



M.E./CFS and Higher Education

September 2020

We have produced this factsheet for students with M.E./CFS to share with support services and other staff at their college or university.

For more information and support, including speaking to one of our team about advocating for your rights, wishes, and reasonable adjustment, please call us on 0117 927 9551, email questions@actionforme.org.uk or visit www.actionforme.org.uk/students

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What is M.E.?

Myalgic Encephalomyelitis (M.E.) is a long-term (chronic), fluctuating, neurological condition that causes symptoms affecting many body systems, more commonly the nervous and immune systems. M.E. affects an estimated 250,000 people in the UK, and around 17 million people worldwide.

People with M.E. experience debilitating pain, fatigue and a range of other symptoms associated with **post-exertional malaise**, the body and brain's inability to recover after expending even small amounts of energy.

The causes of M.E. are still being investigated. Emerging evidence indicates that there are likely to be a number of factors involved and that there may be a number of different types or sub-groups of the illness.

There is evidence that certain infections can trigger the illness. Many are viruses but M.E. may be triggered in other ways.

Not everyone will experience the same symptoms so it's important not to compare someone who has M.E. to another person who has the illness. People with M.E. can vary enormously in their experience of the illness, and also how long their symptoms last. Some make good progress and may recover, while others can remain ill for a number of years and may not get better.

The National Institute for Health and Care Excellence (NICE) acknowledges that the physical symptoms of M.E. can be as disabling as multiple sclerosis, systemic lupus erythematosus, rheumatoid arthritis, congestive heart failure and other chronic conditions. Other research shows that people with M.E. score lower overall on health-related quality of life tests than most other chronic conditions (Hvidberg et al, 2015).

What are the symptoms?

Everyone who experiences M.E. has a different pattern of illness, and symptoms and severity can fluctuate and change over time. **M.E. is not "feeling tired."**

M.E. comes with a range of symptoms. Some people with M.E. may only experience a few of them and at varying levels of severity.

Simple physical or mental activities, or combinations of activities, can leave people with M.E. feeling utterly debilitated. They can also experience 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. This is a key feature of M.E., and is known as **post-exertional malaise** (sometimes called 'payback').

Along with post-exertional malaise, people with M.E. may experience the following:

Fatigue

- very different from ordinary tiredness
- simple physical or mental activities, or combinations of activities, can lead to struggling to function
- persistent and overwhelming tiredness, experienced as physical and mental exhaustion
- not significantly improved by resting

Feeling generally unwell

- having flu-like symptoms
- 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 (eg. 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
- dizziness on standing up
- orthostatic intolerance (symptoms when standing upright which are relieved when reclining)
- hyper-sensitivity to light and sound
- sweating
- loss of balance

Digestive problems (which can also be Irritable Bowel Syndrome)

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

Intolerance and increased sensitivity to

- bright lights
- noise
- odours
- some foods (eg. dairy or wheat)
- some medications
- alcohol
- other substances

Frustration, anxiety, low mood and depression are sometimes experienced by people with M.E. as a consequence of having to cope with the impact of the condition and its symptoms. This does not mean that M.E. is a mental health condition, and it should not be treated as such.

Managing symptoms

Because of the complexity of the illness, its fluctuating nature and the wide spectrum of symptoms, different things work for different people, and with different degrees of success.

While there is no single pharmacological cure for M.E., despite the efforts of dedicated scientists and clinicians around the world, there are a number of medications that may help with individual symptoms, such as pain, sleep and orthostatic intolerance. See www.actionforme.org.uk/medication

The symptom management approach that most people with M.E. report to be of benefit is pacing, a self-management technique that focuses on balancing activity and rest to keep symptoms within manageable levels.

Action for M.E.'s pacing booklet offers a step-by-step pacing guide plus daily and weekly planning, pacing versus real life, explaining M.E. and pacing to others, and managing stumbling blocks. See www.actionforme.org.uk/pacing

Disability legislation and M.E.

M.E. 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 M.E.

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

Disability Student Allowance can be used to help pay for the costs of specialist equipment related M.E. How much you get depends on your individual needs – not your household income – and it doesn't have to be paid back. See www.gov.uk/disabled-students-allowances-dsas and useful contacts on p 9.

How might M.E. symptoms affect studying?

Presenting issue	Potential solution
Fluctuating levels of symptoms.	<ul style="list-style-type: none"> • Establish a firm work/rest balance, using pacing techniques. • Take frequent rest breaks. • Student must avoid physically over-reaching themselves, but listen to their body and pace themselves, not push too hard. • Apply for Disabled Students' Allowance (DSA) to purchase computer equipment that enables them to work at home and take frequent rests.
Peaks and troughs of wellness/illness – appearing well one day and then absent the next due to drop in stamina.	<ul style="list-style-type: none"> • 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.	<ul style="list-style-type: none"> • Take frequent rest breaks and change sitting position if possible. • DSA may provide portable ergonomic cushion to reduce pain when seated. • DSA may also provide ergonomic seating for use at home to prolong ability to study there.
Problems completing work to deadlines due to constant need for rest and recovery.	<ul style="list-style-type: none"> • Avoid temptation to try to catch up when feel better – doing more will usually set them back • Request flexible and extended deadlines • DSA-paid mentor to help with work/life balance

How will M.E. symptoms affect studying? (continued)

Presenting issue	Potential solution
<p>Low concentration levels and difficulty assimilating new information, especially over long periods without breaks.</p>	<ul style="list-style-type: none"> • Take frequent rests. • Study in short bursts interspersed with rests. • DSA may provide digital recorder to aid memory recall of taught sessions.
<p>Poor immunity to infection – leading to more frequent and longer absences than is usual for other students.</p>	<ul style="list-style-type: none"> • 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).
<p>Maintaining a balanced diet can be expensive.</p>	<ul style="list-style-type: none"> • Eat a balanced healthy diet. • DSA may provide allowance to compensate for additional expense of high-quality food.
<p>Hard to join in with general student activities, leading to isolation and little social life.</p>	<ul style="list-style-type: none"> • 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 M.E. have a much-reduced social life, and/or seek low-energy alternatives to socialising in person.
<p>Depression and anxiety, which many people with M.E. develop as a consequence of living with this complex illness.</p>	<ul style="list-style-type: none"> • Develop coping mechanisms to support dealing with stressful situations. • Seek professional counselling support for low mood and depression, eg. student counselling service.

What can departments do to help?

Be flexible with attendance requirements – offer reduced attendance or part-time study (please 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 M.E./CFS-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 eg. 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 M.E.

42 Temple Street, Keynsham, BS31 1EH

Crisis, Support and Advocacy Service: 0117 927 9551

Email questions@actionforme.org.uk

www.actionforme.org.uk/students

Disabled 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

www.disabilityrightsuk.org/how-we-can-help/helplines/disabled-students-helpline

If you have found the information in this factsheet helpful, please consider making a donation to Action for M.E. at www.actionforme.org.uk or by calling 0117 927 9551. Thank you.



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