Infection Associated Chronic Conditions:

ME/CFS and Long Covid

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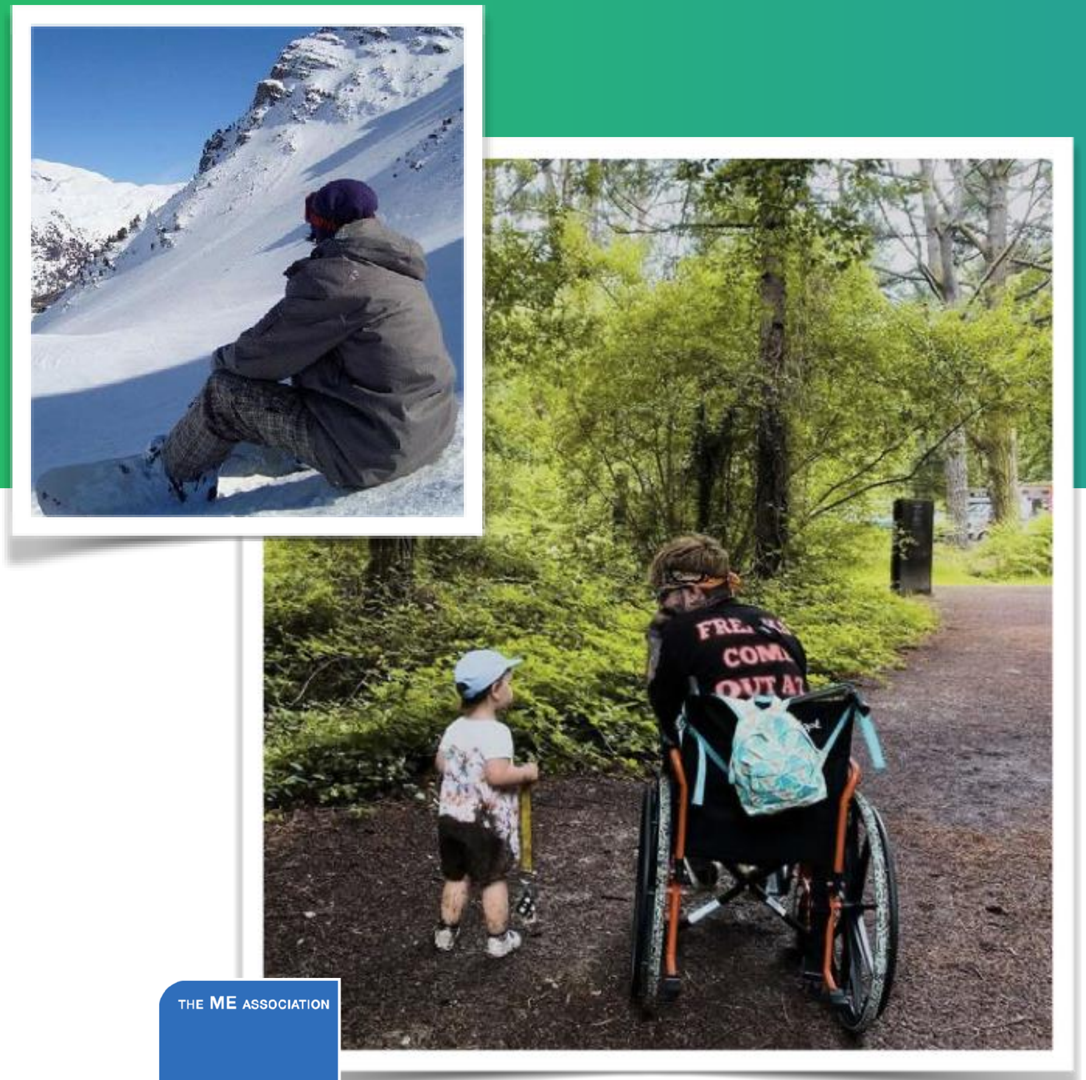

The ME Association

ABOUT YOUR CHARITY

We Deliver

The ME Association has been providing expert help since 1980. We have established an excellent reputation over the last 45 years and consistently deliver high standards. We believe that nobody should struggle alone and are committed to improving health and social care for all.

Covid-19 Pandemic

During the pandemic, we were quick to recognise the similarities between ME/CFS and Long Covid and have been welcoming people with Long Covid to the community in increasing numbers ever since.

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Changing attitudes and improving lives…

Professional Support

Expert Knowledge

Reliable Information

Raising Awareness

Improving Health & Social Care

Investing in Medical Research

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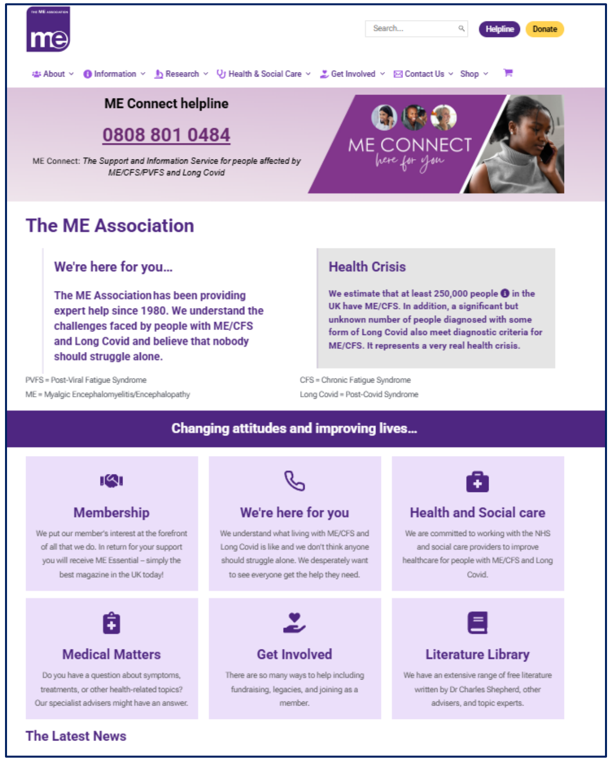
Changing attitudes and improving lives…

Improving Health and Social Care

- MEA Healthcare Team: Pilot.
- The National Institute for Health and Care Excellence (NICE): Clinical Guideline (Oct. 2021).
- The Department of Health and Social Care (DHSC) & NHS England: Delivery Plan (2022-2025).
- NHS England, NHS Wales, NHS Scotland, NHS Northern Ireland: Integrated Specialist Services?
- 28% ICBs approved integration reviews incl. SNEE which has just accepted a £5.5M bid for a new ME/CFS and Long Covid specialist service.

