



## #MillionsMissing 2021- US Letter to the Editor Toolkit

Over the past year #MEAction has been focusing on reaching out to the national press to make sure journalists and medical professionals are educated about ME and can provide the correct context when writing articles about long COVID and long haulers. Our efforts have paid off and we continue to receive coverage and new opportunities to speak with journalists.

Our press outreach efforts have helped lead to coverage in major news outlets:

- [The Washington Post](#)
- [CNN](#)
- [The Atlantic](#)
- [Time](#)
- [Bustle](#)
- [The Guardian](#)

The [#MEAction press conference](#) to educate journalists about the intersection between #longCOVID & #MyalgicEncephalomyelitis.

With this in mind, we want to expand our press outreach to local papers across the globe and this is where you come in! This year, during #MillionsMissing week, we are asking for people to send letters to the editors for their local papers. Letters to Editors are a great way to get published and can be a powerful advocacy tool.

### **Here is Why Letters to Editors are Important:**

1. You can reach a large audience .
2. Great way to start a conversation around an issue that is important to you.
3. Helpful way to educate and spread awareness about ME.
4. Letters to Editors are often monitored by elected officials.
5. Letter to Editors are a great way to catch the attention of journalists at the newspaper who may write a full article.

### **How to Find Where to Submit Your Letter**

Do an internet search with “name of publication” + “letter to editor”.

- A link to a page with information about your publication’s process should pop up. They will usually give you the option to send it through an online form, a pop up box, an email address (usually Letters@ ...), or a mailing address.

- Make sure to read over the instructions.
- Take note of any word or character specifications.

### **When to Submit Your Letter**

We recommend submitting your letter to your publication of choice between mid April-May 14th.

### **Tips for Writing Your Letter to Editor:**

1. **Stick to one message.** Most newspapers have a limit for how long letters to the editor can be in order to be published. It is important to make your point in a clear and concise manner. We recommend around 300 words (some places have a 150 word limit).
2. **Make it personal.** Speaking in your voice adds authenticity to the letter and allows the editors to know the author understands the issues personally.
3. **Stick to the facts.** It is important to only share what has been proven to be true. Exaggerating or overstating facts can harm your credibility.
4. **Provide your contact information.** Most newspapers will not print your letter if they cannot verify your information.
5. **Connect your letter to a recent news article.** While some papers will print general commentary, some prefer the letters be in reference to a previously posted article. We recommend you find out if an article has been written about long COVID or the long term medical harm COVID-19 has caused within your local community in your local newspaper.

### **Letter to Editor Structure & Sample Language**

Here is a general structure to follow when writing a letter to an editor, plus we provided some sample language to use at the end of this document. As mentioned previously, it is important to make the letter personal; share your story. Make sure to adhere to the word and/or character requirements of your chosen publication.

#### Letter Structure:

1. Dear Editor
2. Introduction
3. Provide Information about COVID-19 & ME or stats about ME
4. Share your story
5. Request an action to be taken by the editor/publication

#### 2. Possible Intros:

- I want to bring your attention to May 12th Myalgic Encephalomyelitis International Awareness Day, a day for the #MillionsMissing
- While the world is opening up, there are still millions missing from work, education and family life due to ME.
- Thank you for your article about long COVID.
- I noticed in your article about long COVID you did not mention Myalgic Encephalomyelitis (ME).
- In your publication's coverage about COVID-19 an important conversation has been missing, how long COVID can possibly lead to Myalgic Encephalomyelitis (ME), a post-viral disease.

- Many of us with Myalgic Encephalomyelitis (ME), anticipated the increase of post-viral illness happening after COVID-19 because that happened with previous viral epidemics, including SARS.

### 3. Stats

Here are some general stats about ME, plus information about the connection between long COVID & ME. Select which points connect best to the point you are making in your letter, feel free to use this templated language as is.

