



MANAGEMENT FILE

by DR CHARLES SHEPHERD, our medical adviser

This leaflet is based on an article which first appeared in the ME Association's quarterly *ME Essential* magazine. MEA membership costs £18 a year for people living in the UK/BFPO. For contact details, see foot of this page.

the ME association



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Obtaining an ill-health pension

ME/CFS can result in all kinds of work-related problems. But one of the most difficult can be trying to obtain an early payment of a pension on the grounds that a person has reached the point where there is no realistic chance of a substantial degree of recovery taking place.

Fortunately, most pension schemes allow their members to apply for early payment of their pension benefits in such circumstances. For some people with ME/CFS, the process proceeds without any hitch. For others, it soon becomes clear that the pension provider is putting up all kinds of hurdles in order to resist making an early payment.

So, for anyone thinking of taking early retirement on the grounds of permanent ill health, here are some of the key points which need to be considered:

HOW DOES THE SMALL PRINT IN THE POLICY DEFINE PERMANENT ILL HEALTH?

Defining the point at which a condition such as ME/CFS becomes 'permanent' – thus qualifying someone for a pension because they have to retire early on grounds of ill health – varies from scheme to scheme.

This can range from 'on the balance of probabilities' at one end of the spectrum right through to

requiring a medical opinion that almost guarantees that there is never going to be any realistic chance of working again before the normal age of retirement – something that normally requires an impossible degree of foresight in the case of ME/CFS.

So it's important to obtain copies of the relevant documents that set out the exact criteria for granting a pension and, in particular, what they say about permanency.

HOW LONG HAS THE ILLNESS LASTED?

An early pension is very unlikely to be granted to anyone with ME/CFS who has been ill for less than two years unless there are other important considerations that would be relevant – such as being very near to retirement age or having another serious medical condition.

Depending on all the circumstances, it may be possible to obtain a pension in the case of ME/CFS where the illness has lasted for between three and four years. But – once the four-year point has been reached and all reasonable approaches to management have been tried without success – then serious consideration should normally be given to awarding a pension. Not to do so would be unreasonable.

IS THE DIAGNOSIS CORRECT?

A pension would not be granted unless all other possible explanations for an ME/CFS-like illness have been excluded by appropriate investigation.

This would include the sort of investigations referred to in section 6.6 of The MEA clinical and research guide, *ME/CFS/PVFS: An Exploration of the Key Clinical Issues* (11th edition, 2019).

HAS THE ILLNESS BEEN PROPERLY MANAGED?

Before accepting a claim, most pension providers will want to know if all reasonable approaches to treatment have been tried. These would include drug treatments that provide symptomatic relief and lifestyle management, particularly relating to activity management.

HAVE COGNITIVE BEHAVIOUR THERAPY AND GRADED EXERCISE THERAPY BEEN TRIED?

Some pension providers are going one step further in their approach to management by saying that this should also include a course of CBT and/or GET.

The reasoning is partly based on the flawed belief that ME/CFS is primarily a behaviour disorder involving abnormal illness beliefs and the consequences of prolonged inactivity/deconditioning.

It should be noted that in patient evidence submitted to the 2002 Chief Medical Officer's report on ME/CFS:

- 7% found **CBT** to be "helpful"
- 67% reported "no change"
- 26% felt CBT made them "worse"
- With **GET**, 35% found it "helpful"
- 15% reported "no change";
- 50% said GET made them "worse".

A further potential problem with both forms of treatment is that they are not available in some parts of the UK. Exercise regimes must also be prescribed with exactly the same degree of caution and informed consent that applies to drug treatments – otherwise any adverse reaction could become the subject of litigation.

If an inappropriate exercise programme causes an exacerbation/relapse of symptoms, this should be notified in writing to the pension provider, and the exacerbation/relapse should also be recorded in writing in the medical notes.

If a pension provider makes it clear that they will not consider an application until a management programme involving CBT and/or GET has been attempted, this should be discussed with your GP and your specialist. If your own medical advisers do not believe that CBT and/or GET are going to be helpful, this information should be submitted in writing to the pension provider.

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 dentist 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 or dentist.

HOW OLD ARE YOU?

For anyone who is nearing retirement age, it may be much easier for a pension provider to make a decision than in the case of someone who still has 20 or 30 years of a potential working life ahead of them.

HOW FLEXIBLE IS THE PENSION SCHEME ONCE AN APPLICATION HAS BEEN ACCEPTED?

Some pension schemes will grant a pension for life with no further questions or medical assessments whereas others have a policy of reviewing the situation at regular intervals. Where there is some flexibility to allow for the possibility of recovery, and even a return to work, this tends to produce a more flexible approach to the granting of a pension.

The issue of backdating a pension to the point at which someone first becomes incapable of work is another issue where different providers take different approaches. Again, it's important to check the small print.

FURTHER INFORMATION

- *A To Whom It May Concern* letter prepared by The ME Association covers prognosis and permanency (see next page).
- *Living with ME* (Vermilion, 1999) covers prognosis on pages 118-121. There's more detailed information on all aspects of early retirement due to ill health on pages 332-340. CBT and GET are on pages 242-245 and 209-210 respectively. This book is available from any public library.
- The 2002 Chief Medical Officer's Report into ME/CFS covers pension provision in section 3.5.1. Sections 4.4.2.1 and 4.4.2.2 cover GET and

CBT respectively. The report is available to download from the MEA website at <https://tinyurl.com/hwey74o>

CHALLENGING DECISIONS

If you are having problems, and believe that you are being treated unfairly, then make sure that your trade union representative or professional body is aware of the situation – as they should be able to act for you.

If the dispute is unresolved, it may be worth contacting your MP, the Pensions Advisory Service (OPAS), or the Pensions Ombudsman. The Disability Discrimination Act also covers some aspects of pension provision.

You might want to independent legal advice from a solicitor with expertise in this area. One firm of solicitors with experience in this area is Clarke Willmott. They helped establish an important ruling regarding the backdating of a pension to the point at which the person became permanently incapable of work.

This case – Spreadborough v Wandsborough Borough Council – involved the interpretation of the Local Government Pension Scheme. It opened the way for other people to make backdated claims. Judgement in the case:

<https://tinyurl.com/ycrw7898>

PENSIONS CONTACTS

Office of the Pensions Advisory Service

11 Belgrave Road
London SW1V 1RB
Tel: 0300 123 1047 (calls cost no more than national rate)
Website:
www.pensionsadvisoryservice.org.uk

The Pensions Ombudsman

11 Belgrave Road
London SW1V 1RB
Tel: 0207 630 2200
Website:
www.pensions-ombudsman.org.uk

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. And 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, which 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 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
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 download of the 2002 Report of the Chief Medical Officer's CFS/ME Working Group is available at the MEA website: <https://tinyurl.com/hwey74o>