Investing in Medical Research

- MEA Ramsay Research Fund = biomedical and healthcare research.
- £3,000,000 invested to 2025 (January):
  - Incl. £750,000 UK ME/CFS Biobank at the London School of Hygiene & Tropical Medicine.
- Major new biomedical investments approved in 2025. Including:
  - £570,000 clinical trial in Canada of Low-Dose Naltrexone, and,
  - The largest ever study examining causes and potential treatments from a UK charity!



ME Connect helpline

0808 801 0484

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

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We're here for you...

The ME Association has been providing expert help since 1980. We understand the challenges faced by people with ME/CFS and Long Covid and believe that nobody should struggle alone.

Health Crisis

We estimate that at least 250,000 people in the UK have ME/CFS. In addition, a significant but unknown number of people diagnosed with some form of Long Covid also meet diagnostic criteria for ME/CFS. It represents a very real health crisis.

PVFS = Post-Viral Fatigue Syndrome
ME = Myalgic Encephalomyelitis/Encephalopathy
CFS = Chronic Fatigue Syndrome
Long Covid = Post-Covid Syndrome

Changing attitudes and improving lives...

Membership

We put our member's interest at the forefront of all that we do. In return for your support you will receive ME Essential – simply the best magazine in the UK today!

We're here for you

We understand what living with ME/CFS and Long Covid is like and we don't think anyone should struggle alone. We desperately want to see everyone get the help they need.

Health and Social care

We are committed to working with the NHS and social care providers to improve healthcare for people with ME/CFS and Long Covid.

Medical Matters

Do you have a question about symptoms, treatments, or other health-related topics? Our specialist advisers might have an answer.

Get Involved

There are so many ways to help including fundraising, legacies, and joining as a member.

Literature Library

We have an extensive range of free literature written by Dr Charles Shepherd, other advisers, and topic experts.

The Latest News

The ME Association Website

The ME Association

REAL LIVES

Hannah Avery shows just how life-changing this disease can be: Right Where You Left ME.


CHRISTMAS 2021

Surviving M.E.

by Russell Fleming, Communications Manager, ME Association

Back in the summer I was delighted to be asked to write a blog on my personal experience with ME/CFS for the Cabinet Office Disability Unit and I thought you might like to read about the improvements that I have been able to enjoy, especially as we enter the holiday season.

Russell Fleming wrote about ‘Surviving M.E.’ after 20 years with the disease.

IACC, PVFS, ME/CFS, and Long Covid.

What do we mean?

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Infection Associated Chronic Conditions?

PVFS

Post-Viral Fatigue Syndrome

ME

Myalgic Encephalomyelitis

CFS

Chronic Fatigue Syndrome

Long Covid

Post-Acute Sequelae of Covid-19 (PASC)

Post-Covid Syndrome

‘CFS’ is preferred by some in the medical profession because it makes no assumption as to cause, but it is disliked and viewed as inappropriate by the patient community. This is a view that the charity shares. It is like describing dementia as a ‘chronic forgetfulness syndrome’. ME/CFS is a compromise that many - including NICE, the NHS, and the DHSC - are using until we really understand what is causing and perpetuating the disease.

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ME/CFS =

Myalgic Encephalomyelitis
Myalgic Encephalopathy
Chronic Fatigue Syndrome

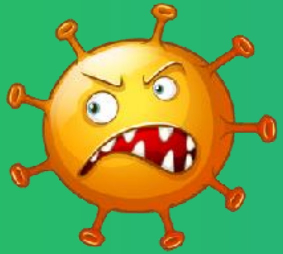
Long Covid =

Post-Acute Sequelae of Covid-19 (PASC)
Long-term Covid Syndrome
Post-Covid-19 syndrome

Triggering Infection

Viral or Bacterial

c.80% of people who develop PVFS/ME/CFS can trace the onset back to an infection that is often acute.



Types of infection

Includes any infection from Epstein Barr (Glandular Fever) to Influenza (The Flu) to previous Coronavirus outbreaks to Ebola in ME/CFS and Covid-19 in Long Covid.

Failure to Fully Recover

Research suggests c.5-10% of people acutely affected by a viral or bacterial infection are at risk of not recovering fully and developing a chronic disease state.

Post-Viral Fatigue Syndrome

Main symptoms often like the triggering infection with additional complications or damage often resulting in a loss of mobility and energy and an inability to perform previous activities with greater reliance on other people for help and support.

Infection Associated Chronic Disease?

Why might someone develop ME/CFS?

01

Predisposing factors

Predisposing factors could include a genetic component, meaning that certain people are at higher risk, which might explain in ME/CFS why more than one family member can be affected.

02

Precipitating factors

Precipitating factors commonly include infections, viral such as EBV or Covid-19, or bacterial, but in ME/CFS can occasionally include vaccinations or exposure to a toxin or pesticide.

