THE ME ASSOCIATION

PROGNOSIS, PERMANENCY AND QUALITY OF LIFE IN ME/CFS

What to expect following a diagnosis of ME/CFS in terms of disability, improvement, recovery, and quality of life

Including:

- Prevalence
- Prognosis: Chance for improvement or recovery
- Fluctuation and symptom severity
- What factors can influence prognosis?
- Research into prognosis
- Quality of life
- Mental health
- Permanent ill-health

JULY 2025

PROGNOSIS, PERMANENCY AND QUALITY OF LIFE IN ME/CFS was written by Dr Charles Shepherd, Trustee and Hon. Medical Adviser to The ME Association.

DISCLAIMER

We recommend that the medical information in this leaflet is discussed with your doctor. It is not intended to be a substitute for personalised medical advice or treatment. You should consult your doctor whenever a new symptom arises, or an existing symptom worsens. It is important to obtain medical advice that considers other causes and possible treatments. Do not assume that new or worsened symptoms are solely because of ME/CFS or Long Covid.

PROGNOSIS, PERMANENCY AND QUALITY OF LIFE IN ME/CFS

CONTENTS

This information covers what people may expect following a diagnosis of ME/CFS in terms of disability, improvement, recovery, and quality of life. The information is based on extensive evidence from people with ME/CFS, their partners or family members, a small number of research studies, and clinical opinion from doctors who are involved in the management of ME/CFS.

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

Based on the most recent research evidence from the University of Edinburgh (Samms and Ponting, 2025), around 402,000 adults and children in the UK have ME/CFS. This figure is likely to be even higher due to a significant number of the 2 million people with Long Covid, possibly around 50%, also meeting diagnostic criteria for ME/CFS.

This means that ME/CFS is not uncommon and has a higher prevalence than multiple sclerosis and several other serious long-term medical conditions. Yet it receives a disproportionately low amount of government funding for services and research.

There is no sound research evidence about the scale of illness severity. However, it is generally accepted that around 25% of people with ME/CFS (possibly as many as 100,000) are severely affected at some point, and perhaps around 2% (8,000) are bedbound and very severely affected and require a great deal of care and support.

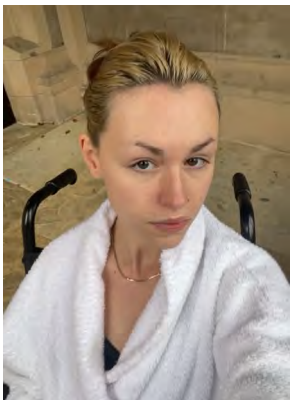
PROGNOSIS: WHAT ARE THE CHANCES OF IMPROVING OR RECOVERING FROM ME/CFS?

Prognosis is a forecast, based on patient and clinical experience, and research evidence, of the likely course of a medical condition. However, it is difficult to predict individual outcomes in a condition like ME/CFS that affects different people in different ways.

Overall, and taking into account the fluctuating nature of ME/CFS, most people with ME/CFS fall into one or more of the descriptions set out on the following page.

Please note that some people follow a more complicated course and do not fit neatly into any one of these six basic descriptions. For example, some people make a significant degree of improvement, have a relapse, but then only make a partial improvement. And some people who return to normal health, or almost normal health, then find that their ME/CFS recurs after an infection.

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



Unfortunately, the percentage of adults who make a full recovery from ME/CFS appears to be only around 5% and probably no more than 10%.

Recovery

This refers to a return to full and sustained normal health, or near normal health. Unfortunately, the percentage of adults who make a full recovery from ME/CFS appears to be only around 5% and probably no more than 10%. In some cases, where recovery has occurred in less than a year from symptom onset, a more appropriate diagnosis may have been a self-limiting post-viral fatigue syndrome. The situation for children and young people is generally considered to be significantly better than for adults (references: Bell and Rowe).

