



The ME Association
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To Whom it may concern

Students with a diagnosis of ME/CFS are clinically vulnerable to Covid-19 infection

People with a diagnosis of ME/CFS (myalgic encephalomyelitis/chronic fatigue syndrome) have a serious medical condition that makes them clinically vulnerable to Covid-19 infection. We would be very grateful if you could provide additional help and support for students with ME/CFS at this difficult time.

Students with ME/CFS will have overcome many difficulties to enable them to be studying at your university, college or school. Some may have taken years to improve from a severely housebound state to successfully entering education, but only managing to do so with varying types and levels of support.

ME/CFS often occurs as a hidden chronic medical condition. As a result, some students with ME/CFS prefer not to share their diagnosis or practical support needs and management requirements with peers or teaching staff.

About ME/CFS

ME/CFS is a complex multisystem disease involving abnormalities that affect the brain, muscle, and the immune system. It directly affects a person's ability to function normally, restricts movement and participation in all aspects of daily living.

It is classified by the World Health Organisation as a neurological disease and recognised as such by the NHS in the SNOMED CT medical classification index.

The disease is diagnosed in people of all ages and ethnicities. Around 265,000 people in the UK are thought to be affected. It is often triggered by an acute infection and can lead to loss of function and chronic ill-health for many years.

Relapses and exacerbations are also commonly caused by infections. With the Covid-19 pandemic, we are particularly concerned at the increased risk this new infection poses to people with ME/CFS.

Research into the quality of life of people with this condition has found that it is just as disabling and has a greater impact on function and well-being than other chronic illnesses such as cancer and multiple sclerosis.

Around 25% of people with ME/CFS are severely or very-severely affected – meaning that they are housebound or bedbound for all or most of the time, rely on others for care and support, and may experience swallowing and/or respiratory problems.

People with ME/CFS are classified as having a disability under the 1995 Disability Discrimination Act and the current 2010 Equalities Act in relation to both education and employment.



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About COVID-19

In relation to COVID-19 infection, the Government has stated that anyone who is entitled to a flu vaccine on the NHS should be regarded as 'clinically vulnerable', or at increased risk of infection, and most students with ME/CFS will fit into this category.

Students who are clinically vulnerable will need to pay particular attention to the advice currently in place, limit social contacts, practice stringent social distancing measures, maintain a high level of personal and household hygiene, and use a face covering (mask) while encouraging others to do so as well. There will be additional measures in place depending on the university, college, or school, and some students may elect to stay at home (and study remotely) for the duration.

Students with ME/CFS are deserving of extra support where required. Because this condition affects a student's ability to function, they will often be unable to access essential services and will be more dependent than before on the help and understanding of others.

There are also students with ME/CFS who have other serious health conditions that make them 'clinically extremely vulnerable'. Previous shielding measures are now back in place in England, and people in this category are advised to stay at home as much as possible (although exceptions do apply).

The clinically extremely vulnerable will be contacted by the NHS and eligible for help with grocery and medication deliveries for example. With regard to the lockdown in England, and measures in place in Scotland, Northern Ireland, and Wales, they are advised to adopt the practices that are most relevant to where they live and to any alert level that is in place.

Supporting students with ME/CFS

For many young people with ME/CFS, a viral infection will have been the trigger that caused a Post-Viral Fatigue Syndrome, which then developed into ME/CFS. They will be acutely aware of the consequences of contracting a serious viral infection and there may be increased levels of anxiety during this crisis. It would be helpful if Student Services and Disability Advisors are aware of the students with ME/CFS in their care.

Students who are away from home

These students may need extra help with deliveries of groceries and medication supplies, which may be very difficult or impossible in "closed" residences. We would therefore urge university and college administrators to take their vulnerability to Covid-19 infection into consideration in relation to residential accommodation arrangements.

A minority of students with ME/CFS will have council funded practical support staff attending daily, weekly, or fortnightly. However, the majority rely on family members. It is understandable that universities, in order to ensure protection and support for the whole student population, may not currently allow such "visitors" to enter accommodation buildings. We would be grateful if other arrangements, such as studying remotely from home or an alternative location where there is support, could be permitted.



