THE ME ASSOCIATION

Myalgic Encephalomyelitis/
Chronic Fatigue Syndrome (ME/CFS)

COULD YOU HAVE ME/CFS?

MAIN **SYMPTOMS**

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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

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

HELPLINE

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ME/CFS and LONG COVID

ARE THEY **THE SAME?**

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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**

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**

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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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ME/CFS
THE FACTS

CAN AFFECT **ANYONE**

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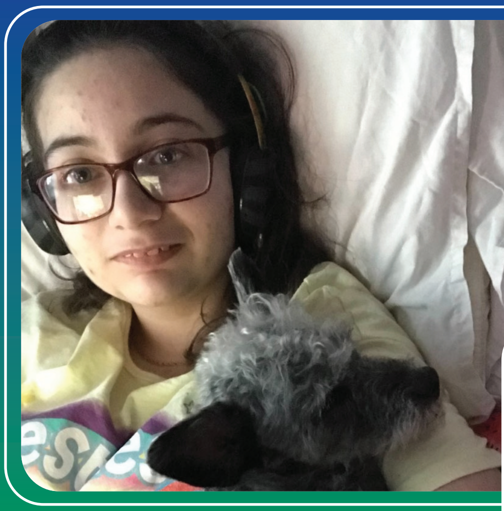

GRACE
ME/CFS sufferer
since 2021

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)"*

- **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**

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DIAGNOSING
ME/CFS

SYMPTOM CHECK

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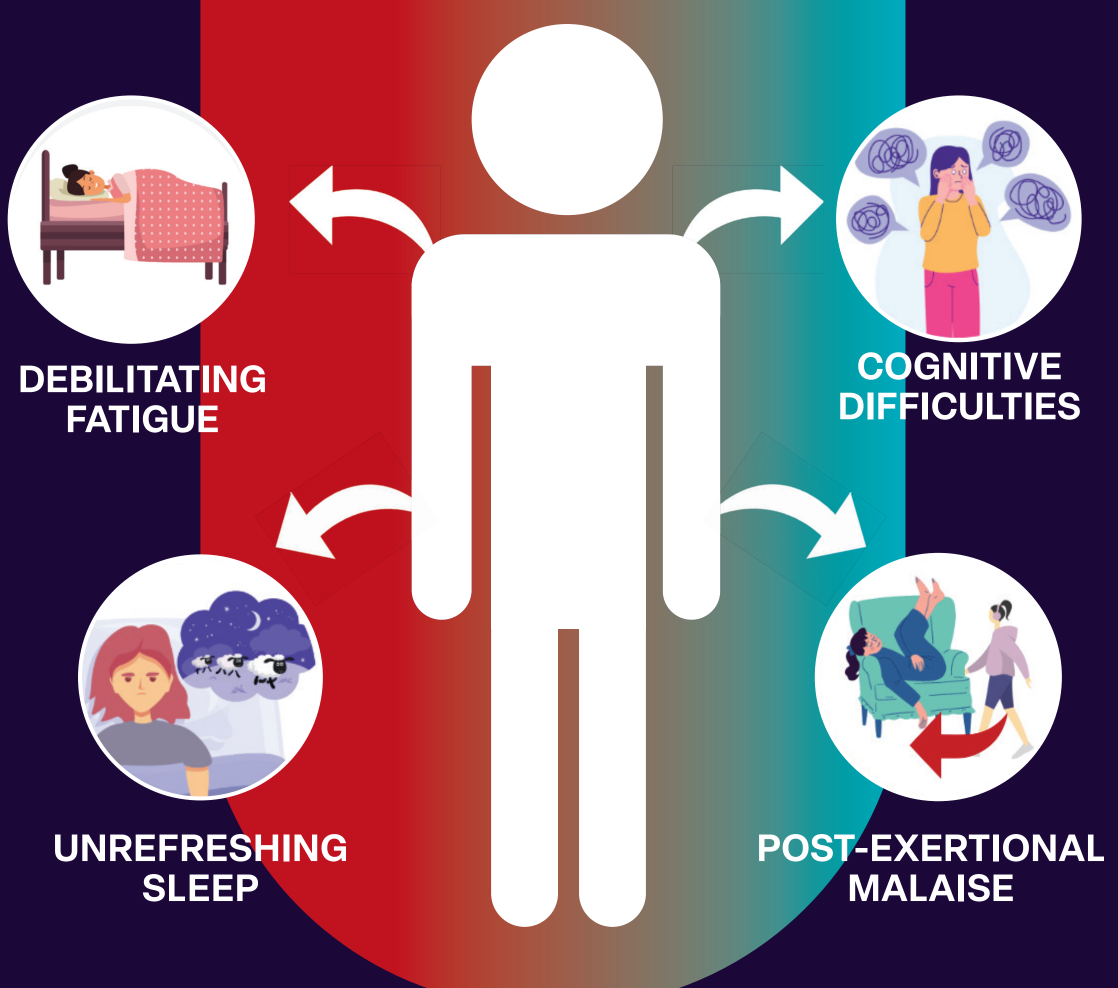

DEBILITATING FATIGUE

COGNITIVE DIFFICULTIES

UNREFRESHING SLEEP

POST-EXERTIONAL MALAISE

> *"GPs 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

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