Significant improvement

A gradual overall improvement in functional ability and symptom severity, which tends to occur within the first few years. This group often then reach a 'glass ceiling' from which there is no further improvement. For others, the process may take much longer.

Partial improvement

Some degree of improvement, which again is followed by stabilisation but at a much lower level of physical and mental capability compared to before the development of ME/CFS.

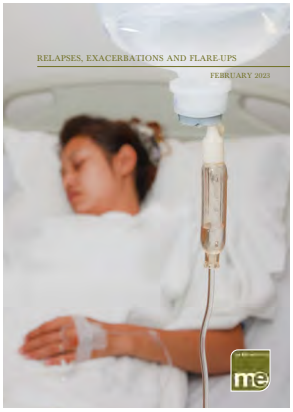
No improvement

A failure to make any improvement following the acute or post-infectious phase of their illness.

Severe and very severe ME/CFS

Estimated to affect around 25% of people at some point in their illness. Some people are severely affected at the onset of their illness. In others this follows a slower deterioration in health.

Most people with ME/CFS find that their illness fluctuates over the course of days, weeks, months, and years... ME/CFS can be very unpredictable.



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

Progressive deterioration

Although a progressive deterioration is not the norm this does sometimes happen. Where any form of progressive deterioration occurs, a detailed medical re-assessment is essential to rule out other possible causes, especially conditions like hypothyroidism, that can cause ME/CFS-like symptoms.

FLUCTUATION AND SYMPTOM SEVERITY

As already noted, most people with ME/CFS find that their illness fluctuates over the course of days, weeks, months, and years. Symptoms fluctuate in both severity and range, as does the level of discomfort and disability they bring. ME/CFS can be very unpredictable.

More significant exacerbations or relapses are often precipitated by:

- Frequent episodes of post-exertional malaise (PEM) – the characteristic symptom of ME/CFS
- Infections, operations, temperature extremes, stressful life events and sometimes vaccinations

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

- The MEA has published an information leaflet covering exacerbations and relapses. Relapses, Exacerbations and Flare-ups can be downloaded free here:

https://meassociation.org.uk/42mz

- The MEA Disability Rating Scale can be used if you need to describe in percentage terms the effect ME/CFS is having on your ability to care for yourself and your level of mobility, as well as monitoring progress.

https://meassociation.org.uk/f7fq

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 indicates that a number of factors appear to influence both severity and outcome in ME/CFS.

Evidence from people with ME/CFS, their clinicians, and the limited amount of published research in this area indicates that a number of factors appear to influence both severity and outcome in ME/CFS.

Factors which may indicate a better prognosis:

- Early diagnosis with appropriate identification and management of any other factors – physical, psychological and/or social – which may be relevant.
- An acute-onset illness, often post-viral, particularly when this occurs in the presence of an uncomplicated psychological background.
- Onset in older age (Ghali *et al*, 2022).

The MEA website section called Medical Matters covers ageing and ME/CFS in more detail:

https://meassociation.org.uk/7k4c

Factors which may indicate a less favourable prognosis:

- Diagnostic delay, especially when this is accompanied by no management or bad management during the very early stages of ME/CFS.
- Onset of symptoms following a severe infective illness or without any clear precipitating event.
- Background of adverse psychological and social factors.
- Co-existence of other chronic medical conditions.
- Management which has involved inappropriate guidance on activity and energy management or failed to recognise symptoms which may be treatable to some extent.
- Presence of severe, unremitting, and often multiple symptoms.

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

RESEARCH INTO PROGNOSIS

Research into prognosis indicates that ME/CFS often becomes a chronic and very disabling illness with complete and sustained recovery only occurring in a small minority of cases.

Several research studies indicate 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. This includes kidney and heart disease, multiple sclerosis, and cancer – all of which is likely to have an adverse effect on the outcome or prognosis in any individual case.

Research into prognosis also indicates 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%. The median proportion of patients who improved during follow-up was 39.5%.

The section on Prognosis in the 2002 ME/CFS Working Group Report to the Chief Medical Officer, which examined all the evidence at the time, concluded:

"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".

