December 2020

PENSIONS

Obtaining an Ill-Health Pension, Prognosis & Permanency

ME CONNECT HELPLINE: **FREEPHONE 0808 801 0484**

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Hon Medical Adviser to the MEA

OBTAINING AN ILL-HEALTH PENSION

All employees have a right to ask their employer to make reasonable adjustments to ensure they are not disadvantaged at work due to a medical condition or disability. And if these adjustments make it possible to continue working, taking early retirement is not going to be an option.

However, there are situations where adjustments are far more difficult to make – in which case taking a pension earlier than anticipated is an option that may need to be considered. Ill health retirement – also known as being 'medically retired' – is when you draw your pension before the age of 55 (or the scheme's ordinary retirement date) due to on-going ill health or disability. To be successful a decision will normally be based on the fact that you can no longer continue to work in your normal job, or one that seriously reduces your earning potential.

Most pension schemes have their own criteria as to what sort of conditions will entitle you to draw your pension early and how they define permanent ill health or disability. So you will almost certainly need to:

- Establish that you are permanently incapable of continuing to do your current job – this can be due to a physical or mental condition.
- Demonstrate that there are no treatments available that could enable a successful return to work before normal pension age. This could apply to a current role or any alternative employment. Pension schemes will also consider whether you are working full- or part-time, and may suggest part-time working as a solution.
- Apply while you are in pensionable employment for maximum benefits. This is not essential, but is recommended.

Not surprisingly, some pension schemes are now placing much greater emphasis on rehabilitation and reasonable adjustments to enable an employee return to work. So if an employer is genuinely able to facilitate a return to work, the application will be less likely to succeed. However, if an employer offers a different role or fewer hours, you may still be able to apply for ill health retirement from your original position.

When it comes to decisions about early retirement on the grounds of permanent ill health in ME/CFS this can be a fairly straightforward process. However, for some people it soon becomes clear that all kinds of hurdles are being erected in order to delay making an early payment.

These are the key factors that are likely to affect a decision as to whether an application will be accepted:

Obtaining an Ill-Health Pension, Prognosis and Permanency was written by Dr Charles Shepherd (pictured above), Trustee and Hon Medical Adviser to The ME Association.

1. How does the small print in the pension policy define permanent ill-health?

Defining the point at which a condition like 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.

It can include a decision based 'on the balance of probabilities' at one end of the spectrum right through to the requirement for an unrealistic medical 'guarantee'

that there is never going to be any chance of working again before the normal age of retirement – something that would require 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. If you don't have a copy of your pension documents then you should request the details from your employer or pension provider.

2. How long has your ME/CFS persisted and how is it progressing?

Based on my experience in helping the DWP to assess applications for an early pension, this is 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 individual circumstances, it may be possible to obtain a pension where the illness has lasted for between three and four years, is causing significant disability and an inability to perform normal duties at work.

Once the four-year point has been reached, and all reasonable approaches to management have been tried without success, serious consideration should then be given to awarding a pension. Not to do so would be unreasonable.

How your illness is progressing, especially if it is fluctuating to any significant degree, or is deteriorating, will also need to be considered.

3. Is the diagnosis of ME/CFS correct?

A pension would not be granted unless all other possible explanations for an ME/CFS-like illness have been excluded by appropriate medical investigation and the actual diagnosis confirmed by a medical practitioner.

These would involve the sort of investigations and assessments referred to in section 6.6 of the ME Association guide for health professions:

- The ME Association Clinical and Research Guide 2020:

https://tinyurl.com/y4xemla9

For more information:

- ME/CFS The Importance of Early and Accurate Diagnosis:

https://tinyurl.com/y3m3r7l5

- ME/CFS Disability Classifications and Illness Severity Definitions:

https://tinyurl.com/y3zjr4e3

4. Has ME/CFS 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 activity management.

With the new NICE Clinical Guideline on ME/CFS (see below) it has been recognised that effective treatments and cures are not available and that ME/CFS is caused by an underlying disease pathology – although the exact nature of this pathology remains unknown.

5. Have cognitive behavioural therapy (CBT) and graded exercise therapy (GET) been attempted?

Despite the removal of GET as a recommended approach to management in the new NICE clinical guideline on ME/CFS (2020 draft edition), it will take some time for this significant change to feed through to employers and to pension providers.

