



DISABILITY AND ME/CFS:

Definitions, Classification and the MEA Disability Rating Scale

In this leaflet we examine illness severity, explain how Myalgic Encephalopathy/ Encephalomyelitis or Chronic Fatigue Syndrome (ME/CFS) is officially recognised as a disability, and provide a useful disability rating scale.

The disability rating scale can be helpful when providing information for benefit, employment, and insurance assessments, or to simply keep you and those who care for you informed about your current state of health.

DEFINING ILLNESS SEVERITY

There are no agreed upon definitions for illness severity in ME/CFS. The degree to which symptoms can affect an individual do vary, as does the level of disability and the duration spent experiencing the varying degrees of functional impairment. There have been some attempts to quantify severity – but it can be very unique to the individual.

The ME Association most closely identifies with the definitions of illness severity in the 2002 Report to the Chief Medical Officer (below) that were initially produced by Cox and Findley (1998) and influenced the current NICE clinical guideline on ME/CFS (2007).



The NICE clinical guideline is important as it provides a framework of recommendations to the NHS and influences funding for service provision and clinical care. One of the issues we have with the current guideline is that it fails to acknowledge the distinction between severe and very severe ME/CFS.

As a result, we have been advocating that this be reinstated in the new guideline (to be published April 2021). Official acknowledgement of severe ME/CFS should then lead to more appropriate attention being paid by the NHS to those who are most vulnerable in our community.

Mild

Are mobile and can care for themselves and can do light domestic tasks with difficulty. The majority will still be working. However, in order to remain in work, they will have stopped all leisure and social pursuits, often taking days off. Most will use the weekend to rest in order to cope with the week.

Moderate

Have reduced mobility and are restricted in all activities of daily living, often having peaks and troughs of ability, dependent on the degree of symptoms. They have usually stopped work and require rest periods, often sleeping in the afternoon for one or two hours. Sleep quality at night is generally poor and disturbed.

Severe

Will be able to carry out minimal daily tasks only, face washing, cleaning teeth, have severe cognitive difficulties and be



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wheelchair dependent for mobility. These people are often unable to leave the house except on rare occasions with severe prolonged after-effect from effort.

Very Severe

Will be unable to mobilise or carry out any daily tasks for themselves and are in bed for the majority of the time. These people are often unable to tolerate any noise and are generally extremely sensitive to light.

■ Read the MEA leaflet: Prognosis, Permanency, and Quality of Life in ME/CFS: <https://tinyurl.com/y2y7xand>



MORE DETAILED DEFINITIONS

Severe

Those who are severely affected are very likely to be housebound and require long periods in bed because they are unable to do otherwise. Employment and education will most likely have to be curtailed or significantly reduced in scope and complexity. A wheelchair or other aid to help them mobilise will probably be required – even when indoors – because standing and walking will be an issue. Help and support will be needed to cope with normal responsibilities, household tasks and other activities such as cooking and with personal care such as bathing. Home visits from healthcare professionals are important because most patients will not be ambulatory, and particular attention to diet and nutrition will be needed. Periods of sensitivity to light, noise, and touch will make coping, caring, and communication, a challenge.

Very Severe

The very severely affected will be bedbound for all or most of the time and require full-time care and support. They will be unable to mobilise or sit upright in bed, to work or take part in any formal education. It is very likely that all responsibilities will need to be fulfilled by a family member and it will be necessary to employ a professional to provide homecare i.e. social care. Home visits from health professionals will be essential, with special attention paid to diet and nutrition – tube-

feeding may be necessary – and extra assistance with toileting and sanitary needs. Prolonged periods of sensitivity to light, noise, and touch will make coping, caring, and communication, a very real challenge.

■ See the MEA Disability Rating Scale below for additional descriptions.

References:

The Report to the Chief Medical Officer by an Independent Working Group on CFS/ME (2002): <https://tinyurl.com/ybrjgqhc>

Cox, Findley, The Management of Chronic Fatigue Syndrome in an Inpatient Setting: Presentation of an Approach and Perceived Outcome, Br J Occupational Therapy 1998: <https://tinyurl.com/y4xhjhnw>

IS ME/CFS CLASSED AS A DISABILITY BY THE UK GOVERNMENT?

The best way to answer this question is to refer to the 2010 Equality Act – where ME/CFS is listed as a specific medical condition.