QUALITY OF LIFE IN PEOPLE WITH ME/CFS AND THOSE WHO CARE FOR THEM

Quality of Life is the medical term that describes how an illness affects all aspects of a person's life.

Research studies that have examined quality-of-life measures in people with ME/CFS 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.

"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 study from Luis Nacul *et al* (2011) 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."

Another 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.

They 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.

Two of the more recent studies on prognosis come from Dr Nina Muirhead and colleagues who looked at quality of life in people with ME/CFS (Muirhead *et al*, 2024) and in those who are partners or family members of people with ME/CFS (Vyas *et al*, 2022).

The first study analysed data from 876 people with ME/CFS in 26 countries and confirmed previous reports relating to significant reductions in quality of life. They concluded that: *contrary to popular misconception, anxiety and depression are the least often affected areas in people with ME/CFS who are most impacted by their inability to perform usual activities.*

Accepting ME/CFS and often having to make major adjustments to a previously enjoyed lifestyle can be extremely difficult to achieve.

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

QUALITY OF LIFE IN PEOPLE WITH ME/CFS AND THOSE WHO CARE FOR THEM

The second study, which involved 1,418 partners or family members from 30 countries concluded: *Family members were most impacted emotionally by worry, frustration and sadness, and personally by family activities, holidays, sex life and finances.*

The high level of physical disability associated with ME/CFS often stems from a combination of symptoms such as fatigue, pain, orthostatic intolerance, sleep disturbance, cognitive impairment and, in some cases, depression. This is further hampered by activity-induced muscle fatigue and post-exertional malaise (PEM) which can make the pursuit of increased activity extremely difficult.

However, as indicated above, some people find 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 is unlikely for most adults – and may be hampered by other factors such as age and co-morbidities – improvements to moderate and milder illness severities do occur, allowing for improvements in quality of life.

QUALITY OF LIFE - MENTAL HEALTH

Accepting ME/CFS and often having to make major adjustments to a previously enjoyed lifestyle can be extremely difficult to achieve.

So in the first few years after diagnosis, drastic and unwelcome changes to lifestyle, work, relationships and friendships can lead to the added burden of mental health problems.

It can also be extremely demoralising to encounter a relapse when improvements have been made. And just living with any form of debilitating chronic illness can impact a person's mental health.

It is important to seek medical help for mental health 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 comfortable level of financial security – is not something most people are prepared for, and issues that affect your mental health will lessen your overall quality of life.

PERMANENT ILL-HEALTH

Overall, there is a wide variation in both severity and duration of illness. Some people will have some degree of improvement over a period of time, although this is often years rather than months.

In the absence of high-quality research evidence on long-term prognosis, it is very difficult to provide accurate, individual assessments on longer-term outcomes. 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.

So there is an urgent need to carry out what are called longitudinal studies that track the progress of people with all degrees of severity over long periods of time for at least 10 years.

In relation to situations such as an application for retirement on the grounds of permanent ill-health, where an estimate has to be made on prognosis and permanency, conclusions are largely based on a combination of subjective clinical opinion and the very limited research evidence on long-term prognosis.

Overall, as already noted, there is a wide variation in both severity and duration of illness. Some people will have some degree of improvement over a period of time, although this is often years rather than months.

However, their health and functioning rarely returns to a previous level of health, and most people who improve tend to stabilise at a much lower level of functional ability than before the start of their illness.

In relation to forecasting permanency, research evidence indicates that the chances of returning to full normal health are very small, especially after being ill for four years or more. Most people will pursue a fluctuating course with periods of better health coupled with exacerbations and relapses. A significant minority will become severely and permanently disabled. Some will have a progressive deterioration in health.

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

PROFESSIONAL OPINION: *Dr Charles Shepherd*

Where ME/CFS has persisted for four years or more with good management but without any significant improvement, and the overall level of ill health and disability has stabilised, ME/CFS becomes far more likely to be permanent.

