ME/CFS and Long Covid

What you need to know

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The ME Association

WELCOME

AN INTRODUCTION

meassociation.org.uk

OVERVIEW

Medical Research

Evidence-based NICE Guideline

Expert Medical Opinion

Causation

Predisposing, precipitating, and perpetuating factors

Underlying disease process

https://meassociation.org.uk/1n2w

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

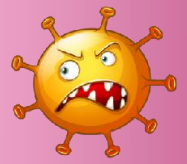
PVFS=

Post Viral Fatigue 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.

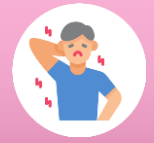
Post-Viral Fatigue Syndrome

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.

Similarities

Debilitating physical and mental fatigue

Post-exertional malaise



Pain

Flu-like symptoms

Cognitive dysfunction

Dysautomnia

Sleep disturbances

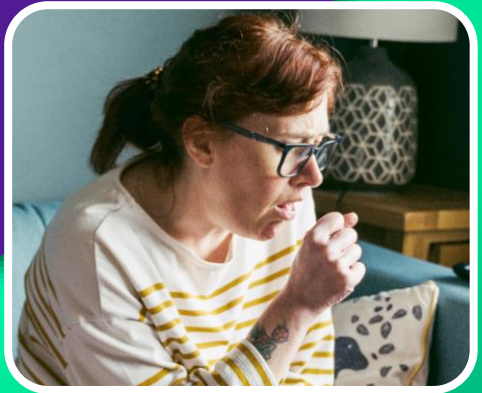
Headaches

Poor temperature control

Sensory disturbances

Differences

Symptoms relating to organ damage from Covid-19 virus

Shortness of breath and/or cough	Chest pains	Heart-rhythm disturbances/arrhythmias	Palpitations on exertion	Periodic fevers
	Loss of change of taste and/or smell	Abdominal pain and diarrhoea/IBS	Skin rashes and ‘Covid toe’	Hair loss

Causation

Medical debate

NICE Guideline

DHSC Delivery Plan

Covid Pandemic & Long Covid

ME/CFS perpetuated by physical disease process

Is ME/CFS and Long Covid a 3-stage illness?

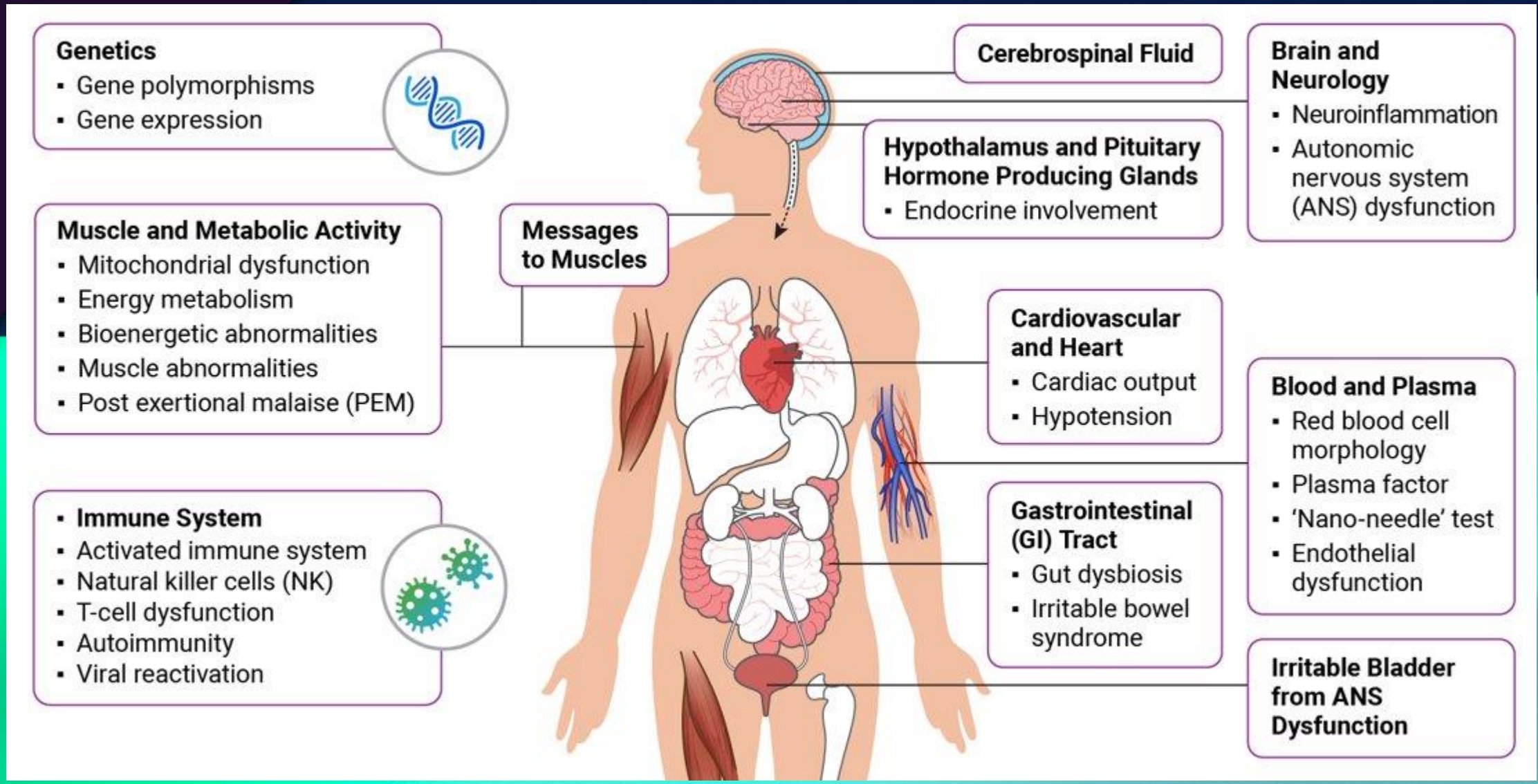
Predisposing, precipitating, and perpetuating factors