But this does not mean that everyone with a diagnosis – regardless of severity – is automatically classed as having a disability.

‘A person has a disability for the purposes of the Act if he or she has a physical or mental impairment, and the impairment has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities.’



■ The definition requires that the disability must arise from a physical and/or mental impairment. As far as ME/CFS is concerned, section A5 in the Guidance to the Act makes it clear that ME/CFS is a fluctuating medical condition that can cause substantial impairment.

■ Almost all of the criteria for a diagnosis of ME/CFS make it clear that the symptoms must cause a significant functional impairment in relation to a person's ability to carry out their normal daily activities (at home, work, school, etc).

■ The requirement that an adverse effect on normal daily activities should be a substantial one reflects the general understanding of disability as a limitation going well beyond the normal differences in ability which may exist among people. A substantial effect is one that is more than a minor or trivial effect.

Example from the 2010 Equality Act Guidance:

“A man has had chronic fatigue syndrome for several years. Although he has the physical capability to walk and to stand, he finds these very difficult to sustain for any length of time because he experiences overwhelming fatigue. As a consequence, he is restricted in his ability to take part in normal day-to-day activities such as travelling, so he avoids going out socially, and works from home several days a week. Therefore, there is a substantial adverse effect on normal day-to-day activities.”

Day-to-day activities are things people do on a regular or daily basis.

Examples include shopping, reading, and writing, having a conversation or using the telephone, watching television, getting washed and dressed, preparing, and eating food, carrying out household tasks, walking and travelling by various forms of transport, and taking part in social activities.

Normal day-to-day activities can include general work-



related activities, study, and education-related activities, such as interacting with colleagues, following instructions, using a computer, driving, carrying out interviews, preparing written documents, and keeping to a timetable or a shift pattern.

Having a long-term effect of the impairment is defined as:

- Lasting at least 12 months, or
- From the onset it is likely to last 12 months or more, or
- Likely to (i.e. may well) last for the rest of the person's life

Reference:

The **2010 Equality Act Guidance** covers each component of the definition – impairment, substantial, day to day activities, long term. Detailed guidance and illustrative examples are also provided where relevant (Published May 2011): <https://tinyurl.com/y7uusfdo>

THE ME ASSOCIATION DISABILITY RATING SCALE

Most people with ME/CFS find that their level of physical and mental functioning fluctuates – sometimes quite widely. If you are going to make use of this disability rating scale to help with employment, education, or benefit application purposes you will probably find it helpful to indicate the level of disability you have for most of the time – as well as the range of disability you experience across the range of descriptors below.

As noted above, a person is disabled under the 2010 Equality Act if they have a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on their ability to do normal daily activities. Consequently, as with most other disability rating scales, the MEA scale focuses on the sort of physical and mental impairments that are regarded as being important in relation DWP benefit applications and the ability to carry out meaningful employment.



A major limitation with disability rating scales is that they do not therefore provide an assessment of the effect of chronic ill health in conditions like ME/CFS, especially the impact of symptoms such as exhaustion, pain, sleep disturbance and feeling flu-like. Any form of chronic ill health is likely to have a significant impact on whether, for example, someone can return to employment or education and would no longer need to claim a sickness or disability benefits.

In addition to submitting evidence on the level of your physical and mental function, it is important to also point out the effect that ME/CFS symptoms are having on your ability to carry out a wide range of normal daily activities.

VERY SEVERE

100% DISABLED

Severe symptoms – often on a continual basis. Cognitive function (i.e. short-term memory, concentration, attention span) is likely to be very poor. Bedridden and incapable of living independently. Requires a great deal of supervision and practical support – including disability aids such as a hoist or a stair lift – with all aspects of personal care (i.e. feeding, dressing, washing) on a 24-hour basis.

90% DISABLED

Severe symptoms, normally including marked cognitive dysfunction, for much or all of the time. Bedridden and housebound

for much or all of the time. Has considerable difficulties with all aspects of personal care. Unable to plan or prepare meals. Requires practical support and supervision on a 24-hour basis.

