



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 Hagart-Alexander

To Whom It May Concern

MEA Statement: People with a diagnosis of M.E. should be regarded as vulnerable and are deserving of increased support where required

We would be very grateful if you could provide additional help and support to people who are struggling to cope with myalgic encephalomyelitis (M.E.) at this very difficult time.

M.E. 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.

M.E. (also known as chronic fatigue syndrome) 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 M.E.

Research into the quality of life of people with M.E. 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 M.E. 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.

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 vulnerable, or at increased risk of infection, and needs to practice stringent social distancing measures.

People with M.E. fit into this category and should be deserving of extra support where required. Because this disease affects a person's ability to function, they will often be unable to access services and will be more dependent than before on the help of others.

This extra help might be in the form of access to community initiatives, online shopping and home delivery of groceries and medications, and modifications at work or when working from home, if they are still able to work.

There are also people with M.E. who have other health conditions that are included on the Government's extremely vulnerable list. These people will be practising shielding (self-isolation) for at least 12 weeks and registering with the Government – if they haven't already been registered – and should be entitled to additional help and support including home deliveries of groceries and medications.



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We would be grateful if you could take whatever steps are necessary to provide help to people with M.E. We understand that this is a very troubling time for many people with chronic illness, but people with M.E. are being overlooked and left to fend for themselves – when they are deserving of your support.

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, M.E. 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 source: Best Practice Toolkit for GP Practices](#)

■ [The NHS also makes it very clear that M.E. is a neurological condition.](#)

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 the Chapter (19) on flu vaccine to say that ME and CFS are not covered by the flu vaccine list and are not therefore vulnerable conditions.

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.

■ Source: [Public Health England/Department of Health: Green Book Immunisation against infectious disease: Chapter 19: Influenza.](#)

3. We therefore consider ME/CFS to be a chronic neurological disease that meets the Government's definition of being a condition that causes an increased risk in relation to coronavirus infection.

People with ME/CFS are vulnerable in relation to coronavirus 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 coronavirus infection should be taken into consideration by organisations providing community support, supermarkets providing on-line deliveries, and employers where a person is still able to work.