TO WHOM IT MAY CONCERN

This letter contains information on exam procedures that relate to both a candidate with ME/CFS and the centre organising the exam.

Examinations and ME/CFS



Sitting a school, college or professional examination may well present a number of problems for someone who has ME/CFS and feels that they are well enough to attempt to do so.

Consideration will therefore need to be given by examination authorities to the person's current level of ill health and disability and, where possible or appropriate, to how various aspects of the exam procedure may need to be modified.

The information below is designed to assist officials at schools, colleges and other organisations who have to deal with students, or people taking exams, who have disabilities or problems resulting from ill health. Inclusion of both disability and ill health is important in relation to ME/CFS because people with this illness are likely to have a combination of problems linked to their disability (eg mobility difficulties) and their ill health (eg feeling flu-like or experiencing pain).

In the case of school exams, officials should already have copies of the relevant guidance booklets – eg Assessment Arrangements for KS1, KS2 and KS3, Candidates with Special Assessment Needs: Special Arrangements and Special Consideration – that cover tests and exams up to A-level.

Further information on these publications can be found in the leaflet produced by The Young ME Sufferers (Tymes) Trust. Other sources of information are listed at the end.

BACKGROUND INFORMATION ON ME/CFS

ME/CFS can cause a wide range of symptoms which result in both ill health and disability. Symptoms that are likely to be relevant to exam procedures include:

- Physical fatiguability
- Mobility and balance problems
- Orthostatic intolerance (ie difficulty in carrying out tasks which involve prolonged standing) and postural hypotension (which may result in feeling faint on standing)
- Cognitive dysfunction –
 particularly involving short-term
 memory, concentration,
 attention span, information
 processing
- Pain which can affect muscles, joints or nerves
- Problems with temperature control (thermoregulation) – including sensitivity to both the cold and excessive heat

 Variability and fluctuation of symptoms

Being aware in advance of any symptoms or disabilities that are likely to cause significant problems during an exam should help those in charge to make adjustments that are either necessary or appropriate in the circumstances. Officials and those taking the exams should therefore liaise with each other well before the exam is due to take place. A letter from the candidate's own doctor, detailing any specific difficulties and requirements, will also be helpful for the examination authority.

For more about symptoms, see section 6:4 of *ME/CFS/PVFS*: *An Exploration of the Key Clinical Issues*, available only from The MEA.

SPECIFIC ISSUES

Examination Centres

Schools and colleges normally have an examination officer, who may or may not be a teacher. Their job is to enter students for exams and deal with any problems connected to disability or ill health. They can deal with some types of concessions, including allowing extra time, rest breaks and having a separate room.

Permission for other types of concessions such as taking an exam at home, using a computer or scribe/ reader may have to be referred to the Examining Board that awards the certificate or degree. An approach to the examinations officer needs to be made as soon as possible because there are normally specific deadlines a few months before the exam for applying for these concessions.

With exams being a very stressful part of student life, it's better to have any concessions that may be required to be approved and in place – even though they may not be needed on the actual day.

Keeping a note of all written/ telephone communications and copies of any correspondence is essential.

Venue and time of exam

Consideration should be given to both the time the exam takes place and the location of the exam.

People with ME/CFS often experience a considerable degree of fluctuation in symptoms throughout the day (even from hour to hour) and consequently find that they are able to function better at certain times (eg midmorning; early afternoon) of the day.

Being able to sit an exam at a time of day when they are more likely to function at their best would obviously be helpful if this can be arranged.

Changing the actual day when an exam takes place will be more difficult to achieve.

Taking the exam at home is an option that will have to be considered for students who do not normally attend school, or have great difficulty in doing so. Exam-type conditions will have to be established at home and an invigilator will need to be present for the duration of the exam.

Travel

People with ME/CFS find that they have strictly limited amounts of physical and mental energy. Once this is used up, they require a period of rest/relaxation before starting again on a new task or returning to an existing task.

Travel, especially that which is prolonged and/or involves public transport at busy times of the day, is likely to be tiring. So arranging to sit an exam shortly after a period of travel should generally be avoided if possible.

The candidate may find it helpful to be able to rest/lay down for a period, in a suitable room, once he/she has arrived at the exam location. The practicalities of travel can cause particular problems when an exam is planned to start early in the morning.

If a candidate feels that he/she is not going to be able to travel and then take an exam, consideration should be given towards taking the exam at home, or at a location that would be easier to reach.

Written exams

As noted already, people with ME/CFS often have significant problems with short-term memory, concentration, attention span and information processing. Consequently, a candidate may only be able to produce written material for a period of time that is significantly shorter than the total time allowed for the exam.

Consideration should therefore be given to allowing extra time in which to take the exam and having a number of rest periods – possibly in a separate room, where the candidate can lay

down – during the course of the exam.

Candidates should be able to take as many rest breaks as they need and rest breaks should not count as part of exam time or any of the extra time that has been granted.

Consideration may also need to be given to allowing the person to dictate their answers to a scribe, or to use a computer if this is their normal method of writing due to muscle fatigue, rather than having to write them down by hand.

If the candidate has to take more than one exam on one day, or over the course of several days, consideration will need to be given to the possibility of longer intervals between exams.

Oral exams

Extra time may need to be allowed to compensate for cognitive problems.

Practical exams

If a practical exam involves standing

or physical activity, this will need to be discussed with the candidate beforehand. Again, splitting the exam up to allow for some rest periods in between may be helpful.

Medication and nutrition

It is unlikely that people with ME/CFS will need to take medication during an exam – with the possible exception of painkillers. If medication is likely to be needed this should be indicated to the authorities beforehand.

Some people with ME/CFS find it helpful to have small frequent meals and snacks, in order to stabilise their blood sugar levels. They should also have access to water as required.

Disability Discrimination Act

It should be noted that ME/CFS is an illness that can be covered by the Disability Discrimination Act 1995 and that this Act contains a section on education.

FURTHER INFORMATION

- ↑ The Young ME Sufferers Trust (Tymes Trust) publishes an excellent leaflet aimed at children and young people who are taking tests or exams at school or college. The leaflet, School Examinations and ME: Special Assessment Arrangements, covers both Special Arrangements and Special Considerations. Please contact Tymes Trust for an initial discussion: www.tymestrust.org
- Documents produced by the Joint Council for Qualifications – Access Arrangements and Special Consideration (explains concessions) and Instructions for the Conduct

or phone their advice line:

0845 003 9002

- of Examinations (explains timetable variation) can be downloaded from the JCQ website at: www.jcq.org.uk, or by phoning 0207 638 4132. The JCQ acts as a single voice for most organisations in the UK that award qualifications.
- ◆ For specific advice on Scottish exam concessions, contact the Scottish Qualifications Authority on 0345 279 1000 or their website: www.sqa.org.uk for the document: Guidance on Special Arrangements for Candidates with Disabilities and/or Additional Support Needs.

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Medical information contained in this leaflet is not intended to be a substitute for medical advice or treatment from your doctor. We say that you always consult your doctor or healthcare professional about any specific problem. We also recommend that any medical information provided by The MEA is, where appropriate, shown to and discussed with your doctor.