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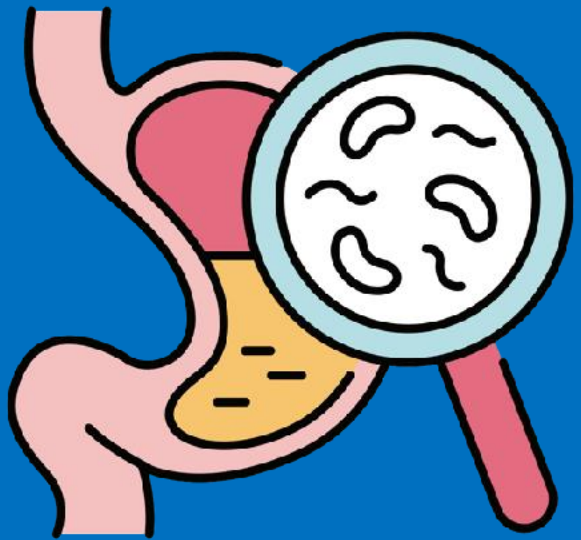
Why might someone develop ME/CFS?

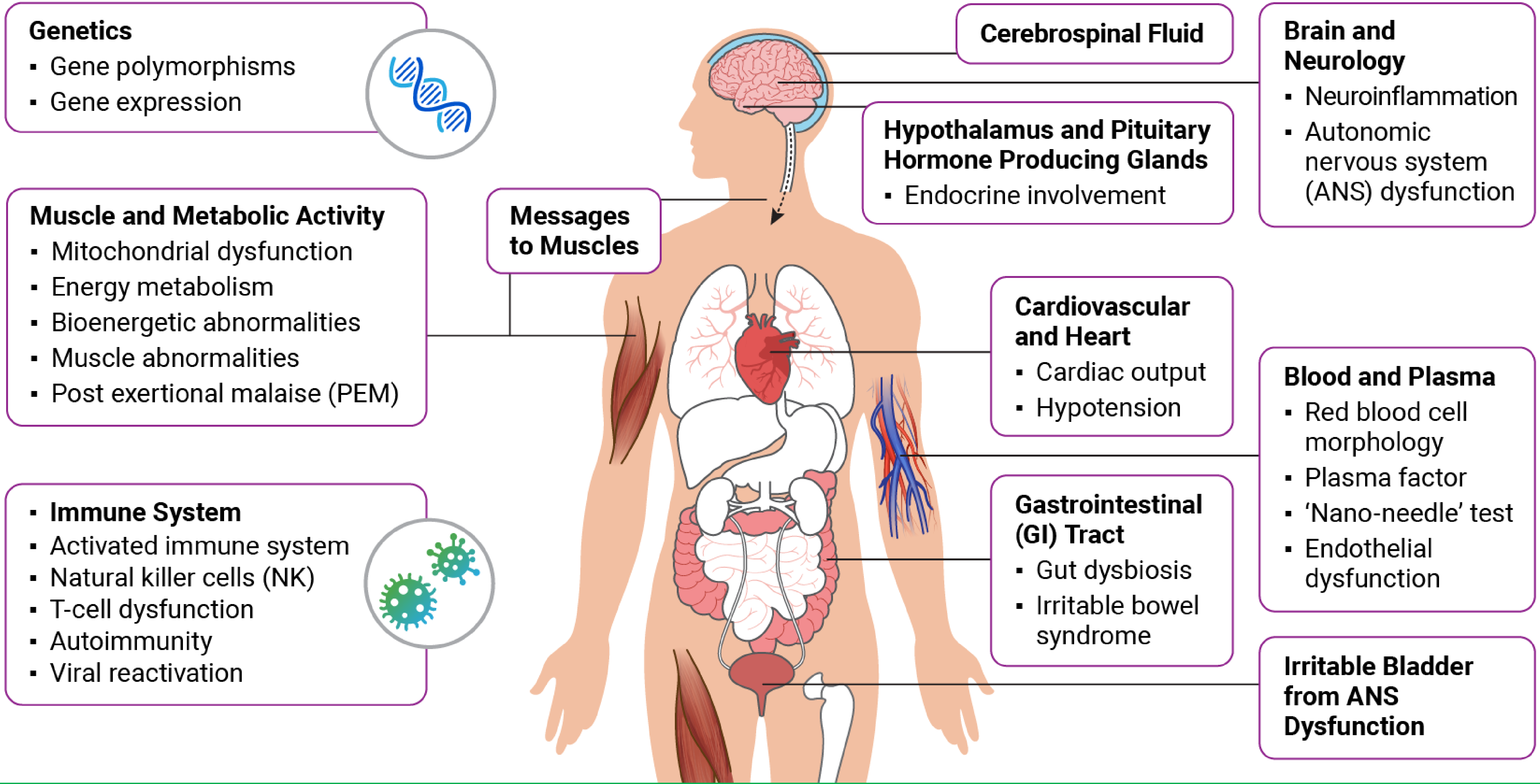
03



Perpetuating factors

Abnormalities that have been found which might contribute to increased functional impairment include:

- Blood and plasma.
- Cardiac dysfunction.
- Cellular dysfunction.
- Gene expression problems.
- Immunological dysfunction/viral reactivation.
- Metabolomic (small molecules) dysfunction.
- Microbiome disturbances (dysbiosis).
- Mitochondria, Cellular Bioenergetics and problems affecting Exercise Physiology.
- Neurological (central, peripheral and autonomic nervous system abnormalities).
- Hypothalamic-pituitary-adrenal Axis problems (Hormones).



