ME and higher education

Updated: April 2025

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What is ME?

Myalgic Encephalomyelitis (ME), sometimes referred to and diagnosed as Chronic Fatigue Syndrome (CFS), is a chronic, fluctuating disease, causing symptoms such as post-exertional malaise (PEM), sleep problems, problems with thinking and memory (brain fog), pain and crushing fatigue.

PEM is the hallmark symptom of ME and is the body and brains inability to recover after expending even small amounts of energy. PEM can also lead to an increase in other symptoms. The impact of this may be felt straightaway but it can typically take a day or two to kick in and is not significantly improved by resting.

Latest research estimates that 404,000 people in the UK have ME/CFS.

Further research estimates around 50% of the 1.9 million people in the UK with long Covid are also thought to have symptoms that are very similar to ME, including post-exertional malaise, the hallmark symptom of ME.

Therefore, we estimate there are up to 1.3 million people in the UK with ME or ME-like symptoms.

It is difficult to know exactly how many people have ME. The figures vary greatly due to issues such as underdiagnosis and lack of access to diagnosis.

There is also uncertainty about how many people with long Covid have symptoms that could be classed as ME. Studies have reported different figures. Some of these studies were small, did not include people from a wide range of backgrounds, used different definitions of ME, or did not clearly include post-exertional malaise.

Sadly the majority of people with ME remain ill for decades. A small proportion do recover fully, and others to a degree, however it is not clear why this happens.

More research and improvements in diagnosis and recording are needed to fully understand how many people have ME.

ME symptoms

While there are key symptoms that must be present for an ME diagnosis, not everyone with ME experiences the same set of symptoms and the illness can vary enormously, including how long symptoms last.

ME is not “feeling tired”.

Women often find that symptoms worsen at different times in their menstrual cycle.

Along with PEM, people with ME may experience the following symptoms:

Debilitating fatigue

- very different from ordinary tiredness
- persistent, overwhelming tiredness, experienced as physical and mental exhaustion
- not significantly improved by resting.

Feeling generally unwell

- having flu-like symptoms (‘general malaise’)
- recurrent sore throat, with or without swollen glands

Pain

- aching muscles or joints
- nerve pains or pins and needles
- headache or migraine
- twitching muscles or cramps
- abdominal pain (stomach or bowel problems)

Sleep disturbance

- unrefreshing sleep
- difficulty getting off to sleep
- waking for long periods in the early hours
- light, dreamy, restless sleep
- sleep reversal (e.g. sleeping from 4am till midday)
- hypersomnia (sleeping for a long time)

Concentration, thinking, and memory (often described as “brain fog”)

- reduced attention span
- short-term memory problems
- word-finding difficulties
- inability to plan or organise thoughts
- loss of concentration

Problems with the nervous system

- poor temperature control
- orthostatic intolerance (symptoms when standing upright which are relieved when reclining)
- hypersensitivity to light and sound
- sweating
- loss of balance

Digestive problems (including IBS)

- nausea
- loss of appetite
- indigestion
- excessive wind/bloating
- cramps
- alternating diarrhoea and constipation

Intolerance and increased sensitivity to

- bright lights
- noise
- odours
- some foods (e.g. diary or wheat)
- some medications
- alcohol
- other substances

Frustration, anxiety, low mood, and depression are sometimes experienced by people with ME as a consequence of having to cope with the impact of the condition and its symptoms.

This does not mean that ME is a mental health condition and it should not be treated as such.

Managing symptoms

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There are, however, a number of treatment approaches that some find help manage their symptoms.

For example, most respondents (88%) from our 2019 Big Survey reported that they had tried pacing, an energy management technique, in the past five years, with a further 70% said they use pacing to do what they feel able to within their manageable limit.

It should be remembered that treatment that helps one person might not work the same way for someone else. While advice from others with ME can be useful, it's important to only follow medical advice from qualified healthcare professionals.

Disability legislation and ME

ME is a long-term, fluctuating illness and symptoms can be very disabling.

