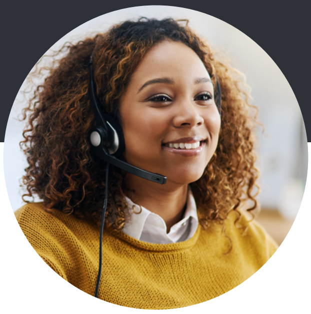
ME CONNECT

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

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!

✉ meconnect@meassociation.org.uk

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meassociation.org.uk