



**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  
John Rutter CBE

**TO WHOM IT MAY CONCERN**

## **SUPPORTIVE MEDICAL EVIDENCE FOR BLUE BADGE APPLICATIONS FROM PEOPLE WITH ME/CFS AND LONG COVID**

I have been asked to provide some background information on the classification, causation, symptoms, severity and prognosis/permanency of ME/CFS (myalgic encephalomyelitis/chronic fatigue syndrome) and Long Covid in relation to Blue Badge applications.

### **Classification of ME/CFS**

ME/CFS is classified by the WHO as a disease of the central nervous system in section G93.3 of ICD-10. It is coded under various severities in the NHS SNOMED coding system (1).

Long Covid is a fairly new condition that affects people who remain in some way symptomatic three months after an infection with Covid-19.

### **Causation of ME/CFS and Long Covid**

Research evidence indicates that ME/CFS may involve a convergence of immune, neurological, metabolic and genetic influences following an initial insult – which is often a viral infection. Proposed pathophysiological mechanisms include immune and metabolic dysregulation, neuroendocrine abnormalities, central nervous system and circulatory system dysfunction, cardiovascular defects and disturbances of the gut microbiome. People with ME/CFS have significant genetic differences in their DNA compared to the general population.

While similar pathophysiological mechanisms appear to be involved in Long Covid, this condition may also involve the presence of persisting viral infection and organ damage to the heart, lungs, etc from the original Covid infection.

### **Symptoms**

The 2021 NICE guideline on ME/CFS (2) describes four key symptoms which must be present in order to make a diagnosis of ME/CFS:

Debilitating fatigue that is worsened by activity, is not caused by excessive cognitive, physical, emotional or social exertion, and is not significantly relieved by rest.

Post-exertional malaise/symptom exacerbation after activity in which the worsening of symptoms is often delayed in onset by hours or days; is disproportionate to the activity and has a prolonged recovery time that may last hours, days, weeks or longer

Unrefreshing sleep which may include feeling exhausted, feeling flu-like and stiff on waking, broken or shallow sleep, altered sleep pattern or hypersomnia.



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Cognitive difficulties (sometimes described as 'brain fog'), which may include problems finding words or numbers, difficulty in speaking, slowed responsiveness, short-term memory problems, and difficulty concentrating or multitasking.

People with ME/CFS and Long Covid also experience pain, which may be musculo-skeletal, arthralgic (affecting the joints) or neuropathic (nerve pain).

Most people with Long Covid have some ME/CFS symptoms, especially debilitating fatigue and cognitive dysfunction, and a significant proportion meet diagnostic criteria for ME/CFS. Organ damage to the lungs and heart is the main cause of Long Covid symptomatology in some cases where it can also cause debilitating fatigue and reduced mobility.

### **Severity**

It is estimated that up to 25% of people with ME/CFS fall into the severely-affected category – meaning that they are largely or constantly housebound, wheelchair-bound or even bed-bound. This level of severity inevitably involves significant problems with mobility, balance, being able to stand unaided, and cognitive function (i.e. problems with memory, concentration, information processing).

Those with moderate to severe ME/CFS will experience similar problems, and while they are not normally house-bound or wheelchair-bound, they may not be able to walk unaided for more than a short distance.

The fact that a significant proportion of people with ME/CFS become moderately or severely affected, and consequently require various forms of practical assistance, which may include an indoor and/or outdoor wheelchair, is fully recognised by the Department of Work and Pensions in their medical guidance relating to applications for disability benefits and in section 1.8.8 of the NICE guideline on ME/CFS.

Research studies that have examined functional status and quality-of-life measures in ME/CFS confirm that the scale of impairment across a range of physical and mental activities can be just as great or greater than is seen in many other long term medical conditions, including some types of cancer (3,4,5,6,7).

As with ME/CFS, there is a wide range of severity of symptoms and resulting disability in people who have Long Covid. Some are severely or very severely affected in relation to all aspects of daily living in the same way as those with ME/CFS. In addition to ME/CFS-type symptoms, some people with Long Covid have severe breathlessness on exertion due to pulmonary involvement and this will also affect how far they can walk. At present, there is no firm data on the percentage of people who have severe or very severe Long Covid.

### **Prognosis and permanency**

Research studies into the long-term outcome in ME/CFS indicate that only a very small minority of people with ME/CFS return to pre-illness levels of health and functioning (8). For most people ME/CFS becomes a long-term medical condition and, once symptoms have persisted for more than 5 years, the Chief Medical Officer's report on ME/CFS (9) concluded in section 1:4:3 on prognosis that full recovery becomes rare.

As Long Covid is a relatively new condition, research into the long-term prognosis is limited. However, a large number of research studies that have examined outcomes after 3 or 4 years indicate that a significant proportion remain unwell and continue to experience a significant degree of functional impairment.

### **NICE guideline on ME/CFS: Recommendations relating to disability aids and appliances:**

**1.8.8 For people with moderate ME/CFS or severe or very severe ME/CFS, consider providing or recommending aids and adaptations (such as a wheelchair, blue badge or stair-lift) that could help them maintain their independence and improve their quality of life, taking into account the risks and benefits.**



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### House of Lords question on Blue Badge eligibility for ME/CFS tabled by the Countess of Mar:

Concerns that people with ME/CFS are being refused a Blue Badge, even though they have very limited mobility, led to a parliamentary question in the House of Lords from the Countess of Mar in May 2012.

In a written answer Lord Attlee (Department for Transport) replied:

*Eligibility for a Blue Badge is set out in the governing regulations. These are the Disabled Persons (Badges for Motor Vehicles) (England) 2000, as amended. Since the 1980s, the regulations allow people to apply to local authorities for a badge through two main routes: “without further assessment” and “with further assessment”. Under the “with further assessment” category, a person may be eligible for a badge if they have a permanent and substantial disability which means they are unable to walk or have very considerable difficulty walking.*

*It is for the relevant local authority to make decisions on whether or not a person is eligible for a badge. To help ensure consistency, the Department for Transport issues non-statutory guidance to local authorities on the factors that should be taken into account when they are making an assessment.*

*This guidance is intended to explain that eligibility for a badge under the “with further assessment” criteria is not condition-specific. Local authorities should take into account the effect of a person’s condition on their ability to walk. The guidance gives examples of conditions like myalgic encephalomyelitis (ME) and mental and cognitive impairments like autism and dementia. In these cases, people might be eligible for a badge if their condition means they are unable to walk or have very considerable difficulty walking. They might, however, not be eligible if their ability to walk is unaffected.*

This parliamentary reply, along with the NICE guideline on ME/CFS recommendation, makes it quite clear that people with ME/CFS should be eligible for a Blue Badge if their condition means that they are unable to walk, or have very considerable difficulty in walking.

Yours sincerely

**Dr Charles Shepherd**

Hon Medical Adviser, The ME Association  
June 2026

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