The Equality Act 2010 defines disability as "a physical or mental impairment that has a substantial and long-term adverse effect on the ability to carry out normal day-to-day activities." **This includes ME**.

The Act makes it unlawful to discriminate against students with a disability. It means reasonable adjustments should be made to accommodate students with ME in all services which universities supply, from learning and assessment to all aspects of student support.

Disability Student Allowance (DSA) can be used to help pay for the costs of specialist equipment related to ME. Amounts received depend on your individual needs - not your household income - and it doesn't need to be paid back. See www.gov.uk/disabled-students-allowances-dsas/ and useful contacts on the back page.

How might ME symptoms affect studying?

Presenting issue	**Potential solution**
Fluctuating levels of symptoms.	• establish a firm work/rest balance, using pacing techniques • take frequent rest breaks • student must avoid physically over-reaching themselves, but listed to their body and pace themselves • apply for DSA to purchase computer equipment that enables them to work at home and take frequent rest breaks.
Peaks and troughs of wellness/illness - appearing well one day and then absent the next due to PEM/symptoms.	• frequent rest breaks are especially important during setbacks • negotiate flexible or reduced attendance - or part-time study where possible.
Physical pain, including muscle ache - make it hard to concentrate for long periods in lectures or to undertake sustained periods of research for assignments.	• avoid temptation to try and catch up when feeling better - doing more will usually set them back. • request flexible and extended deadlines • DSA-paid mentor to help with work/life balance.
Low concentration levels and difficulty assimilating new information, especially over long periods without breaks.	• take frequent rests • study in short bursts interspersed with rests • DSA may provide digital recorder to aid memory recall of taught lessons.

Presenting issue	**Potential solution**
Poor immunity to infection - leading to more frequent and longer absences than is usual for other students	• explain their difficulties to their personal tutor or departmental disability representative • negotiate flexible/reduced attendance or part-time study where possible (part-time study may not be an option on all courses as there may be compulsory requirements and limits on time completion.
Maintaining a balanced diet can be expensive.	• eat a balanced, health diet • DSA may provide allowance to compensate for additional expense of high-quality food.
Hard to join in with general student activities, leading to isolation and little social life.	• student must avoid over-reaching themselves • be realistic and listen to their body • be selective with extra-curricular activities • in order to meet academic requirements many students with ME have a much-reduced social life, and/or seek low-energy alternatives to socialising in person.
Depression and anxiety, which many people with ME develop as a consequence of living with this complex illness.	• developing coping mechanisms to support dealing with stressful situations • seek professional counselling support for low mood and depressions, e.g. student counselling service.

What can departments do to help?

Be flexible with attendance requirements - offer reduced attendance or part-time study (people note, part-time study may not be an option on all courses as there may be compulsory requirements and limits on time completion).

Offer extended submission deadlines for assignments and projects.

Be aware that stress and anxiety can worsen symptoms.

Accept one GP’s letter to cover all ME-related absences.

Be flexible with examination requirements by offering:

- a separate room
- extra time
- rest breaks.

Timetable long gaps between exams to allow for time to pace revision sessions and also allow several rest days for recovery after long exams.

Consider what alternatives to exams might be compatible with the learning outcomes of the course e.g. offer additional coursework or longer written assignments/essays to replace exams, so that students can demonstrate their knowledge while being able to pace themselves and take adequate rests.

Useful contacts

Action for ME
Unit 2.2 Streamline, 436-441 Paintworks
Bristol, BS4 3AS
Tel: 0117 927 9551 (Mon to Fri 10am to 4pm)
Email: infosupport@actionforme.org.uk

Disability Student Helpline
Managed by Disability Rights UK, with information and support for students in England
Tel: 0330 995 0414 (11am to 1pm Tuesday and Thursday)
Email: students@disabilityrightsuk.org

Registered office:

Action for ME
Unit 2.2 Streamline
436-441 Paintworks
Bristol, BS4 3AS

Telephone: 0117 927 9551
Info & Support: infosupport@actionforme.org.uk
Fundraising: fundraising@actionforme.org.uk

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