However, it may still follow a fluctuating course with relatively good and bad periods of health.

My own view, which is shared by many of my medical colleagues, is that it is almost 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 appropriate forms of management but have found that their condition has plateaued at a level of ability below that which is expected of a healthy person.

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

Reference:

Medical Matters Q and A on permanency and retirement on the grounds of permanent ill health:

https://meassociation.org.uk/qxq2

I followed a "return to work" plan after a few months (my ME began with a virus), stuck to it religiously, ignoring how tough it was and how exhausting (being in tears driving to work sometimes because I didn't know how I'd get through the day). I had a sudden, massive symptom crash about three months in, that made me so much worse overnight.

CATHERINE
(Facebook Post)

THE ME ASSOCIATION'S FACEBOOK POST

Dr Charles Shepherd posted:

On a personal basis I have now had Ramsay-diagnosed ME for 45 years. I was very ill for the first two years - partly, I believe, as a result of not having a diagnosis, coupled with no management or bad management, especially being refused benefits, returning to work on many occasions and not being able to carry on.

After being diagnosed by Dr Melvin Ramsay and Professor Peter Behan, and receiving some sensible self-help management guidance, I made a gradual, erratic but significant improvement over several years to reach my current glass ceiling of round about 60% of normal self.

Like everyone else, I have fairly frequent exacerbations and occasional periods of more prolonged relapse.

There were over 450 comments following the MEA Facebook post on Prognosis. A few are featured below. To read the full feed please visit:

https://meassociation.org.uk/bw7u

Jamie: Difficult… I've had it for over 25 years. I had a stretch of time where significant improvement was there, then had relapses which eventually contributed to losing/having to leave my job. The stress and effort required to keep working and survive just finished me off.

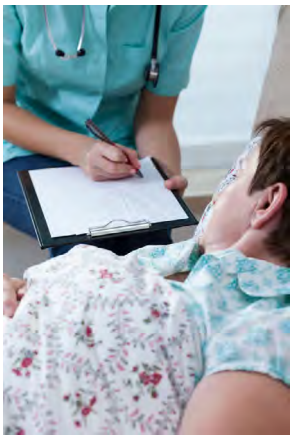
And that led to worsening of the condition and advice from the ME clinic that really knocked me for six and brought me back full circle to experiencing the majority of symptoms that I had at the start. This was around 13 years ago and the only difference was that I knew what I was dealing with better than when I first had it.

I've improved a bit again, but other symptoms have been present and, after some drawbacks, finally had further investigations into the possibility of something else going on (ie, not just everything being put under the umbrella of ME/CFS).

So, yeah, fluctuation… hopefulness and then reminders that ME/CFS ain't done with me yet.

Catherine: I've fluctuated but probably sit at level 3 now with moderate ME. I'd be interested in how prognosis is affected by how you act in the early stages of the illness.

THE ME ASSOCIATION'S FACEBOOK POST



I don't fit into any one category, I think that, long-term (decades), many of us experience a few of these. At first I deteriorated over two years to being severe (due to no diagnosis and pushing hard in ignorance), then gradually and modestly improved to "moderate/severe" with fluctuations for about 20 years.

JESSICA
(Facebook Post)

I followed a "return to work" plan after a few months (my ME began with a virus), stuck to it religiously, ignoring how tough it was and how exhausting (being in tears driving to work sometimes because I didn't know how I'd get through the day). Ihad a sudden, massive symptom crash about three months in, that made me so much worse overnight.

Despite some extremely gradual improvements I've never (in 12.5 years) got back to the point I was at before that crash. I will always wonder if being much more careful early on would have led to a full, or much increased, recovery.

Jessica: I don't fit into any one category, I think that, long-term (decades), many of us experience a few of these. At first I deteriorated over two years to being severe (due to no diagnosis and pushing hard in ignorance), then gradually and modestly improved to "moderate/severe" with fluctuations for about 20 years. I then started to improve more until four years ago I experienced drastic deterioration following two Covid jabs and now have progressive deterioration. So I can't separate my ME into only one category.

