



# The ME Association: ME Awareness Week Guide to Creating a Local Press Release

## Real People. Real Disease. Real M.E.

The ME Association's Real M.E. campaign – How YOU can help

The ME Association need YOU to help our campaign for this year's ME Awareness Week.



We are showcasing the real faces of ME sufferers to highlight how this cruel, misunderstood disease does not discriminate.

We want you to help us to reach out through local newspapers and broadcasters, and to spread the word on social media, that M.E. is a REAL disease, affecting REAL people.

M.E. can affect anyone at any age and each person deserves REAL respect, REAL medical care and REAL and effective treatments.

## Here's how you can help

Use the draft below to contact your local paper/radio station/regional news show and give them YOUR REAL story of life with M.E.

**EMBARGOED UNTIL MONDAY 6<sup>th</sup> MAY 2019**

### 1. The Heading

The heading should be typed in bold and centered. Keep it short, snappy and to the point.

For example:

**M.E. is REAL! THIS IS WHAT IT FEELS LIKE TO LIVE WITH M.E.**

## 2. The Sub-Heading

This is optional and is used to elaborate on the information in the heading.

For example:

**BRISTOL MUM DESCRIBES THE REAL TORMENT OF LIVING WITH MISUNDERSTOOD DISEASE**

## 3. The Initial Paragraphs – that set out your story

Here is an example:

A young Bristol mum has spoken of her heartbreak at living with a misunderstood illness that some people wrongly refuse to accept is real.

Behind the closed doors and curtains of tens of thousands of UK homes, there is a hidden epidemic of lives blighted by an unexplained and devastating illness.

Jane Smith, 24, has candidly spoken about life with M.E. (Myalgic Encephalomyelitis) to raise awareness of the cruel condition, which affects around 250,000 people in the UK.

## 4. The Main Body of the Article

Tell them:

- About you
- Where you live
- Your age
- Relevant work or education history

About your ME:

- What is your story?
- How is M.E. 'REAL' to you?
- When were you diagnosed, how long did it take?
- How has M.E. changed your life (work/social life/day-to-day/friendships)?
- How would you describe your life with M.E. in the strongest terms?

Here is an example:

Jane, who quit her job as a teaching assistant after being diagnosed with M.E. in 2015, said:

“The fatigue I feel is like a thousand bricks being tied to my body. I can’t muster up the energy to put one foot in front of the other.”

“I can’t get dressed and ready for the day without a blackness descending over my eyes. I often can’t manage to string words together let alone carry on a conversation.”

## 5. Photographs

Don’t forget to include photographs if you have them or to say that you would be happy to send photos in should the article be accepted.

Occasionally, the newspaper might want to come to your home and/or complete an interview over the phone and take photographs or video. You can explain in your initial submission what you would be happy with.

The Real M.E. campaign is all about putting REAL faces to M.E. We are all fed-up with newspapers using inappropriate ‘stock images’ to represent our disease.

## 6. The ME Association

You may wish to include these paragraphs and/or use the content to help inform your writing.

This week is ME Awareness Week – where people affected by M.E. and the ME Association are campaigning to shine a light on this cruel and often invisible disease.

Manifesting as profound flu-like symptoms, there is no known cure for M.E. and worse still, there remains vast misconceptions – even in medical circles – that M.E. is ‘made up’, ‘in the mind’ or even just ‘laziness’.

Yet one in four people are so severely affected that they are rendered housebound or bedbound – with some even reliant on tube feeding and 24-hour care.

Sufferers are often confined to their beds, unable to walk, and need help with personal hygiene such as washing or going to the toilet and with basic daily activities – things that could prompt post-exertional malaise and lay them low for hours, days or weeks.

The ME Association is leading the campaign to make the UK a better place for people with M.E. a disease recognised by the World Health Organisation as being neurological in origin.

Dr Charles Shepherd, medical adviser to the ME Association, said:

“It is often an invisible illness. When you do see us, we might not always look ill, but when our symptoms flare, the effects are obvious.”

“It can feel like a constant flu, the smallest exertion can floor us, our bodies are painfully sore, restful sleep eludes us, light and noise can become intolerable, and ‘brain fog’ causes confusion and short-term memory problems.”

“M.E. is an often-misunderstood disease and there is no known cure.”

“Many doctors still don’t know how to diagnose and manage M.E. and lack of research funding means that we still don’t have any effective forms of treatment.”

“This is a completely unacceptable situation for a disease that is twice as common as multiple sclerosis and is estimated to be costing the UK economy around £3.5 billion in lost tax revenue, healthcare and welfare benefits.”

## 7. For more information please contact:

Give names and telephone numbers of someone a journalist can contact for further information. You might also include the following:

Find out more about the ME Association at their website: <http://www.meassociation.org.uk> or download the FREE ME Factsheet: [What you need to know about ME](#) or ME Research Summary: [Explaining research developments](#).

## 8. Finalise your article with the following:

### Notes to editor

### M.E. Fact File

- Myalgic Encephalopathy/Encephalomyelitis (M.E.) is a chronic neurological disease that affects around 250,000 men, women and children in the UK today. It is also known by the disparaging term: ‘chronic fatigue syndrome’.
- M.E. causes activity-induced muscle fatigue and flu-like symptoms that are characterised by post-exertional malaise. It significantly impacts a person’s functional ability.

- M.E. can cause greater functional impairment and poorer quality of life than many other serious medical conditions, including multiple sclerosis and cancer.
- Symptoms include post-exertional malaise, activity-induced muscle fatigue, cognitive dysfunction, sleep problems, ongoing flu-like symptoms, orthostatic intolerance, muscle and joint pain, severe headaches, problems with balance and temperature control, sensitivity to light and sound, gastrointestinal symptoms.

## The ME Association

- The ME Association supports people with M.E. and their families. It campaigns to have this life-changing condition recognised as a severe neurological illness that deserves to be taken seriously.
- The ME Association promotes and invests in biomedical research that seeks to understand the nature and causes of M.E. via [The MEA Ramsay Research Fund](#).
- The ME Association has produced over 90 leaflets and factsheets about M.E. and how best to live with the disease, and provides the ME Connect telephone helpline which is open 365 days a year.
- Find out more about the ME Association at their website: <http://www.meassociation.org.uk> or download the Free ME Factsheet: [What you need to know about ME](#) or ME Research Summary: [Explaining research developments](#).