Genetics
- Gene polymorphisms
- Gene expression

Muscle and Metabolic Activity
- Mitochondrial dysfunction
- Energy metabolism
- Bioenergetic abnormalities
- Muscle abnormalities
- Post exertional malaise (PEM)

- **Immune System**
- Activated immune system
- Natural killer cells (NK)
- T-cell dysfunction
- Autoimmunity
- Viral reactivation

Messages to Muscles

Cerebrospinal Fluid

Hypothalamus and Pituitary Hormone Producing Glands
- Endocrine involvement

Brain and Neurology
- Neuroinflammation
- Autonomic nervous system (ANS) dysfunction

Cardiovascular and Heart
- Cardiac output
- Hypotension

Blood and Plasma
- Red blood cell morphology
- Plasma factor
- 'Nano-needle' test
- Endothelial dysfunction

Gastrointestinal (GI) Tract
- Gut dysbiosis
- Irritable bowel syndrome

Irritable Bladder from ANS Dysfunction

UK Prevalence of

ME/CFS and LC

ME/CFS = 440,000+
2 x Multiple Sclerosis
ME/CFS & Long Covid = 1,400,000+

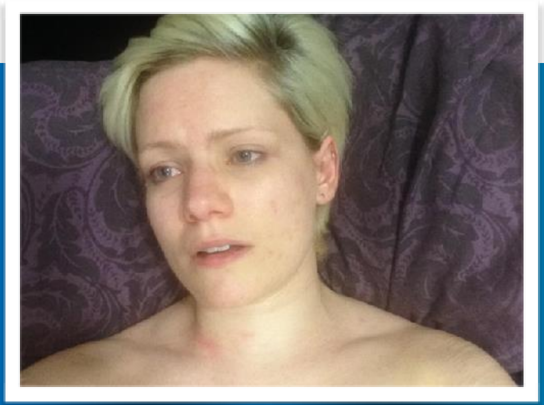
- ME/CFS = 0.6% LC = 2.6%
- Latest ME/CFS epidemiology research (2025).
- Both are indiscriminate affecting people of all ages, ethnicities, and socio-economic backgrounds.

4:1 Ratio

More women
than men

- 25% could be severely or very severely affected at any one time.
- ME/CFS likely to develop between the ages of 10 - 19 and 30 - 39.
- ME/CFS = £3.3bn Long Covid = £20bn, annual economic cost.

- We don’t know how many people have a clinical diagnosis of ME/CFS or Long Covid.
- It has been suggested that most people are undiagnosed and do not receive any support.
- 45+ NHS ME/CFS Specialist Services and 100+ Long Covid Clinics in England in 2024.
- Integrated ME/CFS & LC services are being developed, but LC services are closing.



ME/CFS and Long Covid: More than ‘chronic fatigue’

- Fatigue reduces energy, the ability to do things and focus. Ongoing fatigue affects the quality of a person’s life.
- Almost everyone feels it during short-term illness. Fortunately, fatigue usually goes away when the illness is over.
- Sometimes fatigue can be traced to one or more lifestyle issues, such as poor sleep habits or lack of exercise, that can be corrected.
- Chronic Fatigue is a common symptom in many different diseases and is NOT caused by lifestyle factors.
- It doesn’t get better with rest and can coexist or even dominate other symptoms.
- We don’t know why this kind of fatigue occurs and there are no drug treatments.

ME/CFS and Long Covid: More than ‘chronic fatigue’

Chronic fatigue is a debilitating symptom in any of the following:

- Adrenal insufficiency
- Amyotrophic lateral sclerosis (ALS)
- Anemia
- Anxiety disorders
- Cancer
- Chronic infection or inflammation
- Chronic kidney disease
- COPD (chronic obstructive pulmonary disease)
- Covid-19
- Depression and other mood disorders
- Diabetes
- Fibromyalgia
- Heart disease
- Heart failure
- Hepatitis A, B, and C
- HIV/AIDS
- Hyperthyroidism (overactive thyroid)
- Hypothyroidism (underactive thyroid)
- Inflammatory bowel disease (IBD)

ME/CFS and Long Covid: More than ‘chronic fatigue’

Chronic fatigue is a debilitating symptom in any of the following:

- Liver disease
- Long Covid
- Low vitamin D
- Lupus
- Mononucleosis/Glandular Fever
- Multiple sclerosis
- Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)
- Obesity
- Parkinson's disease
- Polymyalgia rheumatica
- Rheumatoid arthritis
- Sleep apnea
- Traumatic brain injury

THE NICE GUIDELINE ON ME/CFS

‘It has been estimated that c.50% of people who developed Long Covid meet the diagnostic criteria for ME/CFS…’ MEA.

Things to be aware of with ME/CFS

It is a complex, chronic medical condition affecting multiple body systems and its pathophysiology is still being investigated.

It affects everyone differently and its impact varies widely – some people can initiate and complete certain activities, whereas in others the same activities cannot be done, or can’t be done without substantial incapacity.

It is a fluctuating condition in which a person's symptoms can change unpredictably in nature and severity over a day, a week or longer.

It can affect different aspects of the lives of both people with ME/CFS and their families and carers, including activities of daily living, family life, social life, emotional wellbeing, work and education.

Recognise that people with ME/CFS may have experienced prejudice and disbelief and could feel stigmatised by people (including family, friends, health and social care professionals, and teachers) who do not understand their illness.

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THE NICE GUIDELINE ON ME/CFS

‘Definitions of severity are not clear cut because individual symptoms vary widely in severity and people may have some symptoms more severely than others. The definitions used here provide a guide to the level of impact of symptoms on everyday functioning.’ NICE.

FLUCTUATING

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Illness Severity Definitions

1. People with MILD ME/CFS:

- can generally care for themselves and manage light domestic tasks (may need support) but might have difficulties with mobility.
- most are still working or in education, but to do this they have probably stopped all leisure and social pursuits.
- they often have reduced hours, take days off and use the weekend to cope with the rest of the week..

2. People with MODERATE ME/CFS:

- have reduced mobility and are restricted in all activities of daily living, although they may experience fluctuations in symptoms and abilities.
- they have usually stopped work or education, and need rest periods, often resting in the afternoon for 1 or 2 hours.
- their sleep at night is generally poor quality and disturbed.

3. People with SEVERE ME/CFS:

- are unable to do any activity for themselves or can carry out minimal daily tasks only (such as face washing or cleaning teeth).
- they have severe cognitive difficulties and may depend on a wheelchair for mobility.
- they are often unable to leave the house or have a severe and prolonged after-effect if they do so.
- they may also spend most of their time in bed and are often extremely sensitive to light and sound.

4. People with VERY SEVERE ME/CFS:

- are in bed all day and dependent on care.
- they need help with personal hygiene and eating and are very sensitive to sensory stimuli.
- some people may not be able to swallow and may need to be tube fed.

