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

Date as postmark

To Whom it may concern

ME/CFS and disability aids, wheelchairs, home adaptations, and the provision of social care services

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 an application for a disability aid, including a wheelchair, or an adaption in the home, or help from social care services.

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.

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 Capabaility 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).

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.

Draft NICE Guideline ME/CFS (expected publication 18 August 2021)

The National Institute for Health and Care Excellence (NICE) will be issuing a new guideline in August 2021. We have extracted relevant information from the draft guideline below (6).

Maintaining independence

If a person with ME/CFS needs support at home, conduct a social care assessment, record, and provide information and support on:

- activities of daily living,
- mobility, including transferring from bed to chair, access to and use of the toilet and washing facilities, use of stairs, and access to outside space,
- dexterity and poor balance, including avoiding falls,
- their home, including environmental controls to avoid glare from lights, loud noise, and temperature fluctuations,
- the feasibility of equipment and adaptations,
- access to technology, including online access,

- where to get financial support and advice, for example signposting to advice on money management and making personalised arrangements with banks or the Post Office to access personal finances, and how to claim carers' and disability benefits and grants.

Give families and carers information on how to access training and resources about how to care for the person with ME/CFS.

Aids and adaptations

Provide aids and adaptations identified in the person's management plan without delay, so that people can carry out activities of daily living and maintain their quality of life as much as possible.

Enable prompt assessment for funding for home adaptation. If the person is not eligible for funding, continue to offer information and support in arranging home adaptations.

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 management plan.

Access to care

The committee was aware that difficulties accessing care are intensified in people with severe or very severe ME/CFS, particularly when they need hospital care.

The evidence showed that, as a result of this, some people with severe or very severe ME/CFS have little contact with and support from health and social care services. To address this, the committee highlighted the flexibility and specific support needed by people with severe or very severe ME/CFS.

ME/CFS can affect a person's ability to carry out activities of daily living and maintain their independence and quality of life. The committee agreed that everyone with ME/CFS should be asked how their symptoms affect their independence and then a social care assessment carried out if needed.

The committee also made further recommendations based on their own knowledge and experience, including that:

- many families and carers do not know the most appropriate ways to support someone with ME/CFS and need advice on this

- people with ME/CFS often have difficulty getting the equipment they need to support their activities of daily living and maintain their quality of life.

Some of these recommendations might need extra staff time or other healthcare resource use, for example to offer flexible appointments and home visits, make adjustments during inpatient stays and provide aids and adaptations. However, for equity reasons, people with ME/CFS need the same access to healthcare and support as other NHS patients that is commensurate with the severity of their illness.

Charles B Shepherd

Dr Charles Shepherd
Hon Medical Adviser, ME Association
Juy 2021

MORE INFORMATION

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**

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 - 29

3: Nacul LC et al. (2001)
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, 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. (2002)
Department of Health.
Available as a downloadable pdf from The ME Association website: **https://tinyurl.com/hwey74o**

5: Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): Diagnosis and management of CFS/ME in adults and children (2007)
National Institute for Health and Clinical Excellence, (NICE guideline 53).
Available online: **http://guidance.nice.org.uk/CG53**

6. The NICE Clinical Guideline ME/CFS: New draft issued with final publication expected 18 August 2021:
https://tinyurl.com/aatcs5t3