CBT is still featured in the new guideline but as a tool that might be employed for learning to accept, adapt, and to cope with the understandable effects that ME/CFS can bring to a person's mental wellbeing.

Neither GET or CBT can be regarded as curative for ME/CFS. However, some pension providers may still want to know what efforts have been made to try and improve a person's health and how effective any effort might have been.

The new NICE guideline will formally be published in April 2021. It recognises that previous efforts to base causation on 'psycho-social' theories had little merit and that explanations for continuing ill-health are more likely to be based on an underlying disease pathology for which there is currently no effective treatment available.

The NICE clinical guideline is now very much centred on symptom relief and energy management (Pacing) – which is a safe approach that the ME Association has been championing for many years.

- The draft NICE Clinical Guideline on ME/CFS can be found here (December 2020):

https://tinyurl.com/yyowlsmo

- The ME Association is a stakeholder in the NICE consultation process and will be submitting a formal response to the draft guideline before 22 December 2020.

6. How old are you?

For anyone who is nearing retirement age, it is often be easier for a pension provider to make a decision about an early pension than for someone who still has 20 or 30 years of a potential working life ahead of them.

However, experiences do vary with some finding their application is granted with relatively little effort while for others it can be a long and complex battle irrespective of their age.

7. Do you have any other medical conditions?

If you have any other long term medical conditions that affect your ability to work these will also need to be taken into consideration.

Challenging decisions:

If you are having problems, and believe that you are being treated unfairly, do make sure that your trade union representative or professional body is aware of the situation – as they should be able to act on your behalf and arrange for a medical report. If not, it can be very helpful to obtain an independent medical report that addresses all the key points above. But you will need to consult a medical specialist who understands ME/CFS and preferably one who is used to writing these type of reports.

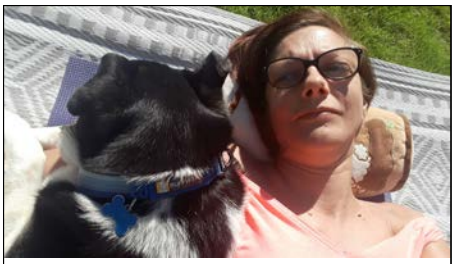
If the dispute is unresolved, it may be worth contacting your MP, the Pensions Advisory Service, or the Pensions Ombudsman. The 2010 Equality Act also covers some aspects of pension provision. You might also want to obtain independent legal advice from a solicitor with expertise in this area.

2010 EQUALITY ACT AND PENSIONS - Information from Slater Gordon Solicitors: https://tinyurl.com/y7vp4vxm

THE PENSIONS ADVISORY SERVICE
0800 011 3797
Website: www.pensionsadvisoryservice.org.uk/

THE PENSIONS OMBUDSMAN
0800 917 4487
Website: www.pensions-ombudsman.org.uk

PROGNOSIS, PERMANENCY AND QUALITY OF LIFE IN ME/CFS



This section will consider what to expect from a diagnosis of ME/CFS in terms of disability, improvement, recovery, and quality of life, based on research evidence and clinical opinion.

PREVALENCE: HOW MANY PEOPLE ARE AFFECTED BY ME/CFS IN THE UK?

Based on current research evidence, we believe over 404,000 adults and children in the UK suffer from Myalgic Encephalopathy (or Encephalomyelitis), also known as chronic fatigue syndrome (ME/CFS).

This means that the condition is not uncommon and has a higher prevalence than multiple sclerosis and other serious medical conditions. These numbers make it hard to understand why there is not a similar level of support and understanding from the UK Government and the NHS.

We have no sound research evidence about the scale of illness severity. But it is thought that around 25% of people with ME/CFS at any one time will be severely affected, and perhaps 2% will be very severely affected and require a great deal of care and support.

Reference:

Estimates based on 0.2-0.4% ME/CFS prevalence and using research-defined diagnostic criteria: Nacul *et al*. Prevalence of ME/CFS in three regions of England: a repeated cross-sectional study in primary care, BMC Medicine, 2011. https://tinyurl.com/y2v7h7hn

PROGNOSIS: WHAT ARE THE CHANCES OF RECOVERING FROM ME/CFS?