Suspect ME/CFS if:

THE NICE GUIDELINE

‘Explain to people presenting with possible symptoms that there is no diagnostic test for ME/CFS, and it is recognised on clinical grounds alone…’

NICE.

01

- the person has had all the persistent symptoms (below) for a minimum of 6 weeks in adults and 4 weeks in children and young people and…

02

- the person's ability to engage in occupational, educational, social or personal activities is significantly reduced from pre-illness levels and…

03

- symptoms are not explained by another condition.

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Diagnosing ME/CFS
All these symptoms should be present:

01

Debilitating fatigue that is worsened by activity, is not caused by excessive cognitive, physical, emotional or social exertion, and is not significantly relieved by rest.

02

Post-exertional malaise after activity in which the worsening of symptoms:
- is often delayed in onset by hours or days
- is disproportionate to the activity
- has a prolonged recovery time that may last hours, days, weeks or longer

03

Unrefreshing sleep or sleep disturbance (or both), which may include:
- feeling exhausted, feeling flu-like and stiff on waking
- broken or shallow sleep, altered sleep pattern or hypersomnia

04

Cognitive difficulties (sometimes described as 'brain fog'), which may include problems finding words or numbers, difficulty in speaking, slowed responsiveness, short-term memory problems, and difficulty concentrating or multitasking.

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The NICE Guideline on ME/CFS

ME/CFS GUIDE FOR PRIMARY CARE

INTRODUCTION

ME/CFS IS A COMPLEX MULTISYSTEM DISEASE THAT INVOLVES THE BRAIN, MUSCLE AND IMMUNE SYSTEM.

- It affects at least **250,000 people in the UK** and often has a significant impact on functional ability and quality of life.
- All age groups are affected - including children and young people. The commonest age of onset is during early and mid adult life.
- Around 25% of people are severely or very severely affected - meaning they are housebound and in some cases bedbound.
- This provides an overview of what to do in primary care and when to refer to secondary care - the information is based on the new NICE guideline on ME/CFS.
- ME/CFS is recognised in the NHS SNOMED-CT coding system.

SUSPECT ME/CFS

- When a patient is failing to return to normal health after a viral infection - the commonest triggering factor.
- ME/CFS can also be triggered by vaccinations and other immune system stressors.
- In a minority there is no clear triggering event and symptoms develop gradually.

DIAGNOSE ME/CFS

When the following symptoms, which often fluctuate in severity, persist for three months or more and there is no other explanation:

- Debilitating fatigue that is made worse by minimal exertion.
- Post exertional malaise / symptom exacerbation - where there is a delay in exacerbation of symptoms after physical or cognitive activity and a prolonged recovery period.
- Unrefreshing sleep or sleep disturbance.
- Cognitive dysfunction ('brain fog') involving problems with short-term memory, attention span, information processing, word finding ability.
- Orthostatic intolerance or other symptoms relating to dysautonomia.
- People with ME/CFS will often report feeling flu-like with sore throats and tender glands and are generally unwell.

Many of these symptoms also occur in Long-Covid and a significant proportion of people with Long Covid meet diagnostic criteria for ME/CFS.

RED FLAGS

A more thorough clinical assessment is required in older age groups, where there is no clear triggering event, and where there are more unusual or prominent symptoms, abnormal examination findings or abnormal blood test results.

For example:
- Weight loss
- Painful swollen joints
- Enlarged lymph glands
- Raised inflammatory markers - ESR and CRP

DIFFERENTIAL DIAGNOSIS

This should always include common conditions that produce fatigue and ME/CFS like symptoms and less common conditions where the history, examination or blood test findings are not typical of ME/CFS.

Examples:
- Addison's disease
- Fibromyalgia
- Hypothyroidism
- Hepatitis C infection
- Lyme disease
- Multiple sclerosis
- Primary biliary cirrhosis
- Sleep apnoea

ASSOCIATED SYMPTOMS

May include:

Central nervous system
- Alcohol intolerance
- Dysautonomia - postural orthostatic tachycardia syndrome/PoTS, cold hands and feet
- Fasciculations and myoclonic jerks
- Headaches
- Hypersensitivity to light, sound, touch and some medications
- Poor temperature control
- Pain - which can affect muscles, nerves or joints

Ear, nose and throat
- Tinnitus

Gastrointestinal
- Irritable bowel type symptoms

CO-MORBID CONDITIONS

May include:
- Endometriosis
- Hypermobility
- Interstitial cystitis
- Irritable bowel syndrome
- Mast cell activation syndrome
- Migraine type headaches
- PoTS

INVESTIGATIONS

The following investigations should always be checked, and reported as normal, before confirming the diagnosis:

- C-reactive protein and/or ESR
- Calcium and phosphate
- Coeliac screening
- Creatine kinase
- Full blood count
- HbA1c
- Liver, renal and thyroid function
- Serum ferritin
- Urea and electrolytes
- Urinalysis for blood, protein and glucose

Further investigation required in selected cases. Examples:
- **NASA lean test - if PoTS is suspected**
- **Vitamin B12**
- **9am serum cortisol for adrenal insufficiency**

WHAT CAN THE PRIMARY CARE TEAM DO?

- Make an accurate and early diagnosis
- Believe and empathise with the way in which ME/CFS is impacting on all aspects of normal life
- Provide information and guidance on activity and symptom management in line with the updated NICE guidance on ME/CFS
- Help with benefits, disability aids, education, employment, social care
- Carry out regular monitoring and review.

SPECIALIST REFERRAL SERVICES

- The NICE guideline on ME/CFS recommends that GPs should refer people with ME/CFS to a specialist ME/CFS service to confirm the diagnosis and provide a care and management programme.
- This should include a domiciliary service for people with severe or very severe ME/CFS.
- People with severe ME/CFS often experience difficulties with eating, swallowing and digestion and require expert guidance on nutritional support.
- The MEA website has a directory of all the UK ME/CFS referral services.