Rachel: My son developed ME/CFS which we now believe derived from chronic Lyme Disease in Oct 2022 aged 9. He was very poorly, but improved during 2023 until he relapsed in October 2023.

There was no improvement before worsening further in January 2024 and no improvement since. He is now housebound and trying to do six academic lessons a week but it's too much for him.

Leaving the house almost invariably results in a dip/crash. The NHS gives him a psychologist appointment at intervals but his paediatrician refused to follow Dr Weir's advice. The first round of improvement was definitely connected with homeopathic treatment. Nothing has worked since the relapse.

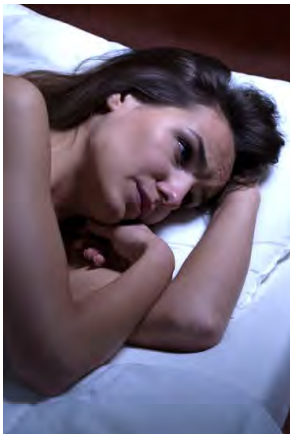
David: With caution, would say I'm probably at level 3. Put this down to finally learning to manage my ME better after nearly 10 years - thanks to MEA advice and outside influences, such as getting a mobility scooter and being "allowed' out now and again. It can so easily change though, such as when I got colitis and went from moderate to nearer severe for many months.

Emma: I took 15 years to recover from having pretty severe ME to almost full recovery. For 15 years I had a 40-minute rest after lunch every day, with relaxation music, and this reset me for the rest of the day. Without that I wouldn't have been able to do anything else and felt unwell.

THE ME ASSOCIATION'S FACEBOOK POST

I'm not sure anyone can accurately predict the prognosis for anyone with ME/CFS until there's an actual diagnostic blood test for the condition... Eventually, I hope that everyone will get a diagnosis and prognosis.

TIM
(Facebook Post)



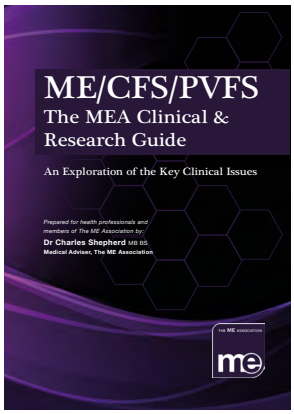
I now live within my capacity and experience ME symptoms for a short period of time if I over-do things. I have totally adjusted my work and lifestyle. I couldn't recover in the early years because I had two young children, so what I had to do was greater than my baseline. Once I started recovering, I bounced the boundaries and found fulfilling voluntary work and then paid work.

Angela: I had a diagnosis at 14 and I'm now 38. I've experienced fluctuating symptoms, but always had symptoms that affect my life significantly, as well as periods where I'd consider myself severely affected. Currently I am single, unable to work and still living with my parents, all due to my ME. From my experience I don't think I'll ever 'recover' but I will continue to manage my ME through pacing and planning how to use whatever energy I do have.

Tim: I'm not sure anyone can accurately predict the prognosis for anyone with ME/CFS until there's an actual diagnostic blood test for the condition. I'll wager that not everybody currently assigned by doctors to the ME/CFS medical dustbin has the same illness. Eventually, I hope that everyone will get a diagnosis and prognosis, but the wheels of medical research around ME/CFS grind slowly.

Debbie: It took two years until I could do small things for myself and now, six years on, I can go for walks for about 30 minutes. However, I need a rest when I get back. As long as I don't overdo things, my life has somewhat improved.

ADDITIONAL INFORMATION



Use this QR code to link to the MEA's **Clinical and Research Guide ME/CFS/PVFS: An Exploration of the Key Clinical Issues (The Purple Book).**

ME Association ME/CFS/PVFS Clinical & Research Guide 2022 Edition (The 'Purple Book')

The most comprehensive, evidence-based summary of ME/CFS/PVFS currently available. It contains everything that health professionals, patients, and the people who care for them need to know about this devastating neurological disease.

