

THE ME ASSOCIATION

Myalgic Encephalomyelitis/  
Chronic Fatigue Syndrome (ME/CFS)

me

# COULD YOU HAVE ME/CFS?

## MAIN SYMPTOMS

The ME  
Association

CHANGING ATTITUDES,  
IMPROVING LIVES



**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.



**Post-exertional Malaise** after activity in which the worsening of symptoms: is often delayed by hours or days; is disproportionate to the activity; has a prolonged recovery time lasting hours, days, weeks, or longer.



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



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

Find out more  
[meassociation.org.uk](http://meassociation.org.uk)

LOUISA  
ME sufferer since 2011



*"My GP did not listen to me or even try to understand the symptoms I was dealing with or the life changing effects they were having. His comments were detrimental. It's been a very hard journey and I felt largely unsupported and worthless."*

## THE ME ASSOCIATION PROVIDES:

- Vital support ■ Expert knowledge
- Reliable information ■ Medical awareness
- Effective campaigning ■ Biomedical research

### MEMBERSHIP

- Stay connected ■ Stay informed
- Support your charity

### ME ESSENTIAL

YOUR QUARTERLY MEMBERS' MAGAZINE  
Simply the best magazine for people with  
ME/CFS and Long Covid  
[meassociation.org.uk/mea-membership](http://meassociation.org.uk/mea-membership)

### HELPLINE

FREEPHONE

**0808 801 0484**



/meassociation



@meassociation



/meassociation



/me-association



/meassociationUKCharity

# ME/CFS and LONG COVID

## ARE THEY **THE SAME?**



**MATTHEW**  
Long Covid sufferer  
since 2020



**JULIE**  
ME sufferer  
since 2017

The ME  
Association

CHANGING ATTITUDES,  
IMPROVING LIVES



*“Long Covid has ruined my life. My GP advised Graded Exercise Therapy (GET) and it made me feel worse every day I tried. I now know that GET is controversial among sufferers of ME/CFS and can severely hinder recovery”*

## SIMILARITIES

- Debilitating fatigue
- Muscle, joint and nerve pain
- Flu-like symptoms
- Brain fog
- Sleep disturbance
- Headaches
- Post-exertional malaise
- Sensory disturbances

## DIFFERENCES

- Shortness of breath
- Cough
- Chest pains
- Heart rhythm disturbances
- Palpitations
- Periodic fevers
- Loss or change of taste or smell
- Skin rashes and hair loss

## THE ME ASSOCIATION PROVIDES:

- Vital support
- Expert knowledge
- Reliable information
- Medical awareness
- Effective campaigning
- Biomedical research

### MEMBERSHIP

- Stay connected
- Stay informed
- Support your charity

### ME ESSENTIAL

YOUR QUARTERLY MEMBERS' MAGAZINE  
Simply the best magazine for people with  
ME/CFS and Long Covid  
[meassociation.org.uk/mea-membership](http://meassociation.org.uk/mea-membership)

### HELPLINE

**FREEPHONE**

**0808 801 0484**



[/meassociation](https://www.facebook.com/meassociation)



[@meassociation](https://twitter.com/meassociation)



[/meassociation](https://www.instagram.com/meassociation)



[/me-association](https://www.linkedin.com/company/me-association)



[/meassociationUKCharity](https://www.youtube.com/channel/UCmeassociationUKCharity)

THE ME ASSOCIATION

Myalgic Encephalomyelitis/  
Chronic Fatigue Syndrome (ME/CFS)



# SEVERE AND VERY SEVERE ME/CFS

## SYMPTOM IMPACT

The ME  
Association

CHANGING ATTITUDES,  
IMPROVING LIVES

### Symptoms of severe or very severe ME/CFS may mean that people:

Need a **low-stimulus environment**, for example a **dark quiet room** and little or **no** social interaction.

Are **housebound** or **bedbound**, may need support with all activities of daily living and require **aids** and **adaptations** to assist mobility and independence.

Need **careful physical contact** when supported with daily living activities, taking into account possible **sensitivity to touch**.

**Cannot communicate** without support and may need someone to be their advocate and communicate for them.

Are **unable to eat and digest food** easily and may need support with hydration and nutrition.

Have **problems accessing information**, for example because of difficulty with screens, **sound and light sensitivity**, **headaches** affecting their ability to read, or **brain fog** affecting their concentration.

Find out more  
[meassociation.org.uk](http://meassociation.org.uk)

**GRAHAM**  
SEVERE ME sufferer  
since 2013



*"I have Severe ME/CFS and I have dysautonomia/  
PoTS, Hypermobility, Raynaud's, heart arrhythmias,  
bradycardia, atrial tachycardia, severe allergies,  
autoimmunity and inflammation. I also suffer with  
GERD, gastroparesis, coughing after food, reactions  
after food and eye conditions"*

### THE ME ASSOCIATION PROVIDES:

- Vital support ■ Expert knowledge
- Reliable information ■ Medical awareness
- Effective campaigning ■ Biomedical research

#### MEMBERSHIP

- Stay connected ■ Stay informed
- Support your charity

#### ME ESSENTIAL

YOUR QUARTERLY MEMBERS' MAGAZINE

Simply the best magazine for people with

ME/CFS and Long Covid

[meassociation.org.uk/mea-membership](http://meassociation.org.uk/mea-membership)