INFORMATION AND SUPPORT

The ME Association is one of the leading charities that provides information and support to people with ME/CFS and their carers – through the website, social media channels and ME Connect helpline and message service.

We provide a range of literature that is available as free downloads and using our medical education budget, we can supply free resources for healthcare professionals. Please scan the QR code for more information.

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meassociation.org.uk

Registered UK Charity 801279

THE NICE GUIDELINE ON ME/CFS

‘Co-morbid conditions are separate illnesses that are (or appear to be) more common or are linked in some way to a health condition that you already have.’ MEA.

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Diagnosis & Comorbidities…

If ME/CFS is suspected, carry out:

- a medical assessment (including symptoms and history, comorbidities, overall physical and mental health).
- a physical examination.
- an assessment of the impact of symptoms on psychological and social wellbeing.
- investigations to exclude other diagnoses…

In the case of ME/CFS there are several conditions that you are more likely to develop at some stage in your illness. These include:

- allergies such as hay fever
- chemical sensitivities
- fibromyalgia
- hypermobile joint syndromes
- interstitial cystitis
- irritable bowel syndrome symptoms
- migraine-type headaches
- postural orthostatic tachycardia syndrome (PoTS)

There are also some other conditions where the evidence of a link to ME/CFS is less certain. These include endometriosis, mast-cell activation syndrome and tempero-mandibular joint dysfunction. Having ME/CFS does place people at increased risk of developing one or more of these conditions as time goes on. But some people won’t develop any of them at all.

THE NICE GUIDELINE ON ME/CFS

Other Common Symptoms

01

Orthostatic intolerance and autonomic dysfunction

Including dizziness, palpitations, fainting, nausea on standing or sitting upright from a reclining position

02

Temperature hypersensitivity

Including profuse sweating, chills, hot flushes, or feeling very cold

03

Neuromuscular symptoms

Including twitching and myoclonic jerks

Primary healthcare professionals should consider seeking advice from an appropriate specialist if there is uncertainty about interpreting signs and symptoms and whether an early referral is needed. For children and young people, consider seeking advice from a pediatrician.

04

Flu-like symptoms

Including sore throat, tender glands, nausea, chills or muscle aches

05

Intolerances

Intolerance to alcohol, or to certain foods and chemicals

06

Heightened sensory sensitivities

Including to light, sound, touch, taste and smell

07

Pain

Including pain on touch, myalgia, headaches, eye pain, abdominal pain or joint pain without acute redness, swelling or effusion

ME/CFS

Severe and Very Severe

Additional symptoms

- Severe and constant pain, which can have muscular, arthralgic or neuropathic features
- Hypersensitivity to light, sound, touch, movement, temperature extremes and smells
- Extreme weakness, with severely reduced movement
- Reduced ability or inability to speak or swallow
- Cognitive difficulties that limit the person's ability to cope with written or verbal communication
- Sleep disturbance such as unrefreshing sleep, hypersomnia and altered sleep pattern
- Gastrointestinal difficulties such as nausea, incontinence, constipation and bloating
- Neurological symptoms such as double vision and other visual disorders, dizziness
- Orthostatic intolerance and autonomic dysfunction, such as postural orthostatic tachycardia syndrome (POTS) and postural hypotension

THE NICE GUIDELINE

Be aware that people with severe or very severe ME/CFS may experience the following symptoms that significantly affect their lives, including their mobility, emotional wellbeing and ability to interact with others and care for themselves

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ME/CFS & Long Covid Symptom Similarities

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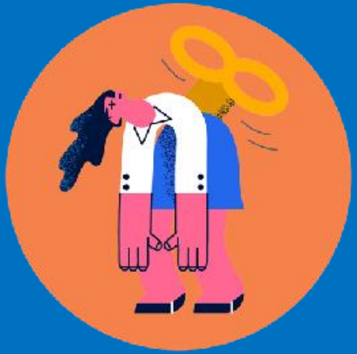
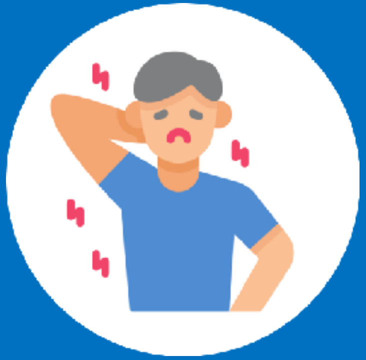
Debilitating physical and mental fatigue


Post-exertional malaise/symptom exacerbation


Pain


Cognitive dysfunction (brain fog)


Flu-like symptoms and feeling generally unwell


Dysautonomia


Sleep disturbance


Headaches that can be migrainous


Poor temperature control


Sensory disturbances

ME/CFS/LC Specialist Services

‘Specialist services are based in a hospital setting and provide outpatient appointments delivered in person or remotely and should be able to visit severely and very severely affected patients at home.’ NICE.

‘They should offer a range of healthcare professionals with training and experience in assessing, diagnosing, treating and managing ME/CFS. These teams should commonly include medically trained clinicians from a variety of specialisms including…’ NICE.

- Rheumatology
- Rehabilitation medicine
- Endocrinology
- Infectious diseases
- Neurology
- Immunology
- General Practice

‘They provide access to other healthcare professionals specialising in ME/CFS and these may include physiotherapists, exercise physiologists, occupational therapists, dietitians, and clinical or counselling psychologists.’ NICE.