#### **ME:**

- ME is a multi-system disease that causes profound metabolic dysfunction and is accompanied by physical and cognitive limitations.
- People experience symptoms on a spectrum from severe to mild, but 75% of people with the disease are unable to work and 25% are homebound or bedridden.
- ME/CFS affects all races, ethnicities, genders, and ages—although 75 percent of those with ME/CFS are female.
- Most cases of ME are initiated by an infection. Nearly 80% of people with ME report an infectious onset, whether it was SARS-CoV-2, MERS, swine flu, Epstein-Barr, or a bacterial infection, and never recovered.
- ME/CFS affects more than 1 million Americans, more than MS or HIV/AIDS. There are an estimated 15-30 million people with ME worldwide.

#### **Long COVID & ME:**

- The pathway to recovery or diagnosis for people with long COVID will not be uniform. Some will recover, some will have organ damage and a subset are expected to [develop chronic illnesses](#) like ME/CFS, autonomic disorders and autoimmune conditions.
- Many long haulers are [reporting](#) symptoms that resemble ME/CFS, most notably post-exertional malaise, a worsening of symptoms after exertion.
- Based on evidence from past [viral outbreaks](#), researchers expect that at least 10-12 percent of COVID-19 patients will go on to develop ME/CFS following COVID-19.

### 4. Share Your Story

Share a few points about how your personal story connects with the messaging above.

### 5. Request an Action

Provide an action you would like the editor to take. Here are some sample actions you can refer to in your letter.

1. Write an article about ME, educating their audience
2. Make sure to connect ME to long COVID moving forward
3. Continue to pay attention to those suffering with chronic illness and how it affects all aspects of their lives.

## **Sample Letter--General Awareness Letter to the Editor**

While we do recommend personalizing a Letter to the Editor, if you would rather copy/paste a letter, we have drafted a sample letter for you to use. The sample letter is general awareness driven and talks about #MillionsMissing and the understanding that millions more will be diagnosed with ME because of long COVID. This focus makes it timely and draws attention to a line of reporting the paper could pursue.

Be mindful that when submitting your letter you may have to change some of the wording in the sample letter provided below.

*Subject Line/Title:* There are Millions Missing from Their Lives due to ME

*Word Count* 353

*Dear Editor-*

*Did you know there are millions missing from their everyday lives due to a disease that many are not aware of, a disease where the medical community often provides incorrect advice, and a disease that lacks proper funding to find treatments and a cure? This disease is Myalgic Encephalomyelitis (ME) and through the non-profit #MEAction, on Wednesday, May 12th we recognize Myalgic Encephalomyelitis as the day of the #MillionsMissing. This is a day to highlight those with ME and the significant issues facing our community- and also to come together and demand change.*

*Myalgic encephalomyelitis or myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), is a multi-system disease that causes profound metabolic dysfunction and is accompanied by physical and cognitive limitations. People experience symptoms on a spectrum from severe to mild, but 75% of people with the disease are unable to work and 25% are homebound or bedridden. This is why we mention millions are missing from their lives. They are not able to participate in their everyday lives like they used to prior to this disease. An estimated 15-30 million people live with the disease worldwide.*

*Nearly 80% of people with ME report an infectious onset, whether it was SARS-CoV-2, MERS, swine flu, Epstein-Barr, or a bacterial infection, and never recovered. Based on evidence from past viral outbreaks, researchers expect that at least 10-12% of COVID-19 patients will go on to develop ME/CFS following COVID-19.*

*As the world continues to open back up and more people are getting the vaccine, I think it is important to remember that there are members of this community who will remain homebound and others who will be wondering if they themselves have ME.*

*May 12th is a day to recognize ME. For the millions more struggling with long COVID, the ME community is here to support you!*

*Thank you for your time and I hope you will continue to educate yourself on ME and how long COVID will greatly increase the chronic illness numbers within our local (City/Town Name)community.*

*For more information about ME, or #MEAction, go to [meaction.net](http://meaction.net).*

-NAME

Add your contact information if not already provided as part of the letter submission process (address, phone number, mailing address).

**Did You Get Published? Let Us Know!**

If your letter gets published, please email [press@meaction.net](mailto:press@meaction.net) to let us know.