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We know that universities, colleges, and schools are working tirelessly to protect and support the whole student population, and we understand that this is a very troubling time for many students with chronic illness. However, we are aware that students with ME/CFS often attempt to struggle on, incurring exacerbation of symptoms or relapses, and may go unnoticed.

We would be grateful if you could take whatever steps are necessary to provide practical help and support for students with ME/CFS to allow them to cope as best they can and continue with their studies at this time. We are very happy to provide additional information if required.

If students with ME/CFS are in doubt about the current restrictions and the help they might be entitled to receive, we would suggest they review the latest Government information, contact their GP if necessary, and visit the ME Association website to consider the free range of Covid-19/ME/CFS leaflets we have made available. We are also hosting regular discussions about the ongoing situation on the ME Association Facebook page.

Yours sincerely

Dr Charles Shepherd,

Hon. Medical Adviser, ME Association

Additional information:

1. The NHS Flu vaccine eligibility list does not include all neurological conditions. In previous years, ME/CFS was specifically included, but the list today only mentions a few broad examples.

The exact wording is as follows: "Those with chronic liver disease, immunosuppression and chronic neurological disease are at increased relative risk of mortality if they contract flu compared to the general population."

■ Public Health England: Best Practice Toolkit for GP Practices 2019/20:

<https://tinyurl.com/y39a7jtb>

■ The NHS also makes it very clear that M.E. is a long-term neurological condition:

<https://tinyurl.com/y6h33er2>



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2. Dame Sally Davies, the former Chief Medical Officer, confirmed that people with ME/CFS should have a flu vaccine if they want one.

However, some doctors are referring to the section on flu vaccine in what is called the health services 'Green Book' and using the list on page 14 of Chapter (19) on flu vaccine to say that ME and CFS are not covered and are not therefore considered vulnerable to the risk of Covid-19 infection.

Again, this list includes neurological diseases and refers to some examples. It is not exhaustive and allows doctors to use their clinical judgement. It does NOT exclude ME or CFS.

■ ME Association information about flu and pneumonia vaccines for 2020/21 – Free Leaflet:

<https://tinyurl.com/y5ba2qsg>

3. ME/CFS is a chronic neurological disease that meets the Government's definition of being a condition that causes an increased risk in relation to Covid-19 infection.

People with ME/CFS are vulnerable (and may be clinically extremely vulnerable) because, as with any new infection, there is a definite risk that this will cause a relapse or significant exacerbation of pre-existing symptoms.

Their vulnerability to Covid-19 infection should be taken into consideration by organisations providing community support, supermarkets providing on-line deliveries, employers (where a person is still able to work), and education providers (where a person is still able to attend school, college, university).

4. People with ME/CFS are classified as having a disability under the 1995 Disability Discrimination Act and the current 2010 Equalities Act in relation to both education and employment.

■ ME Association Information about ME/CFS and Disability Classification:

<https://tinyurl.com/y3zjr4e3>

■ ME Association Information about Prognosis, Permanency, and Quality of Life in ME/CFS:

<https://tinyurl.com/y6s7aeov>

5. Where people with ME/CFS or those without the condition, display the symptoms of Covid-19 infection, or have had Covid-19 and are struggling to recover, we have produced a range of free leaflets that help explain what to do and how to manage Post-Covid Fatigue Syndrome safely.

People in these situations should also refer to the relevant Government advice in place for the region in which they live and consult their GP where necessary. If they display symptoms then the advice is to self-isolate for a period of 14 days and seek a test as soon as possible.

■ UK Government guidance about Covid-19 lockdown and regional restrictions:

<https://www.gov.uk/coronavirusol>



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- NHS guidance: What to do when you display Covid-19 symptoms:

<https://tinyurl.com/y6aa98ne>

- ME Association Information about Covid-19/PVFS/ME/CFS and Post-Covid-19 free range of leaflets:

<https://tinyurl.com/y7eo5do9>

- ME Association Information about education and studying with ME/CFS at university:

<https://tinyurl.com/y6glka3c>

- ME Association Information about children and young people with ME/CFS:

<https://tinyurl.com/y27vheyg>

- ME Association website:

<https://meassociation.org.uk>

- ME Association Facebook page:

<https://www.facebook.com/meassociation/>