M.E./CFS and Higher Education

This factsheet is provided for students with M.E./CFS to share with the support services at their college or university.

More information and support for students, including advice on applying for university, coping with student life and benefits for students, can be found on our Student Hub at www.actionforme.org.uk/students

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What is M.E.?

Myalgic Encephalomyelitis (M.E.) is an illness with many names. Within the NHS it is commonly called Chronic Fatigue Syndrome (CFS or CFS/M.E.). Sometimes it is known as Myalgic Encephalopathy or diagnosed as Post Viral Fatigue Syndrome (PVFS).

M.E. is a long-term (chronic) fluctuating illness that causes symptoms affecting many body systems, more commonly the nervous and immune systems. There is as yet no cure.

Men, women and children of all ages and of all social and ethnic backgrounds can develop M.E., although it is most common in women aged 25-50. It is thought that around 250,000 people in the UK have the illness.

Levels of severity vary from mild to moderate and severe, and from person to person and over time. The NHS recognises that symptoms “can be as disabling as multiple sclerosis, systemic lupus erythematous, rheumatoid arthritis, congestive heart failure and other chronic conditions.”

Researchers don’t fully understand what causes M.E. but common triggers include viruses such as glandular fever or the Epstein-Barr virus (EBV). Other non-viral triggers have also been identified.
What are the symptoms?

Symptoms may include persistent exhaustion (‘fatigue’), muscle and/or joint pain, sleep disturbance, ‘flu-like symptoms such as headache, sore throat, painful lymph nodes, dizziness and/or nausea and problems with memory and concentration.

Worsening of symptoms following too much physical or mental exertion – with a delayed impact and a prolonged recovery period - is a prime feature of M.E., so pacing (balancing activity and rest) is important.

More information about symptoms:

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 (‘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 (eg. sleeping from 4am till midday)
- hypersomnia (sleeping for a long time)
Concentration, thinking and memory
- reduced attention span
- short-term memory problems
- word-finding difficulties
- inability to plan or organise thoughts
- loss of concentration

Any or all of the above are often described by people with M.E. as ‘brain fog.’

Mood
- frustration
- anxiety
- panic attacks
- low mood, depression
- mood swings and irritability

Problems with the nervous system
- poor temperature control
- dizziness on standing up
- 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
Disability legislation and M.E.

M.E. is a long-term fluctuating illness. The 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.”

‘Substantial’ means more than minor or trivial. ‘Impairment’ includes long-term and fluctuating conditions.

The Equality Act brings together a number of different equality laws including the Disability Discrimination Act and the Special Educational Needs and Disability Act (SENDA). The legislation 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.
### How might M.E. symptoms affect studying?

<table>
<thead>
<tr>
<th>Difficulty</th>
<th>Solution</th>
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<tbody>
<tr>
<td>• Fluctuating levels of fatigue</td>
<td>• Establish a firm work/rest balance</td>
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<td></td>
<td>• Take frequent rest breaks</td>
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<td>• Student must avoid physically over-reaching themselves, but listen to their body and pace themselves, not push too hard</td>
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<td>• Apply for Disabled Students’ Allowances (DSAs) to purchase computer equipment that enables them to work at home and take frequent rests</td>
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<td>• Peaks and troughs of wellness/illness – appearing well one day and then absent the next due to drop in stamina</td>
<td>• Frequent rest breaks are especially important during setbacks</td>
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<td>• Negotiate flexible or reduced attendance – or part-time study where possible.</td>
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<tr>
<td>• Physical pain, including muscle ache – make it hard to concentrate for long periods in lectures or to undertake sustained periods of research for assignments</td>
<td>• Take frequent rest breaks and change sitting position if possible</td>
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<td></td>
<td>• DSAs may provide portable ergonomic cushion to reduce pain when seated</td>
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<td>• DSAs may also provide ergonomic seating for use at home to prolong ability to study there</td>
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<td>• Problems completing work to deadlines due to constant need for rest and recovery</td>
<td>• Avoid temptation to try to catch up when feel better – doing more will usually set them back</td>
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<td>• Request flexible and extended deadlines</td>
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<td>• DSAs-paid mentor to help with work/life balance</td>
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How will M.E. symptoms affect studying? (continued)

<table>
<thead>
<tr>
<th>Difficulty</th>
<th>Solution</th>
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| Low concentration levels and difficulty assimilating new information especially over long periods without breaks | • Take frequent rests  
• Study in short bursts interspersed with rests  
• DSAs may provide digital recorder to aid memory recall of taught sessions |
| 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 and unsociable               | • Eat a balanced healthy diet – avoiding additives can help in some cases  
• DSAs may provide allowance to compensate for additional expense of high quality food |
| Hard to join in with general student activities – leading to isolation and no 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 M.E. have no social life at all |
| Depression and anxiety                                                    | • Try to avoid stressful situations  
• Seek professional counselling support for low mood and depression, e.g. 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.
The UK’s leading charity for people with M.E. and their carers
PO Box 2778, Bristol BS1 9DJ
General enquiries: 0845 123 2380 or 0117 927 9551 (Mon-Fri 9am-5pm)
Enquiries email: admin@actionforme.org.uk
Welfare Rights Line: 0845 122 8648 (times vary)
Online M.E. Centre: www.actionforme.org.uk

Association of Young People with M.E.
Information, advice and support for people with M.E. under 26 and their families
Tel: 0845 123 2389 (Mon-Fri 10am-2pm)
www.ayme.org.uk

Disabled Student Helpline
Now managed by Disability Rights UK, offering information and support
Tel: 0800 328 5050 (Tue 11.30am-1.30pm and Thu 1.30-3.30pm)
Email: students@disabilityrightsuk.org

National Institute for Health and Clinical Excellence
Guidance on M.E./CFS for healthcare professionals in England
www.nice.org.uk

NHS Scotland
Guidance on M.E. for healthcare professionals in England
www.show.scot.nhs.uk

Royal College of Paediatrics and Child Health
Guidance for healthcare professionals on M.E. in children and young people
www.rcpch.ac.uk

SKILL: National Bureau for Students with Disabilities
www.skill.org.uk

Universities and Colleges Admissions Service (UCAS)
Online information and video advice for students with disabilities
www.ucas.ac.uk/students/wheretostart/disabledstudents

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 0845 123 2380 or 0117 927 9551. Thank you.
Acknowledgements

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- students with M.E.
- representatives from SKILL www.skill.org.uk
- the National Union of Students www.nus.org.uk/en/Campaigns/Disability
- University of St Andrews www.st-andrews.ac.uk
- the Association of Young People with M.E. www.ayme.org.uk

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