Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS)



### Find out more meassociation.org.uk

### LOUISA ME sufferer since 2011



## MAIN SYMPTOMS

**COULD YOU HAVE** 

ME/CFS?

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 exhaused, 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.

"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

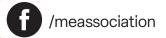
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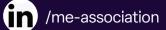








/meassociation





THE ME ASSOCIATION



# ME/CFS and LONG COVID

### ARE THEY **THE SAME?**

The ME Association CHANGING ATTITUDES, **IMPROVING LIVES** 

## **MATTHEW**

Long Covid sufferer since 2020

> JULIE ME sufferer since 2017



"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

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

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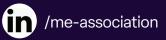
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# SEVERE AND VERY SEVERE ME/CFS

## **SYMPTOM** IMPACT

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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.

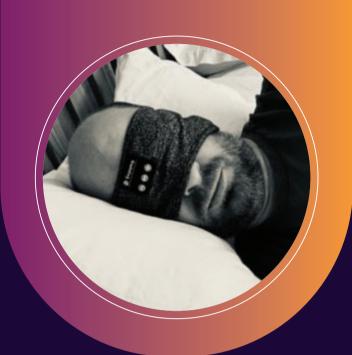
**Cannot communicate** without support and may need someone to be their advocate and communicate for them.

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

### **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"

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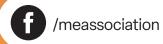
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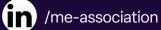
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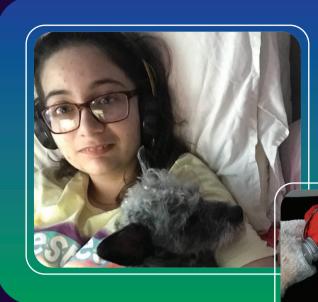
# ME/CFS THE FACTS

## CAN AFFECT ANYONE

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- 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





"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)"

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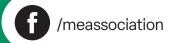
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# DIAGNOSING ME/CFS

## **SYMPTOM** CHECK

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### **AND OTHER SYMPTOMS, LIKE:**



**DYSAUTONOMIA** (Dizziness and fainting)



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



**FLU-LIKE SYMPTOMS** 



**WIDESPREAD PAIN** 



STOMACH & IRRITABLE **BOWEL ISSUES** 

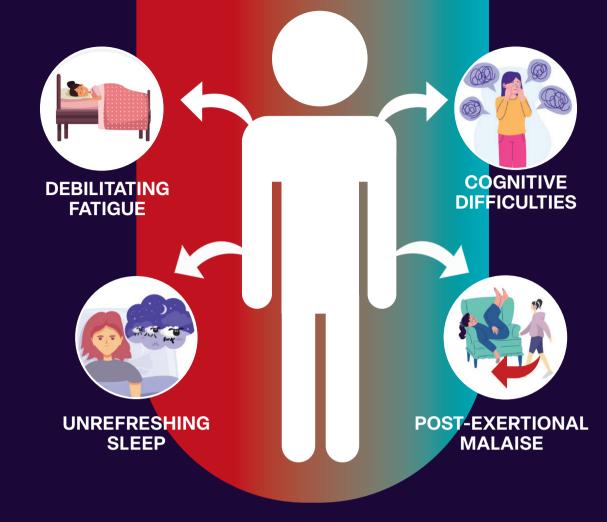
### DIAGNOSING ME/CFS



The Importance of an Early & Accurate Diagnosis

**FREE BOOKLET** 

https://meassociation. org.uk/cb0c



"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"

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