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ME/CFS/LC Specialist Services

Assessment, Tailored Management Advice and Care and Support Plans

- Complete a holistic assessment to confirm the person's diagnosis and inform their **care and support plan**.
- Provide care for people with ME/CFS using a coordinated multidisciplinary approach.
- Discuss the principles of energy management, the potential benefits and risks and what they should expect.
- Advise how to manage flare-ups and relapses.
- Make self-monitoring of activity as easy as possible.
- Do not advise people with ME/CFS to undertake exercise that is not part of a programme overseen by an ME/CFS specialist team.
- Do not offer people with ME/CFS graded exercise therapy.
- Advise people with ME/CFS about:
  - Rest and sleep.
  - Physical functioning and mobility.
  - Orthostatic intolerance.
  - Medicines for symptom management.
  - Dietary management and strategies.
  - **Mental health and wellbeing.**
  - Managing coexisting conditions.
- Provide additional considerations for people with severe and very severe ME/CFS.
- Offer a **primary care review** at least once a year:
  - or more frequent reviews as required depending on severity and need.

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The NICE Guideline on ME/CFS

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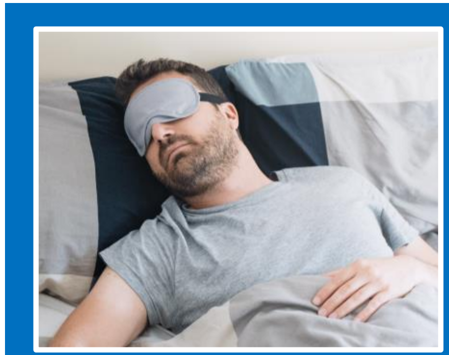
NICE Approved Treatment Approaches

‘…find ways of minimising complications caused by gastrointestinal symptoms (such as nausea), changes to appetite, swallowing difficulties, sore throat or difficulties with buying, preparing and eating food.’

Symptom Management

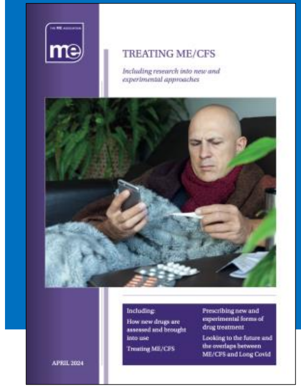


Rest and Sleep

Physical functioning and mobility

Pain

Medicines



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TREATING ME/CFS

Including research into new and experimental approaches

Including:

How new drugs are assessed and brought into use

Treating ME/CFS

Prescribing new and experimental forms of drug treatment

Looking to the future and the overlaps between ME/CFS and Long Covid

APRIL 2024

Treating ME/CFS

Find out what is available, how the different treatment approaches can help, about potential new treatments that are being researched, and the overlap of treatments with Long Covid.

https://meassociation.org.uk/jjho

Orthostatic intolerance

Dietary management

Cognitive behavioural therapy

NICE Approved Treatment Approaches

‘Be aware that ME/CFS symptoms can be managed but there is currently no cure (non-pharmacological or pharmacological) for ME/CFS’ NICE.

Energy Management

A self-management strategy that involves a person with ME/CFS managing their activities to stay within their energy limit, with support from a healthcare professional:

includes all types of activity (cognitive, physical, emotional and social) and considers overall level of activity.

helps people learn to use the amount of energy they have while reducing their risk of post-exertional malaise or worsening their symptoms by exceeding their limits.

recognises that each person has a different and fluctuating energy limit, and they are experts in judging their own limits.

uses a flexible, tailored approach so that activity is never automatically increased but is maintained or adjusted (upwards after a period of stability or downwards when symptoms are worse).

is a long-term approach − it can take weeks, months or sometimes even years to reach stabilisation or to increase tolerance or activity.

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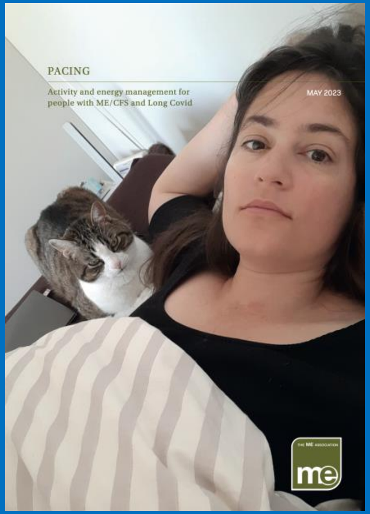


PACING

Activity and energy management for people with ME/CFS and Long Covid

MAY 2023

Pacing: Activity and Energy Management

We explain how you can safely manage functional incapacity by using a management approach known as Pacing. It will help you learn how to live with ME/CFS and Long Covid without triggering an exacerbation of symptoms. It is consistent with the NICE Guideline on ME/CFS.

https://meassociation.org.uk/h8qj

OVERALL MANAGEMENT OF ME/CFS

RESOURCES

NICE guideline on ME/CFS (NG206): https://www.nice.org.uk/guidance/ng206

MEA information leaflets cover all aspects of symptom management: https://meassociation.org.uk/free-literature-downloads/

ME Connect helpline provides information and support to people with ME/CFS: Freephone: 0808 801 0484 Email: meconnect@meassociation.org.uk

NHS referral services on the MEA website directory: https://meassociation.org.uk/nhs-specialist-services-me-cfs-lc/

THE ME ASSOCIATION
meassociation.org.uk
Registered UK Charity 801279

1 EARLY & ACCURATE DIAGNOSIS

- ME/CFS often follows a viral infection. Suspect ME/CFS when someone is failing to recover from an infection or another immune system stressor.
- Confirm the diagnosis when four key symptoms – activity induced fatigue, post exertional malaise (PEM), cognitive dysfunction and unrefreshing sleep - have persisted for three months.
- Exclude other conditions that have ME/CFS symptoms.

2 PROVIDE INFORMATION & GUIDANCE

Provide information and guidance as soon as the diagnosis is suspected:

- ME/CFS is a complex medical condition involving the muscle, brain and immune system.
- Symptoms often fluctuate in both nature and severity. Relapses and exacerbations are often triggered by new infections.
- Good initial management improves the likelihood of stabilisation and improvement but there is no effective treatment for the underlying disease process. Some people find alternative treatments helpful but there is no sound evidence of efficacy.
- Prognosis is difficult to predict but ME/CFS often becomes a long-term condition that has a significant effect on quality of life.

