
TO WHOM IT MAY CONCERN

Prognosis and permanency

Re: Issues relating to prognosis and permanency in ME/CFS which need to be taken into consideration when assessing an application for early retirement from work on the grounds of permanent ill health.

People with ME/CFS (myalgic encephalopathy/chronic fatigue syndrome) who have been unable to return to any form of meaningful employment may seek advice regarding the possibility of taking early retirement on the grounds of permanent ill health.

A key requirement of nearly all pension schemes is that the ill health and disability being experienced will be/is likely to be permanent – a medical judgement in the case of ME/CFS which often requires a level of prognostic foresight by a doctor which may not be realistic in this illness.

However, there are a few pension schemes that allow for on-going assessment of the level of someone's disability once a pension has been granted. In these cases, the criteria are likely to be somewhat less stringent as the pension could then be removed or reduced if the person concerned starts to unexpectedly show some signs of recovery at a later date.

In addition to the issue of permanency, a number of other personal factors will have to be taken into consideration. These include the applicant's age, other health problems which may be relevant, the type of work which is normally undertaken, and whether all reasonable steps have been taken in regard to diagnostic assessment and management.

When arriving at a final decision, general information relating to quality of life and functional status, factors affecting prognosis, and research into prognosis will also need to be taken into consideration. Information on these factors in relation to ME/CFS is set out below:

Functional status and quality of life

Research studies that have examined functional status and quality of life measures in ME/CFS indicate that the scale of impairment across a wide range of physical and mental activities can be just as great, or even greater, than is seen in many other chronic medical conditions, including renal and heart disease, and multiple sclerosis.

Factors which may influence good and bad prognosis

Little is currently known about the reasons for variations in prognosis. However, research has indicated that several factors may be associated with prolonged disease.

Severity of illness appears to be a major factor, with a tendency for the illness to persist longer in more severely affected patients.

Individuals with an acute onset illness (often post-viral), particularly when this occurs in the presence of an uncomplicated psychological background, appear to have a better prognosis than those with a more gradual onset.

Early diagnosis with appropriate identification and management of any other factors – physical, psychological, social – which may be relevant is also thought to be related to a better prognosis.

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Factors that appear to be associated with poor prognosis include:

- Onset of symptoms without any clear precipitating factor set on a background of adverse psychological and social factors or occurring after a severe infective illness.
- Coexistence of psychiatric and other chronic illnesses.
- Presence of severe, unremitting, and often multiple symptoms.
- A management regime which has previously failed to recognise and address symptoms which may be treatable.

Older age

At present, most of these conclusions are based on clinical opinion and evidence collected by the Department of Social Security's Expert Group on Chronicity and Prognosis, who produced their report in 1996.

Overall prognosis

A number of research studies, which have examined prognosis in ME/CFS, have now been published. And while they all demonstrate that only a very small minority of people recover to previous levels of health and functioning, these findings need to be balanced by the possibility of selection bias in that participants have generally been recruited from patients being seen in hospital clinics rather than primary care (where the prognosis may well be better).

Overall, there is a wide variation in both severity and duration of illness and it appears that most people with ME/CFS show some degree of improvement over a period of time, but this is often years rather than months. However, health and functioning rarely return to the individual's previous level of health, and most of those who feel relatively recovered stabilise at a much lower level of functioning than before the start of their illness.

A substantial number, possibly the majority, pursue a fluctuating course with periods of relative remission and relapse.

A small but significant minority become severely and permanently disabled. However, progressive deterioration is fairly unusual.

The above observations all demonstrate how difficult it can be make a judgement on the likelihood of permanent ill health in someone with ME/CFS.

Personal opinion

My own view, which is shared by many of my colleagues, is that it is impossible to make any reliable prediction of prognosis during the first two years of a person's illness.

During the third and fourth years, this type of assessment becomes more realistic – especially in people who have participated in all reasonable approaches to management but have found that their condition has stabilised to a degree where a return to any form of meaningful employment has proved impossible.

In such circumstances, consideration should certainly be given towards the granting of a pension, especially in those who are more severely affected and/or of older age.

When ME/CFS has persisted for four or more years with good management but without any significant improvement, then I believe there would generally be a very strong case for granting a pension.

Dr Charles Shepherd Medical Adviser, ME Association 8 April 2018

Member, Chief Medical Officer's Working Group on CFS/ME (1999-2002)

Member, Expert Group on Chronicity and Prognosis that advised the former DHSS.



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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/