Sharing the story of ME and

World ME Day 2022 with the press

A guide

Are you interested in writing an article for a news outlet about ME and World ME Day? Here’s a guide to get you started.

For opinion pieces from individuals, news outlets usually prefer not to receive a pre-written article, but to work with you to determine the length and focus of the piece.

So, send an email using the template below to a few places, and see if anyone is interested.

If so, you’ll need to write a full article. We’ve provided some stock paragraphs that you could include in your piece. These explain a bit more about ME, the impact it’s having globally, and World ME Day.

You can use or edit them as you see fit.

If you need help, get in touch with us on [info@worldmealliance.org](mailto:info@worldmealliance.org)

**How to use this guide:**

1. Have a read through first.
2. Think about where you might want to pitch your story. Look up your local news sites or papers and see if you can find an email address for their news desk.
3. Edit the template email on the next page to include your details and share a bit of your experience of ME.
   1. You might tell your story of living with or caring for someone with ME
   2. You could share the impact it’s had on your work, social or personal life
   3. You could explain what you wish could be different
   4. Or give a few pointers of what you want the world to learn from ME.
4. Copy and paste this into an email
5. Remember to include the subject line
6. Send!
7. If you get any interest, use our stock paragraphs to help you write your full article. Remember to focus on your story though, as this will be the most powerful part.
8. Get in touch if you need help.

**Template email to pitch your story**

Keep it fairly short and snappy. Remember to change the parts highlighted in yellow!

**Subject: Pitch – Telling my story for World ME Day on May 12th**

Dear editor,

On May 12th its World ME Day. If you’ve not heard of ME, it’s a debilitating disease that affects up to 30 million people across the world, and COVID-19 is triggering the disease in many more people.

For the first time in history an Alliance of organisations from 10 countries is launching World ME Day to raise awareness of the disease. I want to use this opportunity to tell my story of ME, as a local person.

[insert your ME story – here’s an example:

I have lived with ME for nearly 10 years, and it has changed my life beyond recognition. In this time, I have received almost no effective healthcare, and often been stigmatised. I am now seeing people being newly diagnosed with ME following COVID-19, and I wish the world would learn from the mistakes made in history around this disease.]

Let me know if you would be interested in me writing a piece for [insert name of news outlet] about my experience and the impact of ME globally for World ME Day.

Yours sincerely,

[insert your name]

[insert your address]

[insert your phone number]

**Stock paragraphs to use in your piece**

Myalgic Encephalomyelitis (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 organisations from across the globe is jointly launching [World ME Day](http://www.worldmeday.org) on May 12th 2022.

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.

**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](https://www.nice.org.uk/guidance/ng206/chapter/Recommendations) in the UK and [Mayo Clinic Proceedings](https://www.mayoclinicproceedings.org/article/S0025-6196(21)00513-9/fulltext) in the US. As part of the World ME Day theme #LearnFromME, health and care professionals are being asking 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**

To find out more about ME or take action to support the cause visit [www.worldmeday.org](http://www.worldmeday.org)

**Information for the editor:**

* More information about ME is available [here](https://worldmealliance.org/what-is-me/).
* Stock photos – use appropriate images to help decrease stigma. A selection is available on Getty [here](https://www.gettyimages.co.uk/collaboration/boards/utQ1tuO7hEGr8vk3DghYTw).
* Royalty free photos depicting severe ME are available [here](https://www.mecfs.de/stockphotos/).

**Contact details for the World ME Alliance**

* Email: [info@worldmealliance.org](mailto:info@worldmealliance.org)
* Website: [www.worldmealliance.org](http://www.worldmealliance.org)
* Twitter: <https://twitter.com/worldmealliance>
* Facebook: <https://www.facebook.com/worldmealliance>

We are happy to support articles and/or provide quotes. Please don’t hesitate to be in touch.