
TO WHOM IT MAY CONCERN

Supportive evidence for a Blue Badge application from a person with ME/CFS

Date as Postmark

I have been asked to provide some background information on the classification, severity and prognosis/permanency of ME/CFS (Myalgic Encephalomyelitis/chronic fatigue syndrome) in relation to a Blue Badge or wheelchair application.

CLASSIFICATION

ME is classified by the World Health Organisation as a neurological disease in section G93:3 of ICD10 (International Classification of Diseases – version 10). CFS is indexed to this G93:3 classification. The Department of Health has repeatedly made it clear that it fully accepts this neurological classification.

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

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.

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 cancer^(1,2,3,4).

PROGNOSIS

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

HOUSE OF LORDS QUESTION FROM 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.

The Countess of Mar asked the Government why – in the guidance related to Blue Badge eligibility – conditions including myalgic encephalomyelitis (ME) are expressly identified as not being “in themselves a qualification for a badge”; and to what other medical conditions this guidance relates.

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The Myalgic Encephalopathy
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Company limited by guarantee
No. 2361986
Registered in England
Registered Charity Number
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In a written answer supplied on 15 May 2012, Government spokesman Lord Attlee 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. As part of major reforms to the scheme, the department published updated guidance in June 2011 and again in February 2012.

The 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.

“As part of wide-ranging reforms, the Government considered extending eligibility for a Blue Badge. They announced on February 2011 that they had no plans to extend eligibility to other groups of disabled people. With over 2.5 million badges already on issue, the Government decided that it was important to ensure the Blue Badge scheme remains sustainable in the long term and that it protected the concession for those who need it the most, that is, those who are unable to walk or have considerable difficulty walking.”

This parliamentary reply 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.

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Hon Medical Adviser, ME Association
8 April 2018

References:

- 1 Buchwald D et al. (1996) Functional status in patients with chronic fatigue syndrome, other fatiguing illnesses, and healthy individuals. *American Journal of Medicine*, 101, 364 - 370
- 2 Komaroff A et al. (1996) Health status in patients with chronic fatigue syndrome and in the general population and disease comparison groups. *American Journal of Medicine*, 101, 281 - 290
- 3 Nacul LC et al. (2011) The functional status and well being of people with myalgic encephalomyelitis/chronic fatigue syndrome and their carers. *BMC Public Health*, 11, 402
- 4 Schweitzer R et al. (1995) Quality of life in chronic fatigue syndrome. *Social Science Medicine*, 41, 1367 – 1372
- 5 A Report of the Chief Medical Officer’s CFS/ME Working Group (2002), and separately its two published annexes, can be downloaded from The ME Association website at www.meassociation.org.uk/about-the-mea/policies-and-documents/