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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 application.

CLASSIFICATION

ME/CFS is recognised by the World Health Organisation as a neurological disease in section 8E49 Post-Viral Fatigue Syndromes (International Classification of Diseases – version 11).

The Department of Health has repeatedly made it clear that it fully accepts ME/CFS as a neurological disease and the NHS has adopted the WHO classification in its SNOMED-CT electronic health record.

See the information on our website here: <https://tinyurl.com/3kekehff>

SEVERITY

It is estimated that up to 25% of people with ME/CFS fall into the severely affected category at some stage in their illness. This means that they are largely or constantly housebound, wheelchair-bound or even bed-bound. Within this group are people very severely affected who are often extremely weak, unable to speak, intolerant to noise, smell, and touch, are unable to maintain adequate food or fluid intake and who may be malnourished. They are bedbound all of the time and need 24-hour care and support.

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). They also experience pain, which can like other symptoms, vary in intensity throughout the day, and may be musculoskeletal, 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 completely 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 recognised by the Department of Work and Pensions in, for instance, their Work Capability Assessment Handbook.

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).



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Please see the following references and information our website:

The MEA Association Disability Rating Scale: <https://tinyurl.com/5aez6rp7>

Nutrition Assessment and Malnutrition: <https://tinyurl.com/u2mvmc9r>

Severe ME: Helping You Cope: <https://tinyurl.com/49nmdesw>

PROGNOSIS

Research studies into long term outcome indicate in ME/CFS that only a small minority of people 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 five years full recovery becomes rare (5).

Most people with ME/CFS fall into one of four broad groups:

1. Those who manage to return to normal health, or near normal health. The outlook for children and young people is generally considered to be better than for adults. Some may experience a significant recovery in functional ability and symptom severity within a couple of years, while for others it may take much longer.
2. The majority who make some degree of improvement and eventually stabilise. They then follow a fluctuating pattern with both good and bad periods of health. Relapses or exacerbations are often precipitated by:
 - a. Frequent episodes of post-exertional malaise (PEM) – a characteristic symptom of ME/CFS,
 - b. Infections, operations, temperature extremes, or stressful life events.
3. A significant minority who remain severely or very severely affected and normally require a great deal of care and support.
4. Those who show signs of deterioration. This is unusual but it does happen. When it occurs, a detailed medical re-assessment is advisable to rule out other possible causes. In the case of someone who becomes very severely affected, an increase in medical supervision and care will be necessary.

Please refer to **Prognosis, Permanency, and Quality of Life in ME/CFS**: <https://tinyurl.com/yp9mddte>

Government Guidance

In 2012, in response to concerns that people with ME/CFS were being unfairly denied blue badges by local authorities, Lord Attlee replied:

"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."



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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.

Reference: <https://tinyurl.com/js63b8e7>

Dr Charles Shepherd
Hon Medical Adviser, ME Association

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 <https://tinyurl.com/2uth3n2e>*