



#MillionsMissing 2021- UK 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. Our efforts have paid off and we continue to receive coverage and new opportunities to speak with journalists.

We recently held the [#MEAction press conference](#) to educate journalists about the intersection between #longCOVID & #MyalgicEncephalomyelitis and our press outreach efforts have helped lead to coverage in major news outlets:

- [The Guardian](#)
- [The Atlantic](#)
- [Time](#)
- [Sheffield Telegraph](#)
- [The Scottish Sunday Express](#)

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 of 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 local councillors, MPs and MSPs.
5. Letter to Editors are a great way to catch the attention of journalists at the newspaper who may then 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 postal 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 and 14th May.

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). Local papers tend to be more flexible so it is worth looking at a copy of the paper you have in mind and see what length they print.
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 proved to be true. Exaggerating or overstating facts can harm your credibility.
4. **Provide your contact information, including your postal address.** Most newspapers will not print your letter if they cannot verify your information. However the paper may withhold identifying features if requested e.g. they may print the town only, rather than a street.
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 have 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 statistics about ME
4. Share your story
5. Appeal for support for people with ME from politicians and other readers

2. Possible Introductions:

- I want to bring your attention to 12th May; 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, sometimes called Chronic Fatigue Syndrome.
- 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. Statistics on ME

Here are some general statistics about ME, plus information about the connection between long Covid and 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
- ME affects all races, ethnicities, genders, and ages—although 75% of those with ME 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 affects more than 250,000 people in the UK, more than MS or HIV/AIDS so it is not a rare disease. There are an estimated 15-30 million people with ME worldwide. However, in comparison ME receives much less research funding relative to disease burden.
- There is no known treatment and some people remain ill. 25% of those with ME are bedbound or housebound.
- Graded exercise therapy, which has been one the only treatments recommended, is now regarded as dangerous for people with ME. This recommendation has been removed from revised guidelines. It is now recognised that, for people with ME, keeping within the limits of their energy level is extremely important. It is critical that people with long Covid who have symptoms of ME are aware of this.

Long Covid and 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, autonomic disorders or autoimmune conditions.
- Many suffering from long Covid are [reporting](#) symptoms that resemble ME, 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% of Covid-19 patients will go on to develop ME/ following Covid-19.

4. Share your story

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

5. Appeal for support

Here are some sample actions you can refer to in your letter.

1. With so much emphasis on long Covid, it is important that ME is not forgotten in your coverage or by the wider community - say if you are happy to be contacted for more information about your story.
2. Ask the papers' readers, particularly politicians, to support for people with ME

Sample Letter to the Editor

While we do recommend personalising your 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 348

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 misleading and dangerous advice, and a disease that lacks proper funding to find treatments and a cure? This disease is Myalgic Encephalomyelitis (ME) and #MEAction UK will be raising awareness of ME on Wednesday, 12th May 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.

ME, sometimes called Chronic Fatigue Syndrome, 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 #MillionsMissing - those missing from their careers, education, families and communities because of this disease. An estimated 250,000 people live with the disease in the UK and many more are expected following the Covid-19 outbreak.

Nearly 80% of people with ME report an infectious onset, whether it was a viral or 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 following Covid-19 and the current incidence of long Covid supports this estimate.

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

12th May is a day to recognise ME. For the millions more struggling with long Covid the ME community is here to support you!

Thank you for highlighting the terrible situation of the #MillionsMissing. We ask that you support people with ME in your coverage going forward.

For more information about ME, or #MEAction UK and #Millions Missing, go to meaction.net.

-NAME,

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

Did You Get Published? Let Us Know!

If your letter gets published:

- Email the paper to thank them; if you have energy you could say that you are happy to be contacted if they need more information for future articles
- Please email press@meaction.net to let us know.