World ME Day

What do you know about ME?
World ME Day asks you to learn more

ME dramatically limits the activities of millions of people across the world. In its most severe form, this disease can consume the lives of those affected. For the first time in history, an alliance of organizations from across the globe is jointly launching World ME Day on May 12th 2022.

Solve M.E. is proud to be part of this international effort, led by the World ME Alliance, to battle the stigma associated with ME and call for more research funding into this disease.

The theme for this year's World ME Day is #LearnFromME. It aims to highlight how people with ME and experts have a huge wealth of knowledge that could help to improve the management of this disease across the world. But even with the best management approaches that are available, there is no effective treatment or cure for ME. This is why members of the Alliance are calling for more research funding for this disease.

Sarah's story

"It is so heartbreaking to know you have a disease that may never be cured in your lifetime — that the powers that be are not attempting to cure it, they are not attempting to study it, they are not attempting to develop treatments or palliative care or awareness or anything," Sarah Ramey — an author and person with ME/CFS, POTS, and CRPS — shared with us.

Challenges facing ME patients

Between 17 and 30 million people live with ME across the world. Around 75% of those affected are women, and one quarter are housebound or bedbound.

Stigma has had a huge impact on the treatment and care people with ME receive around the world. It is now understood that the best approach to managing ME includes pacing. This means the people are supported to only use the energy they have available, and not go over their limits. The aim is to reduce the amount of post-exertional malaise (where symptoms get worse after activity) that people experience.

New guidelines for care have been released by two major institutions in the past year that aim to improve provision – the National Institute for Health and Care Excellence in the UK and Mayo Clinic Proceedings in the US.

As part of #LearnFromME, members of the World ME Alliance are asking health and care professionals to ensure their knowledge is up-to-date by reading one or both of these guidelines.

The impact of COVID-19

The coronavirus pandemic has had a two-fold impact on the world of ME. People with ME are known to be vulnerable to relapses from infections of any sort, and COVID-19 has been no different. Many people with ME who have caught COVID-19 have relapsed, and other have been extremely isolated as they avoid contact with others.

The second impact of COVID-19 has been the rise in number of people being diagnosed with ME. Up to 80% of people with ME report an infectious trigger to their disease, and COVID-19 continues to cause a wave of new ME diagnoses. There is a large overlap between Long Covid and ME symptoms, but without a clear diagnostic test for either, it is difficult to separate out the two diseases.

Learn from ME

"Building a coalition of global ME/CFS organizations via the World ME Alliance allows us to share insights and brings us closer to our ultimate goal of identifying diagnostics and treatments for ME/CFS and other post-infection diseases, such as Long Covid," said Oved Amitay, President and CEO of Solve M.E.

To find out more about ME or take action to support the cause visit www.worldmeday.org

Information for the editor:

- More information about ME is available here.
- Stock photos – use appropriate images to help decrease stigma. A selection is available on Getty here.
- Royalty free photos depicting severe ME are available here.

Contact details for the World ME Alliance

- Email: info@worldmealliance.org
- Website: www.worldmealliance.org
- Twitter: https://twitter.com/worldmealliance
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