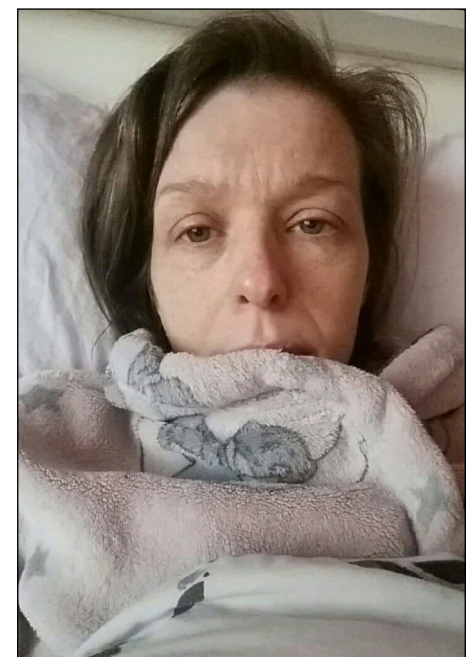
SEVERE

80% DISABLED

Moderate to severe symptoms for most or all of the time. Only able to carry out a very limited range of physical activities relating to personal care without help. Requires help with meal planning and preparation. Frequently unable to leave the house and may be confined to a wheelchair when up or spends much of the day in bed. Unable to concentrate for more than short periods of time. Usually requires daytime and night-time supervision.

70% DISABLED

Moderate to severe symptoms for most or all of the time. Confined to the house for much or all of the time. Normally requires help with various aspects of personal care and meal planning and preparation, possibly on a 24-hour basis. Very limited mobility. Unable to stand unaided for more than a very short period of time. May require wheelchair assistance.



MODERATE

60% DISABLED

Moderate symptoms for much or all of the time. Significant symptom exacerbation follows mental or physical exertion. Not usually confined to the house but has significant restrictions on mobility when outside and may require wheelchair assistance. Unable to stand unaided for more than a short period of time. Likely to require help with aspects of personal care and meal preparation – but not necessarily on a full-time basis. Requires regular rest periods during the day. Unable to resume any meaningful regular employment or education.

50% DISABLED

Moderate symptoms for much or all of the time. Symptom exacerbation follows mental or physical exertion. Not usually confined to the house but mobility restricted to walking short distances. Often unable to stand unaided for more than a short period of time. May require help with some aspects of personal care and with meal planning and preparation. Requires regular rest periods during the day. Able to carry out light activities (i.e. housework, desk work) linked to normal daily living for short periods but not able to resume regular employment or education.

40% DISABLED

Moderate symptoms for some or much of the time. Not usually confined to the house but mobility

often restricted to walking short distances. Normally able to carry out most activities linked to personal care and normal daily living but may require assistance with meal preparation. Often unable to stand unaided for more than a short period of time. May be able to cope with some work-related tasks for short periods – provided they are not mentally or physically strenuous – but not able to resume regular work or education.

MODERATE TO MILD

30% DISABLED

Fluctuating level of mild to moderate symptoms. Normally able to carry out all aspects of personal care and to plan and prepare meals. Able to walk short distances on a fairly regular basis and may be able to walk longer distances at times. Normally unable to stand unaided for longer periods of time. May be able to return to work on a flexible or part-time basis – provided adjustments are made to cope with physical activity or cognitive problems. May have to stop leisure or social pursuits to resume work or education.

20% DISABLED

Normally only mild symptoms at rest but exacerbation will follow activity. Able to carry out all aspects of personal care and to plan and prepare meals. Able to walk short to medium distances on a fairly regular basis and usually able to stand unaided. Normally able to return to flexible or part-time work or education.

10% DISABLED

Generally well with occasional mild symptoms. No problems with personal care or daily living. Mobility and cognitive functions may still be restricted but almost back to previous levels. May be able to return to full-time work or education.

0% DISABLED

Fit and well for at least the past three months. No symptoms at rest or after exertion. Capable of full-time employment or education.



Disclaimer:
 Medical information contained in this leaflet is not intended to be a substitute for medical advice or treatment from your doctor. The ME Association recommends that you always consult your doctor or healthcare professional about any specific problem. We also recommend that any medical information provided by The MEA is, where appropriate, shown to and discussed with your doctor.

References:
 The Report to the Chief Medical Officer by an Independent Working Group on CFS/ME (2002): <https://tinyurl.com/ybrjgqhc>
 Cox, Findley, The Management of Chronic Fatigue Syndrome in an Inpatient Setting: Presentation of an Approach and Perceived Outcome, Br J Occupational Therapy 1998: <https://tinyurl.com/y4xhjhnw>
 The 2010 Equality Act Guidance (Published May 2011): <https://tinyurl.com/y7uusfdo>
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