Order here: **https://meassociation.org.uk/pbme**

Kindle: **https://meassociation.org.uk/4nop**

Research References

The references below cover some of the more important published research studies examining prognosis and quality of life in people with ME/CFS and their carers/partners/parents.

Prevalence

Samms and Ponting. Unequal access to diagnosis of myalgic encephalomyelitis in England. BMC Public Health 25, 1417 (2025).

Prognosis

Bombardier, CH and Buchwald, D. Outcome, and prognosis of patients with chronic fatigue vs chronic fatigue syndrome. Archives of Internal Medicine, 1995, 155, 2105 – 2110.

Cairns R and Hotopf M. A systematic review describing the prognosis of chronic fatigue syndrome. Occupational Medicine, 2005, 55, 20 – 31.

Cox, Findley, The Management of Chronic Fatigue Syndrome in an Inpatient Setting: Presentation of an Approach and Perceived Outcome, Br J Occupational Therapy 1998.

Ghali A, *et al*. Factors Influencing the Prognosis of Patients with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. Diagnostics (Basel), 2022, Oct 19, 12(10): 2540.

Hinds, GME *et al*. A retrospective study of the chronic fatigue syndrome. Proceedings of the Royal College of Physicians of Edinburgh, 1993, 23, 10 – 14.

ADDITIONAL INFORMATION

Joyce J, *et al*. The prognosis of chronic fatigue and chronic fatigue syndrome: a systematic review. Quarterly Journal of Medicine, 1997, 90, 223 – 233.

Report to the Chief Medical Officer by an Independent Working Group on CFS/ME (2002)

Russo J, *et al*. Longitudinal changes associated with improvement in chronic fatigue patients. Journal of Psychosomatic Research, 1998, 45, 67 – 76.

Sharpe, MC *et al*. Follow up of patients presenting with fatigue to an infectious disease's clinic. British Medical Journal, 1992, 305, 147 – 152.

Sieberen P van der Werf *et al*. Natural course and predicting self-reported improvement in patients with chronic fatigue syndrome with a relatively short illness duration. Journal of Psychosomatic Medicine, 2002, 53, 749 – 753.

Vercoulen, JHMM *et al*. Prognosis in chronic fatigue syndrome: a prospective study on the natural course. Journal of Neurology, Neurosurgery and Psychiatry, 1996, 60, 489 – 494.

Wilson, A *et al*. Longitudinal study of outcome of chronic fatigue syndrome. British Medical Journal, 1994, 308, 756 – 759.

Prognosis in children and adolescents

Bell, DS *et al*. Thirteen year follow up of children and adolescents with chronic fatigue syndrome. Pediatrics, 2001, 107 (5): 994–998.

Rowe KS. Long term follow up of young people with chronic fatigue syndrome attending a pediatric outpatient service. Frontiers Paediatrics, 2019, 7, 21.

Rowe K. Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) in Adolescents: Practical Guidance and Management Challenges. Adolescent Health Med Ther, 2023 Jan 4;14:13-26.

Functional status and quality of life

Aylward (M), Chief Medical Adviser Re: Government's expert group has reached consensus on prognosis of chronic fatigue syndrome, BMJ Letter, (05 October 1996).

MEDICAL MATTERS

Medical Matters features questions asked by Members of the ME Association on health-related topics.

Dr Charles Shepherd and the MEA's other advisers answer these questions by sharing their expert knowledge.

Medical Matters is based on the popular 'Ask the Doctor' series in ME Essential magazine.

It is a free resource that supplements the detailed information contained in the full range of literature that can be found on our website.

https://meassociation.org.uk/medm

ADDITIONAL INFORMATION

Buchwald, D *et al*. Functional status in patients with chronic fatigue syndrome, other fatiguing illnesses, and healthy individuals. American Journal of Medicine, 1996, 101, 364 – 370.

