

# Frequently Asked Questions

## **Q. What Is Myalgic Encephalomyelitis/Chronic Fatigue Syndrome or ME/CFS?**

**A.** Myalgic Encephalomyelitis (ME) is the preferred nomenclature for a complex, multi-systemic neuro-immune disease, also known as chronic fatigue syndrome (CFS). This name was coined by Dr. Melvin Ramsay following the 1955 Royal Free Hospital outbreak and is a portmanteau of several of the key signs and symptoms of the disease: myalgic (muscle pain), encephalo (brain), myel (spinal cord), itis (inflammation).

Our organization utilizes the term ME/CFS to reflect the common terminology used in government, academic, and scientific discourse. The ME/CFS field currently lacks an agreed upon research or clinical case definition. As with many diseases, the definition used to diagnose ME/CFS for clinical care differs significantly from the definition used to select ME/CFS research cohorts. At Solve M.E., we use the term ME/CFS Community to refer inclusively to people who have been diagnosed as having M.E. or CFS, and to those who are self-identified as members of the ME/CFS community.

## **Q. What causes ME/CFS?**

**A.** The cause of ME/CFS may vary from person to person. Some people became sick with ME/CFS following a sudden and severe flu-like illness. Others became sick with ME/CFS gradually over a period of months or years without noticing a specific cause. Research has shown that there is genetic, central nervous system, immune and metabolic factors involved in ME/CFS and scientists are studying these connections to develop diagnostic tests and treatments. The Solve ME/CFS Initiative is actively supporting research on diagnosis and treatment.

## **Q. Who gets ME/CFS?**

**A.** ME/CFS does not discriminate and can cause disease in both men and women, young and old. However, it is more common in women than in men and occurs less frequently in young people. ME/CFS occurs in all races and ethnicities in the United States and around the world.

## **Q: Is there a diagnostic test for ME/CFS?**

**A:** There is currently no diagnostic test for ME/CFS. This is an important area of research that the Solve M.E. is actively supporting.

## **Q: Is there a cure for ME/CFS?**

**A:** There is currently no cure for ME/CFS but there is evidence that the sooner you get a diagnosis, the greater the chances of recovering. Getting diagnosed early is important!

## **Q: How many people have ME/CFS?**

**A:** The Centers for Disease Control and Prevention estimate that ME/CFS affects between 1 and 2.5 million individuals in the U.S. People with ME/CFS have the lowest quality of life scores of any disease tested.

**Q. How long will it take to recover?**

**A:** The time to recovery from ME/CFS varies. Some patients recover in small to moderate degrees, while others recover almost fully, but no one knows why. Others have progressively worse symptoms over time. Unfortunately, very little data exists about recovery rates for ME/CFS. Determining what helps people recover from ME/CFS is an important area of research that Solve M.E. is actively supporting.

**Q: Is ME/CFS a psychological disorder?**

**A:** No, researchers agree that ME/CFS is not a form of depression or psychiatric illness. All chronic illnesses have significant medical, psychological and social components. However, the physical symptoms of ME/CFS differ greatly than those of depression and can help to differentiate between the two. While ME/CFS is not a psychological disorder, depression or anxiety may occur as a result of having any chronic, debilitating illness.

**Q: What is being done about ME/CFS?**

**A:** Solve M.E. envisions a world free of ME/CFS and works steadfastly to make this disease understood, diagnosable and treatable. Solve M.E. seeks to actively engage the ME/CFS community in research, works to accelerate the discovery of safe and effective treatments, and strives for an aggressive expansion of funding towards a cure.

- We have a deep and longstanding commitment to this disease. Despite our modest budgets, we were the first to fund research into epidemiology, viral causes, Immunology, neuro-imaging, exercise physiology and the autonomic nervous system.
- We invest in innovative scientific studies and foster a collaborative ME/CFS research workforce through our Ramsay Grant program.
- Our You + M.E. Registry and Biobank is building the largest a collection of patient-reported data and biological samples (e.g. blood) from people living with ME/CFS and control volunteers. This completely online clinical study will provide the research community with critical insight into the lived experience and genetics of ME/CFS and post-viral illnesses.
- Solve M.E. is involved in advocacy efforts aimed at improving the research landscape for the early detection, objective diagnosis and effective treatment of ME/CFS. As part of this effort, we work to validate the burden of illness imposed by ME/CFS in agencies where national policy is made and executed. While there is still much work to be done, we are encouraged that ME/CFS is now receiving much attention on a federal level and we are involved to help maintain this positive momentum.

**Q: What is Solve M.E.?**

- Founded in 1987, the longest standing organization serving ME/CFS patients and advancing rigorous research.
- A national organization with a volunteer board of directors composed entirely of patients and their families.
- Our mission: Making ME/CFS understood, diagnosable and treatable.
- Despite the fundamental complexity of this illness, we believe that ME/CFS can and will be solved in our lifetime.