1. Predisposing
- a genetic predisposition?

2. Precipitating
- a triggering event
- infection e.g. viral or bacterial
- other immune system stressors
- failure to fully recover

3. Perpetuating
- a complex interaction involving changes to the way in which the brain, nervous system, muscle, immune and endocrine systems respond to the triggering event

Research evidence: disease pathology



Research evidence: disease pathology

1. Brain: Neurology

- Autonomic nervous system (ANS) dysfunction
- Neuroinflammation
- Central nervous system
- Cerebrospinal fluid
- Neuroimaging
- Endocrine involvement- hormone producing glands

Research evidence: disease pathology

2. Blood and Plasma

- Red blood cell morphology
- Plasma factor
- ‘Nano-needle’ test
- Endothelial dysfunction
- Microclots

Research evidence: disease pathology

4. Genetics

- Gene polymorphisms
- Gene expression
- DecodeME
- Epigenetic profiling -> EpiSwitch®

Source: DecodeME collaboration 2025 'Initial findings from the DecodeME genome-wide association study of myalgic encephalomyelitis/chronic fatigue syndrome'.
https://meassociation.org.uk/bur1

Hunter *et al*. Development and validation of blood-based diagnostic biomarkers for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) using EpiSwitch® 3-dimensional genomic regulatory immuno-genetic profiling.
https://meassociation.org.uk/7bnj

Research evidence: disease pathology

5. Gut microbiome

Gut dysbiosis

6. Heart

Cardiac output

Hypotension

Research evidence: disease pathology

7. Immune System

- Activated immune system and cytokines
- Natural killer cells (NK)
- T-cell dysfunction
- Autoimmunity
- Viral reactivation

8. Metabolism

- Metabolic pathways

Research evidence: disease pathology

9. Mitochondria, cellular bioenergetics and exercise physiology

Energy, or a lack thereof, is a significant concern in ME/CFS and Long Covid.

- Mitochondrial dysfunction
- Energy metabolism pathways
- Bioenergetic abnormalities
- Muscle abnormalities
- Post-Exertional Malaise (PEM)

Advancing ME/CFS and Long Covid research

We Need …

- much larger studies to see more definitive research and the removal of any false positives.
- well-defined patient cohorts and greater use of sedentary and other relevant controls.
- to have a greater representation of all illness severities.
- to identify subgroups.
- to use new investigative techniques.
- collaboration between different specialties to see the ‘whole picture’.

Advancing ME/CFS and Long Covid research

Ramsay Research Fund (RRF)

- Invest in biomedical research.
- Over £4m in the last 40 years.
- Average investment of £108,000 a year.
- Largest investment into a single study in 2025.

CONCLUSION

ME/CFS and Long Covid is a complex, multi-system disease triggered by an immune system stressor and perpetuated by various changes in the brain, nervous system, muscle, immune and endocrine systems.

We need a better understanding of the underlying disease pathways.

Important discoveries have emerged that need replicating in larger research studies.

Research offers the best chance of improving the lives of people affected by this disease and of preventing it occurring in the future.

The Covid-19 pandemic and Long Covid. Are ME/CFS and Long Covid the same condition?

The ME Association:
changing attitudes and improving lives…

The ME Association provides:

Vital Support

Reliable Information

Medical Training

Effective Campaigning

Research Investment

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YouTube… /MEAssociationUKCharity

Any Questions?

Thank you for listening

The ME Association:
changing attitudes and improving lives…

Booklet- What do you need to know about ME/CFS

https://meassociation.org.uk/1n2w

Booklet- Long Covid and ME/CFS – Are they the same condition?

https://meassociation.org.uk/pluz

MEA Research Review: Post-Exertional Malaise (PEM) in ME/CFS and Long Covid

https://meassociation.org.uk/3h01

MEA Research Review: Reactivation of human herpesviruses and their role in ME/CFS and Long Covid

https://meassociation.org.uk/