Eaton- Fitch N, Johnston SC, Zalewski P, *et al*. Health-related quality-of-life in patients with myalgic Encephalomyelitis/Chronic fatigue syndrome: an Australian cross- sectional study. Qual Life Research 2020, 29, 1521–31.

Hvidberg MF, *et al*. The Health-Related Quality of Life for Patients with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). PLoS ONE, 2015, 10(7).

Kingdon C, *et al*. Functional status and well-being in people with myalgic encephalomyelitis/chronic fatigue syndrome compared with people with multiple sclerosis and healthy controls. PharmacoEconomics Open, 2018, Mar 13.

Komaroff, AL *et al*. Health status in patients with chronic fatigue syndrome and in the general population and disease comparison groups. American Journal of Medicine, 1996, 101, 281 – 290.

Muirhead NL *et al*. Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Impact on Quality of Life (QoL) of Persons with ME/CFS. Medicina (Kaunas), 2024, Jul 27, 60(8):1215.

Nacul LC, *et al*. The functional status and well-being of people with myalgic encephalomyelitis/chronic fatigue syndrome and their carers. BMC Public Health, 2011a, 11: 402.

Rakib, A *et al*. Subjective quality of life in patients with chronic fatigue syndrome. Quality of Life Research, 2005, 14, 11-19.

Schweitzer, R *et al*. Quality of life in chronic fatigue syndrome. Social Science Medicine, 1995, 41, 1367 – 1372.

Vyas J, *et al*. Impact of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) on the quality of life of people with ME/CFS and their partners and family members: an online cross-sectional survey.

BMJ Open, 2022 May 2, 12(5):e058128.

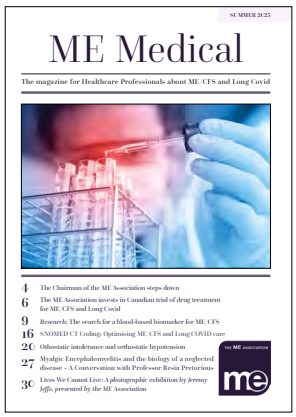
Winger A, *et al*. Health related quality of life in adolescents with chronic fatigue: a cross-sectional study. Health and Quality of Life Outcomes, 2015, 13: 96.

ME ASSOCIATION FREE LITERATURE

- Awareness
- Benefits
- Carers and social care
- Children and Young People
- Covid-19, Long Covid and ME/CFS
- Diagnosis
- Diet and Nutrition
- Education and Employment
- Emotional Health
- Management
- Medication
- NICE Guideline
- Symptoms
- Research Reviews
- Travel
- Vaccinations
- Vitamins and Supplements

https://meassociation.org.uk/fdwc

"Thank you for producing such a helpful magazine. The standard is consistently high and each edition is interesting and varied. I need all the help I can get and this magazine is consistently encouraging, realistic, and helpful."



HOW WE CAN HELP

■ **COMMUNITY:** We provide a safe and welcoming community for people affected by ME/CFS and Long Covid who come together and benefit from sharing their experiences. We provide membership, an essential support service, excellent website resources and we host engaging discussions on the most popular social media channels. Knowing that you are not alone can be a great comfort and we are happy to answer your questions and share helpful tips.

■ **MEMBERSHIP:** We put the interests of members at the heart of everything we do. Your subscription means that we can support more people, campaign more effectively and fund more medical research. Members receive the exclusive ME Essential magazine which carries the latest news, medical information, personal stories, and feature articles. **Join us today**.

■ **SUPPORT:** ME Connect is the charity's support and information service. We listen and we understand. All our staff and volunteers have knowledge and understanding of these medical conditions. We provide a personalised service and we're here when you need us most. You can contact us via our telephone support line (this is a freephone number) or by email. Please see back page for more details. To view the ME Connect telephone support line opening hours, please visit: **https://www.meassociation.org.uk/me-connect**

■ **INFORMATION:** We produce reliable and timely information written by topic experts and have the **largest range of free literature covering all aspects of life with ME/CFS and Long Covid**. We can show you how to recognise and manage symptoms, get an accurate diagnosis, a referral to specialists, and to obtain the healthcare that you deserve. We also provide an **e-newsletter** and free access on the website to **Medical Matters** and other relevant information.