Prognosis is a forecast, based on clinical experience and research, of the likely course of a medical condition. It can help determine what you might expect from a diagnosis. However, it is very difficult predicting outcomes in each individual, especially with a condition like ME/CFS that can affect people differently.

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. Continued deterioration is unusual but it does happen. When this occurs, a detailed medical re-

assessment is advisable to rule out other possible causes. In the case of someone very severely affected, an increase in medical supervision and care will be necessary.

SYMPTOM SEVERITY

For those who don't experience an improvement in health, the condition can maintain a fluctuating course of severity over the course of days, weeks, months, and years. Symptoms will fluctuate, as will the level of discomfort and disability they bring. ME/CFS can be very unpredictable.

You might not experience severe symptoms or severe functional impairment to the same extent all the time. However, this is more likely to occur during the very early stages both pre- and post-diagnosis and during a relapse.

For some, severity of symptoms and the reduction in functional ability is a more progressive process, and health can get worse over time. We don't know why this happens; it remains one of the many unanswered questions about the condition.

Where a progressive deterioration in symptoms is occurring, this requires a careful clinical reassessment to make sure there is not a previously unrecognised medical condition that can cause ME/CFS like symptoms (e.g. hypothyroidism).

WHAT FACTORS ARE BELIEVED TO INFLUENCE PROGNOSIS?

Very little is currently known about the reasons for variations in prognosis. However, evidence from people with ME/CFS, their clinicians, and the limited amount of published research in this area indicate that a number of factors may influence both severity and outcome in ME/CFS.

Good prognostic indicators:

- Early diagnosis with appropriate identification and management of any other factors – physical, psychological, social – which may be relevant.
- An acute onset illness, often post-viral, particularly when this occurs in the presence of an uncomplicated psychological background.

Factors which may indicate a less favourable prognosis:

- Onset of symptoms following a severe infective illness or without any clear precipitating event.
- Background of adverse psychological and social factors.
- Co-existence of psychiatric and/or other chronic illnesses.
- A management regime which has previously failed to recognise and address symptoms which may be treatable.
- Presence of severe, unremitting, and often multiple symptoms.

Those who are severely or very severely affected and persist in a bedbound state for long periods of time, are believed to have the worst prognosis.

RESEARCH INTO PROGNOSIS

Research indicates that the scale of impairment across a wide range of physical and mental activities can be just as great, or greater, than is seen in many other chronic medical conditions, including renal and heart disease, multiple sclerosis, and cancer.

Several studies examining prognosis indicate that ME/CFS often becomes a chronic and very disabling illness with complete and sustained recovery only occurring in a small minority of cases.

A systematic review of 14 studies (Cairns and Hotopf 2005) found a median full recovery rate during follow-up periods of 5%, but the median proportion of patients who improved during follow-up was 39.5%.

The section on Prognosis in the 2002 Report to the Chief Medical Officer noted that:

"Prognosis is extremely variable. Although many patients have a fluctuating course with some setbacks, most will improve to some degree.

"However, health and functioning rarely return completely to the individual's previous healthy levels; most of those who feel recovered stabilise at a lower level of functioning than before the illness...

"Overall, there is wide variation in the duration of illness with some people recovering in less than two years while others remain ill after several decades.

"Those who have been affected for several years seem less likely to recover; full recovery after symptoms persist for more than five years is rare."

Read the MEA leaflet: Disability and ME/CFS: Definitions, Classification and the MEA Disability Rating Scale: https://tinyurl.com/y2rxp2jt

QUALITY OF LIFE - WHAT CAN I EXPECT FOLLOWING DIAGNOSIS?

Studies that have examined functional status and quality of life measures confirm that the scale of impairment across a range of physical and mental activities can be just as great or greater than in many other chronic medical conditions.

One study, from Nacul et al (2011a) and the ME Biobank, reported that:

"ME is as disabling and has a greater impact on functional status and well-being than other chronic diseases such as cancer. The emotional

burden of ME is felt by lay carers as well as by people with ME."

The most recent study on quality of life (Kingdon et al 2018), used anonymised clinical data from people with ME/CFS and multiple sclerosis who had donated blood samples to the ME Biobank.

It reported that people with ME/CFS were measurably more disabled than people with multiple sclerosis and healthy controls. They also worked fewer hours and had lower incomes compared to people in the other two groups.

