

# Women more severely affected by ME/CFS, study shows

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Women with ME/CFS tend to have more symptoms and co-occurring conditions than men, according to initial results from the world's largest study of the disease. It has long been known that women are more likely

to have ME/CFS (myalgic encephalomyelitis/chronic fatigue syndrome) but the DecodeME study has shown for the first time how their experience differs from men.

The study reveals that women who have had ME/CFS—a long-term neurological condition where an excessive increase in symptoms can be triggered by normal levels of exertion—for more than 10 years are more likely to experience increasingly [severe symptoms](#) as they age. The initial results from the study are published in *NIHR Open Research*.

Experts say that gaining a better understanding of how ME/CFS affects people is the first step to developing effective treatment options.

To aid their efforts, the study team from the University of Edinburgh are calling on more people with ME/CFS, aged 16 and over and based in the UK to take part in the study.

Experts analyzed anonymous survey questionnaires from more than 17,000 people with ME/CFS. They included information on how long the respondent has had ME/CFS symptoms, when they were diagnosed, and whether they had any co-occurring conditions.

The study confirmed the well-established sex bias among ME/CFS patients, with women making up 83.5% of respondents.

Two-thirds (66.7%) of women, and slightly more than half (52.7%) of men, reported at least one active co-occurring condition. Similarly, 39.2% of women and 28.6% of men reported at least one inactive co-occurring condition.

A condition was considered active if the participant had experienced symptoms in the preceding six months.

The most common active co-occurring condition was [irritable bowel syndrome](#) (41.3%), with [clinical depression](#) (32.4%), fibromyalgia (29.5%), anemia (14.1%) and hypothyroidism (12.8%) also featuring prominently.

Women also reported, on average, more symptoms than men—42 compared with 36.

The most common of these symptoms were brain fog—a term commonly used to describe the cognitive impairment experienced by participants—unrefreshing sleep, and muscle pain.

Participants were also asked to define the severity of their illness from mild to very severe using definitions from the UK's National Institute for Health and Care Excellence (NICE) guidelines.

Experts identified that being a woman and having ME/CFS for more than 10 years are [risk factors](#) for severe illness, with symptoms increasing in intensity as they age.

To increase their understanding of the disease, the study team want to recruit a further 6,000 participants to the study. People with ME/CFS can sign up here: [www.decodeme.org.uk/portal/](http://www.decodeme.org.uk/portal/)

In the next stage of the project experts will study at least 20,000 individual DNA samples to explore whether the disease is partly genetic and, if so, research its cause.

ME/CFS is estimated to affect more than one quarter of a million people in the UK, of all ages and from all social and economic backgrounds.

Its key feature, called post-exertional malaise, is a delayed dramatic worsening of symptoms following minor physical effort. Other

symptoms include pain, brain fog and extreme energy limitation that does not improve with rest. Causes are unknown and there is currently no diagnostic test or cure.

As well as the University of Edinburgh, the study involves the charity Action for M.E., the Forward M.E. alliance of UK charities, and people who have experienced the condition.

Professor Chris Ponting, study lead from the MRC Human Genetics Unit at the University of Edinburgh's Institute of Genetics and Cancer, said, "ME/CFS is a devastating disease affecting a UK population the size of Derby. We discovered that the disease is worse for women, in [older people](#), and many years after their ME/CFS started. Our hope is that DecodeME's genetic results will shed light on why certain groups are more susceptible to ME/CFS than others."

Sonya Chowdhury, Chief Executive of Action for M.E. and Chair of the Management Group of the study, added, "These findings highlight the very serious impact ME/CFS has on women who are disproportionately affected. It's important to also recognize the impact that it has on men who have ME/CFS, and we thank the 20,000 men and [women](#) who have already signed up to take part in this very important study."

"But we still need more to join us so if you are 16 or older, live in the UK and have a diagnosis of ME/CFS, please do take part now to help us decode ME at [www.decode-me.org.uk/portal](http://www.decode-me.org.uk/portal) ."

**More information:** Andrew D. Bretherick et al, Typing myalgic encephalomyelitis by infection at onset: A DecodeME study, *NIHR Open Research* (2023). [DOI: 10.3310/nihropenres.13421.4](https://doi.org/10.3310/nihropenres.13421.4)

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