



**The ME Association**  
**7 Apollo Office Court**  
**Radclive Road**  
**Gawcott**  
**Bucks**  
**MK18 4DF**

**Telephone:**  
01280 818963  
**Email:**  
admin@meassociation.org.uk  
**Website:**  
www.meassociation.org.uk

**Patrons:**

HRH The Duke of Kent KG GCMG KCVO  
The Countess of Mar  
Etain, Lady Hagar-Alexander  
John Rutter CBE  
Professor Derek Pheby BSc, MB, BS, LL.M,  
MPhil, FFPH

**To Whom it may concern**

## **ME/CFS and vulnerability to COVID-19 infection**

**People with a diagnosis of ME/CFS (myalgic encephalomyelitis/chronic fatigue syndrome) should be regarded as being clinically vulnerable in relation to COVID-19 infection. As a result they may require help, support or modifications to all aspects normal life.**

ME/CFS is a complex multisystem disease involving abnormalities that affect the brain, muscle and immune system. It can produce a wide range of disabling symptoms and has significant effects on all aspects of a person's physical and cognitive/mental functioning and their ability to participate in all aspects of daily living – including education and employment. Research into the quality of life of people with ME/CFS has found that it can be just as disabling and can have a greater impact on function and well-being than many other chronic illnesses such as cancer and multiple sclerosis.

- ME/CFS can range from a relatively mild form of illness, that might allow a return to work or education on at least a part-time basis, to moderate, to severe, and to very severe, where a person will be very ill and confined to bed with a need for 24-hour care. Most people will experience a range of illness severities.
- ME/CFS can affect people differently and will limit their ability to initiate or complete activities that had previously been possible before the triggering event. It often follows a relapsing-remitting pattern of symptom severity and functional incapacity, although for some it can be progressive. The unpredictable and fluctuating nature is one of the things that make this condition so hard to live with.
- ME/CFS is classified by the World Health Organisation as a neurological disease and recognised as such by the NHS in the SNOMED-CT digital coding system.
- ME/CFS is often triggered by an acute infection, including other coronavirus infections. Relapses and exacerbations are also commonly caused by infections.
- For most people, ME/CFS is triggered by an acute infection such as by the Epstein Barr Virus, but it can be triggered by the Covid-19 virus and earlier coronavirus infections (MERS, SARS). Relapses and symptom exacerbations are commonly caused by subsequent infections.

With COVID-19, we are particularly concerned about the increased risk of relapse that this new infection poses to people with ME/CFS. Feedback to the MEA over the past two years indicates that many people with ME/CFS who have caught COVID-19 infection have experienced a significant and sometimes persisting relapse.

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 being vulnerable, or at increased risk of infection, and need to avoid contracting this infection if at all possible. People with ME/CFS meet this criteria and should therefore be able to access extra help and support where required. NHS guidance also states that people with conditions affecting the brain or nerves are at high risk from COVID-19:

<https://tinyurl.com/2v25wx3b>



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Extra help might be in the form of access to community initiatives, online shopping and home delivery of groceries and medications, and modifications or exemptions from certain duties at work or education if a person is still able to work or go to school/college. In relation to employment, consideration should be given to allow people with ME/CFS to continue to work from home where this is possible, especially if they would be coming into close and regular contact with other people at work.

We would ask that doctors also give consideration to the use of one of the new antiviral medications if someone with ME/CFS catches COVID-19 at home in order to reduce the risk of admission to hospital with serious complications from COVID-19, and a relapse of their ME/CFS.

There are also people with ME/CFS who have other health conditions that make them even more vulnerable to COVID-19.

This is a very troubling time for anyone with a chronic debilitating illness that places them at increased risk from COVID-19.

We would therefore be very grateful if you could take whatever steps you can to provide help and support to people who have ME/CFS.

Yours sincerely

**Dr Charles Shepherd,**

Hon. Medical Adviser, ME Association