■ **RESEARCH:** We fund medical research via the **Ramsay Research Fund** and are especially interested in research that can find diagnostic markers, causes, and treatments. We support the UK ME/CFS Biobank and the Manchester Brain Bank, and have invested over £1m in medical research in the last 10 years.

■ **MEDICAL EDUCATION:** We arrange training for healthcare professionals, offer a medical magazine, ME Medical, and are working with the Government, NHS, Royal Colleges of Medicine, and Local Authorities to implement the recommendations of the 2021 NICE Clinical Guideline on ME/CFS – the successful result of 14 years lobbying and hard work.

"The MEA is doing exactly what it said it would by providing support, actively lobbying for recognition, improvements to health and social care, and funding biomedical research."

The ME Association
7 Apollo Office Court
Radclive Road,
Gawcott
Buckinghamshire
MK18 4DF

Tel: 01280 818963

Email: admin@meassociation.org.uk

Registered Charity Number 801279

HOW WE CAN HELP

■ **LOBBYING:** We campaign to raise awareness and bring about positive change. We believe in collaboration and work with the NHS and social care services, the Department of Health and Social Care, the British Association of Clinicians in ME/CFS (BACME), Forward-ME, the ME Research Collaborative (MERC), DecodeME, the All-Party Parliamentary Group (APPG) on ME, Physios4ME, the Chronic Illness Inclusion project (CII), Hidden Disabilities Sunflower, and Long Covid initiatives.

■ **HEALTH & SOCIAL CARE:** The charity works with healthcare providers to successfully implement the NICE Guideline recommendations on ME/CFS and Long Covid to ensure that everyone receives the very best healthcare, wherever they live in the UK. We want well-trained healthcare professionals providing excellent services because timely intervention can lead to better health outcomes and improved quality of life.

■ **DONATIONS:** In order to help more people and invest in medical research we depend on your generosity. If you feel able to make a donation or want to raise funds in other ways, please get in touch with the fundraising team: fundraising@meassociation.org.uk or you can **make a direct donation via the website.**

WHAT ARE ME/CFS AND LONG COVID?

We answer key questions about these medical conditions and compare similarities and differences. You'll also find the NICE Guideline reproduced in full in an easy-to-use database.

MEDICAL MATTERS

Medical Matters is an easy to use online supplement to the more detailed literature. The same topic experts provide answers to commonly asked questions.

NHS REFERRAL SERVICES

If you need to locate an ME/CFS specialist service or Long Covid Clinic then we can help. We have listed all secondary care referral services in an easy-to-use database.

THE ME ASSOCIATION

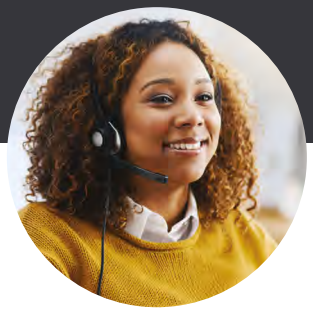
ME CONNECT

The Support and Information Service for people affected by ME/CFS/PVFS and Long Covid

HOW TO GET IN TOUCH:
by phone or email

Freephone 0808 801 0484

For opening hours visit:
meassociation.org.uk/mec



HERE TO LISTEN

We are here to listen, validate and empathise with any issues you might be facing.

VITAL SUPPORT

We are here to help you reach an informed decision.

SAFE ENVIRONMENT

We provide a safe, confidential and understanding environment where you can be heard and understood.

We're here for you!

meconnect@meassociation.org.uk

For all information relating to ME Connect visit: https://meassociation.org.uk/mec