



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
Professor Derek Pheby BSc, MB, BS, LL.M,
MPhil, FFPH

Date as postmark

To Whom it may concern

SUPPORTIVE EVIDENCE FOR AN APPLICATION FOR A DISABLED PERSON'S BUS PASS

I have been asked to provide some general background information on the classification, effect on mobility, and prognosis/permanency of ME/CFS (myalgic encephalomyelitis/chronic fatigue syndrome) in relation to local authority eligibility criteria for a Disabled Bus Pass.

DESCRIPTION OF ME/CFS

ME/CFS is a complex multisystem disease that involves various body systems - muscle, brain, immune system, cardiac function etc - and causes a wide range of symptoms. The main diagnostic symptoms are debilitating fatigue that is activity-induced and exacerbated by exercise; cognitive dysfunction/problems with short-term memory and concentration; dysautonomia/problems with the regulation of pulse and blood pressure which may cause dizziness and fainting, and unrefreshing sleep.

ME/CFS is classified by the World Health Organisation as a neurological disease in section G93:3 of ICD10 (International Classification of Diseases – version 10) The Department of Health recognises this neurological classification.

EFFECT ON ACTIVITY AND MOBILITY

Activity-induced fatigue is the key symptom of ME/CFS. So the condition will worsen if a person with ME/CFS exceeds their individual limitations on physical activity.

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

Those with less 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 are moderately or severely affected and consequently require various forms of practical assistance, which may include an indoor and/or outdoor wheelchair, and or support in the form of a Disabled Bus Pass or Blue Badge parking permit, is fully recognized in section 1.8.8 the new (2021) NICE guideline on the management of ME/CFS:



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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 stairlift) that could help them maintain their independence and improve their quality of life, taking into account the risks and benefits. Include these in the person's care and support plan.

NICE GUIDELINE: <https://tinyurl.com/4y7datwr>

Research studies that have examined functional status and quality of life measures in ME/CFS have also confirmed 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 the long-term outcome of ME/CFS indicate that only a small minority of people with ME/CFS fully recover and return to previous levels of health and functioning. For many people ME/CFS is therefore 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.

The information above makes it clear that ME/CFS can cause significant and permanent problems with activity and mobility. People with ME/CFS should therefore be entitled to receive appropriate help in relation to disability aids and appliances, and financial assistance with using public transport.

I therefore hope that you will now give sympathetic consideration to this application for a disabled bus pass.

Dr Charles Shepherd
Hon Medical Adviser, ME Association

References

- 1 Buchwald D et al.
Functional status in patients with chronic fatigue syndrome, other fatiguing illnesses, and healthy individuals.
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2 Komaroff A et al.

Health status in patients with chronic fatigue syndrome and in the general population and disease comparison groups. American Journal of Medicine, 1996, 101, 281 - 290

3 Nacul LC et al.

The functional status and well being of people with myalgic encephalomyelitis/chronic fatigue syndrome and their carers. BMC Public Health, 2011, 11, 402

4 Schweitzer R et al.

Quality of life in chronic fatigue syndrome. Social Science Medicine, 1995, 41, 1367 – 1372

5 A Report of the CFS/ME Working Group:

Report to the Chief Medical Officer of an Independent Working Group. London, Department of Health, 2002.

Available online: <https://tinyurl.com/2p9ud57s>