#### HELPLINE

**FREEPHONE**

**0808 801 0484**



/meassociation



@meassociation



/meassociation



/me-association



/meassociationUKCharity



THE ME ASSOCIATION

Myalgic Encephalomyelitis/  
Chronic Fatigue Syndrome (ME/CFS)



Find out more  
[meassociation.org.uk](http://meassociation.org.uk)

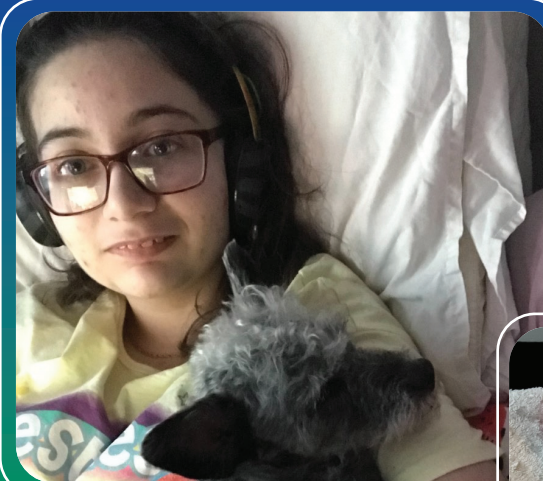
# ME/CFS THE FACTS

CAN AFFECT **ANYONE**

The ME  
Association

CHANGING ATTITUDES,  
IMPROVING LIVES

- It affects more than 250,000 people in the UK, twice as many as have MS
- There is no diagnostic test, no effective treatment and no cure
- 25% are likely to be housebound or bedbound and reliant on the care of others
- 80% more women than men have the condition, suggesting an autoimmune component
- It is indiscriminate and affects people of all ages, ethnicities and social classes
- It can lead to a lower quality of life and be more disabling and socially marginalising than MS, cancer, RA and stroke
- There is unequal access to NHS specialist services in England, and limited healthcare in Northern Ireland, Scotland and Wales
- The 2021 NICE Guideline on ME/CFS has yet to be implemented across the UK



**GRACE**  
ME/CFS sufferer  
since 2021



**MAZ**  
ME/CFS sufferer  
since 2019



*"I had a wonderful doctor who did all she could after we moved to her area. She made a diagnosis of ME which came three years ago, after 20 years of being ignored and sent for mental health assessments, which I also had issues with (partly because I felt so unwell and no one would listen to me)"*

## THE ME ASSOCIATION PROVIDES:

- Vital support ■ Expert knowledge
- Reliable information ■ Medical awareness
- Effective campaigning ■ Biomedical research

### MEMBERSHIP

- Stay connected ■ Stay informed
- Support your charity

### ME ESSENTIAL

YOUR QUARTERLY MEMBERS' MAGAZINE  
Simply the best magazine for people with  
ME/CFS and Long Covid  
[meassociation.org.uk/mea-membership](http://meassociation.org.uk/mea-membership)

### HELPLINE

**FREEPHONE**

**0808 801 0484**



/meassociation



@meassociation



/meassociation



/me-association



/meassociationUKCharity

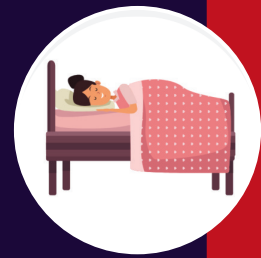


Myalgic Encephalomyelitis/  
Chronic Fatigue Syndrome (ME/CFS)

Find out more  
[meassociation.org.uk](http://meassociation.org.uk)

# DIAGNOSING ME/CFS

## SYMPTOM CHECK



DEBILITATING  
FATIGUE



COGNITIVE  
DIFFICULTIES



UNREFRESHING  
SLEEP



POST-EXERTIONAL  
MALAISE



The ME  
Association

CHANGING ATTITUDES,  
IMPROVING LIVES



*"GP's often assume that every new symptom is because of M.E. and they don't properly investigate. I'm very concerned about the changes that have happened since I become severely ill and my two children have had to become my carers"*

### AND OTHER SYMPTOMS, LIKE:



**DYSAUTONOMIA**  
(Dizziness and fainting)



**HYPERSENSITIVITIES**  
(Light, noise and smells)



**FLU-LIKE SYMPTOMS**



**WIDESPREAD PAIN**



**STOMACH & IRRITABLE  
BOWEL ISSUES**

## DIAGNOSING ME/CFS



The Importance of  
an Early & Accurate  
Diagnosis

FREE BOOKLET

<https://meassociation.org.uk/cb0c>

### THE ME ASSOCIATION PROVIDES:

- Vital support ■ Expert knowledge
- Reliable information ■ Medical awareness
- Effective campaigning ■ Biomedical research

#### MEMBERSHIP

- Stay connected ■ Stay informed
- Support your charity

#### ME ESSENTIAL

YOUR QUARTERLY MEMBERS' MAGAZINE

Simply the best magazine for people with

ME/CFS and Long Covid

[meassociation.org.uk/mea-membership](http://meassociation.org.uk/mea-membership)

#### HELPLINE

FREEPHONE

**0808 801 0484**



/meassociation



@meassociation



/meassociation



/me-association



/meassociationUKCharity