3 RECOGNISE & MANAGE CO-MORBIDITIES

Recognise and manage co-morbidities that may be present. Examples include:

- Joint Hypermobility Syndrome (JHS)
- Interstitial Cystitis
- Irritable Bowel Syndrome (IBS)
- Mast Cell Activation Syndrome (MCAS)
- Migraine type headaches
- Postural Orthostatic Tachycardia Syndrome (PoTS)

4 WHO SHOULD MANAGE PEOPLE WITH ME/CFS?

- Refer to a specialist ME/CFS service for confirmation of the diagnosis, further management advice and preparation of an individualised care and support plan.
- Most of the on-going management should take place in primary care.
- Regularly review progress, especially if there is any deterioration.

5 SEVERE & VERY SEVERE ME/CFS

- Around 25% are severely or very severely affected – meaning the person is often housebound and may be bed-bound.
- People with very severe ME/CFS may have problems with eating, swallowing and digesting food – making them at risk from dehydration and malnutrition.
- Home based management should include regular follow up by the primary care team and domiciliary assessment and management, where necessary, from a specialist referral team.

6 PACING: ACTIVITY & ENERGY MANAGEMENT

- Pacing mental and physical activity is the most important aspect of management.
- Pacing involves a very flexible approach to balancing activity and rest, not exceeding physical or mental limitations and not producing post exertional malaise/symptom exacerbation.
- Any increase in activity levels should be flexible, gradual and individualised.

7 SYMPTOM MANAGEMENT

- ME/CFS can cause a wide range of other symptoms including dysautonomia (orthostatic intolerance and hypotension, PoTS), sensitivity to light and sound, pain involving muscles, joints and nerves, and problems with temperature regulation.
- New symptoms should not be automatically linked to ME/CFS.
- Provide information, guidance and possibly medication for pain, sleep disturbance, dysautonomia etc.
- Pain management should be consistent with the NICE guideline on neuropathic pain.

8 DIET, NUTRITION & SUPPLEMENTS

- Explain the importance of adequate fluid intake and a well-balanced diet.
- No evidence that restrictive diets or vitamin and mineral supplements are of benefit.
- People with ME/CFS, especially when severely affected, are at risk from vitamin D deficiency, and should consider taking a daily vitamin D supplement.
- Refer people who are losing weight to a dietitian with specialist knowledge of ME/CFS.

9 DWP BENEFITS & SOCIAL CARE

- People with ME/CFS are entitled to apply for DWP sickness and disability benefits – including PIP.
- Inform and support people who are likely to require disability aids and appliances.
- Explain how to self-refer to a local authority for a social care assessment.

10 EDUCATION & EMPLOYMENT

- ME/CFS is normally covered by the 2010 Equality Act in relation to adaptions and modifications for education or employment purposes.
- For children and adolescents provide information about education, health and care (EHC) plans and how to obtain one from a local authority.
- Offer to liaise with an educational provider or employer.

ME/CFS/LC Specialist Services

Supporting people with ME/CFS in Work, Education and Training

- Offer to liaise on the person's behalf (with their informed consent) with employers, education providers and support services.

- Give them information about ME/CFS and discuss the person's care and support plan and any adjustments needed.

- Advise and discuss with people with ME/CFS that:

    - they may be able to access reasonable adjustments or adaptations (in line with the Equality Act 2010) to help them continue or return to work or education.

    - there may be times when they are unable to continue with work or education.

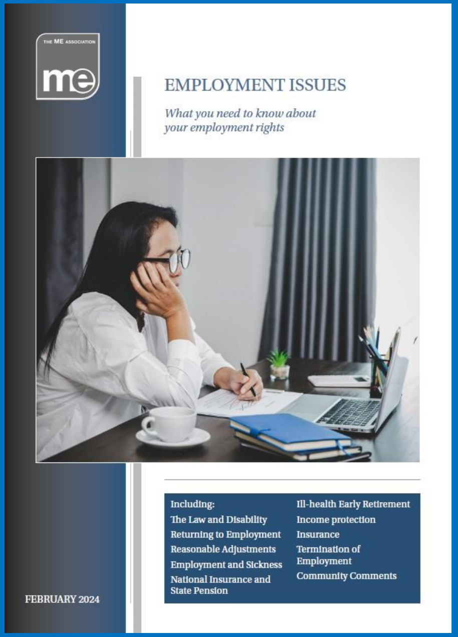
    - some people find that going back to work, school or college worsens their symptoms.

Returning to employment

- ME/CFS is recognised by the 2010 Equality Act:
    - employers should do all they can be reasonably expected to do to find out if an employee is disabled and in need of support.

- Reasonable adjustments:
    - A phased return.
    - Flexible hours.
    - Part-time.
    - Remote working.
    - Accessibility: wheelchair users etc.
    - Quieter work area.
    - Job-share.
    - Disability leave.
    - Modified equipment.
    - Supervision.

    - More information in MEA Employment Issues:



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EMPLOYMENT ISSUES

What you need to know about your employment rights

Including:
The Law and Disability
Returning to Employment
Reasonable Adjustments
Employment and Sickness
National Insurance and State Pension
Ill-health Early Retirement
Income protection
Insurance
Termination of Employment
Community Comments

FEBRUARY 2024

The NICE Guideline on ME/CFS

THE ME ASSOCIATION

We will continue to search for a cure, but we can’t do it without your help

Please consider supporting the ME Association

A small monthly donation through payroll giving

Getting together a team for a challenge event

Or just helping to spread the word

Whatever you can do will help us, thank you

- **A full range of over 100 booklets are available to download for free from the charity's website.**
- **If you would like to get in touch about anything we have discussed today, please email: russell.fleming@meassociation.org.uk**

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EMPLOYMENT ISSUES

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TREATING ME/CFS

Including research into new and experimental approaches

Including:
How new drugs ar
assessed and broug
into use
Treating ME/CFS

APRIL 2024

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Changing Attitudes and Improving Lives...

THANK YOU

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