



# PROGNOSIS, PERMANENCY AND QUALITY OF LIFE IN ME/CFS

ME CONNECT HELPLINE: **0344 576 5326**

**This leaflet 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 but limited research evidence, we believe that somewhere between 135,000 and 270,000 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 (possibly as many as 70,000) at any one time will be severely affected,



and perhaps 2% (around 5,000) 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

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**Prognosis, Permanency, and Quality of Life in ME/CFS** was written by Dr Charles Shepherd (pictured above), Trustee and Hon Medical Adviser to The ME Association.

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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 information literature is available to download from the website shop: https://meassociation.org.uk/shop

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.



DIAGNOSIS OF ME/CFS: The importance of having an early and accurate diagnosis. Includes an introduction, a list of symptoms, and a reference to a BMJ letter.

REBUT EXPLAINED: A short article explaining the ME Association's stance on various issues.

ME - WHAT GETS IN THE WAY OF GOOD MANAGEMENT: A leaflet discussing factors that hinder effective management of ME/CFS.

ME - WHAT GETS IN THE WAY OF GOOD MANAGEMENT (continued): Further details on management challenges.

ME - WHAT GETS IN THE WAY OF GOOD MANAGEMENT (continued): Additional points on management.

ASSESSMENT: A leaflet providing information on how to assess the severity of ME/CFS.

ASSESSMENT (continued): Further details on assessment methods.

FLU VACCINE AND ME/CFS: A leaflet discussing the benefits and risks of flu vaccination for ME/CFS patients.

FLU VACCINE AND ME/CFS (continued): Additional information on flu vaccines.

FLU VACCINE AND ME/CFS (continued): Further details on vaccination.

FLU VACCINE AND ME/CFS (continued): Final section of the flu vaccine leaflet.

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FUNCTIONAL STATUS AND QUALITY OF LIFE

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**THE ME ASSOCIATION** **ME CONNECT**

**me** We're here to help **0344 576 5326**

**Do you need to talk?**  
ME Connect is the telephone helpline service of the ME Association. It provides information and support for people with ME and those who live with or care for them. ME Connect provides a safe and understanding environment for people with ME so that they know they are being heard and understood.

*"Thank you for being there, you provide a wonderful service"*

*"MEConnect gave me information, reassurance and the tools to cope"*

ME Connect is a member of the Helplines Partnership which promotes high standards.

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**every day of the year**

Calls cost the same as other standard landline numbers (starting 01 or 02). If you have a call package for your landline or mobile phone then calls will normally come out of your inclusive minutes.

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**MAJOR FUNDING ANNOUNCEMENT!**  
Read on page 10 for the latest research into your condition.

**CORONAVIRUS**  
Dr Claire Shepherd explains why reducing the risk of catching Coronavirus is vital for those with ME/CFS.

**ME AWARENESS WEEK**  
A special celebration of our members.

**NEWS AND RESEARCH**  
The Committee of Age relates from the House of Lords, interviews with Professor David Swales, Professor Andrew Lewin, and Dr C. S. Bunker.

**DIET AND NUTRITION**  
The Committee, our diet and nutrition members, talks about fat and the other fats in 2020.

MEA Membership:

- £18.00 (UK residents and BFPO)
- £24.00 (Mainland Europe including Republic of Ireland)
- £30.00 (Rest of the World)

<https://meassociation.org.uk/about-the-mea/membership>