An Australian study examined the impact of socio-demographic and patient symptom characteristics on health-related quality of life (HRQoL) and found it to be significantly impaired across all illness domains. The research group concluded that, "ME/CFS has a profound and negative impact on HRQoL."

The high level of disability associated with this condition often stems from a combination of symptoms such as fatigue, pain, orthostatic intolerance, sleep disturbance, cognitive impairment and, in some cases, an associated depression.

It is further hampered by activity-induced muscle fatigue and post-exertional malaise (PEM) – resulting in worsened symptoms or relapse – which can make the pursuit of increased activity extremely difficult.

However, as we have indicated above, some people do find that over time and with careful management and support, symptoms become less severe, and improvements can be made in terms of functional ability.

While a complete recovery to previous levels of health may be unreasonable – and is likely to be hampered by other factors such as age and co-morbidities – improvements to moderate and mild illness severities do occur allowing for greater quality of life.

QUALITY OF LIFE - AGE AND ILLNESS DURATION

The extent to which patients' age and illness duration might affect symptoms and functioning in ME/CFS is uncertain.

In a collaborative study involving researchers from the UK, USA, and Norway (Kidd et al 2016), participants were categorized into four groups based upon age (under or over age 55) and illness duration (more or less than 10 years). The authors explained:

"The groups were compared on functioning and symptoms.... The results suggest that older patients with an illness duration of over 10 years have significantly higher levels of mental health functioning than the three other groups.... In addition, the younger patients with a longer illness duration displayed greater autonomic and immune symptoms in comparison to the older group with a longer illness duration."

The authors concluded that age and illness duration both have to be taken into account when trying to understand the effects of these two variables on function and quality of life in people with ME/CFS.

QUALITY OF LIFE - MENTAL HEALTH

Accepting ME/CFS and making necessary adjustments to a previously enjoyed lifestyle is often extremely difficult to achieve.

In the first years after diagnosis such drastic and unwelcome changes can lead to the added burden of mental health problems.

It can also be extremely demoralising and unwelcome to encounter a relapse when improvements have been made. And simply enduring chronic illness can also impact a person's mental health.

It is important to seek medical help for problems related to coping and adapting to a life with ME/CFS.

Being snatched from a previously active and healthy life – that might have included a level of financial security – is not something anyone is prepared for and issues that affect your mental health will lessen your overall quality of life.

PERMANENT ILL-HEALTH

In the absence of good quality research evidence on prognosis it is very difficult to provide accurate assessments on an individual basis. And while there have been studies published that examine prognosis, some of these have an inherent selection bias, as they are often based on more severe cases and in hospital environments.

There is an urgent need to carry out what are called longitudinal studies that examine the epidemiology of ME/CFS and track the progress of people with the condition over long periods of time.

Most current 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 internal report in 1996.

Overall, there is a wide variation in both severity and duration of illness, and as already noted in the section on prognosis it appears that most people with ME/CFS will show some degree of improvement over a period of time, although this is often years rather than months.

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 functional ability 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 although progressive deterioration is fairly unusual.

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

PROFESSIONAL OPINION – DR CHARLES SHEPHERD

My own view, which is shared by many of my medical colleagues, is that it is impossible to make any reliable prediction of prognosis during the first two years of an ME/CFS diagnosis.

During years three and four, 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 plateaued at a level of ability below that which is expected of a healthy person.

When the condition has persisted for four years or more with good management but without any significant improvement, ME/CFS is far more likely to be permanent. However, it may still follow a fluctuating course with relatively good and bad periods of health.

Reference:

BMJ Letter from M. Aylward Chief Medical Adviser Re: Government's expert group has reached consensus on prognosis of chronic fatigue syndrome, 5th October 1996. https://tinyurl.com/y3mhvavm

ADDITIONAL INFORMATION

A huge range of free literature is available to download from the website: https://meassociation.org.uk/fdwc

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.

RESEARCH REFERENCES

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FUNCTIONAL STATUS AND QUALITY OF LIFE

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The ME Association literature:

The ME Association has the largest selection of free ME/ CFS advice leaflets in the UK on:

Medical Management
Mental Health
ME Connect
Diet & Nutrition
General Information
Fundraising Leaflets
Benefits & Social Care
'To Whom It May Concern' letters

https://meassociation.org.uk/fdwc

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