



action for m·e

# Media Guidelines

for reporting on  
Myalgic Encephalomyelitis (M.E.)



## Why these guidelines are necessary

**For too long, people with Myalgic Encephalomyelitis (M.E.) have struggled to get their condition diagnosed, understood and acknowledged.**

There has been a huge stigma attached to M.E., with people claiming that the condition is not real or even that it is a psychological condition.

At the same time, there have been misleading and damaging treatments recommended such as enforced exercise, encouraging people with M.E. to “push through”, which can make the condition worse.

With so many misconceptions and with a lack of societal understanding, the media can and does play a valuable role in highlighting this debilitating disease. However, at the same time, certain types of media depictions of M.E. can unintentionally perpetuate negative stereotypes and stigma towards people with M.E.

## Use of language

| Do  | Don't  |
|---|--|
| Refer to Myalgic Encephalomyelitis  | Refer to “fatigue” or “chronic fatigue” which can be a symptom of many different conditions    |
| Refer to ‘people with M.E.’ or ‘patients with M.E.’   | Refer to ‘M.E. sufferers’  |
| Consult as widely as possible with people with M.E. when writing your article                     | Refer to conditions as “mild”  |
| Explain the wide variety of symptoms that people with M.E. can experience                         | Just refer to “tired” as a symptom of M.E.   |
| Ask Action for M.E. for advice if you are unsure what language/tone/imagery is appropriate to use | Use the term “high-achievers” for those experiencing M.E. but able to function more ‘normally’ |



## About Myalgic Encephalomyelitis (M.E.)

**Myalgic Encephalomyelitis (M.E.) is a long-term fluctuating neurological condition affecting many body systems, most commonly the nervous and immune systems and can be highly disabling. It affects around 35 million people worldwide.**

People with M.E. experience severe, persistent fatigue associated with post-exertional malaise, the body and brain's inability to recover after expending even small amounts of energy, leading to a flare-up in symptoms.

1 in 250 people in the UK are estimated to have Myalgic Encephalomyelitis (M.E.), and 25% of people with M.E. are severely affected, house or bedbound and unable to care for themselves.

M.E. doesn't discriminate and can impact anyone. Yet at present there is no definitive diagnostic test, no universally effective treatment and no known cure.

For most children, young people and adults with M.E., supported illness management advice is the most they receive. We have not seen the investment in support and care, in research and ultimately in treatments that are needed.

M.E. is not the same as Long Covid and the two terms should not be confused with one another.

## About Action for M.E.

**Action for M.E. is the only charity in the UK supporting people with Myalgic Encephalomyelitis (M.E.) of all ages, and our services have often been referred to as a 'lifeline' by those who have accessed them.** We are working to ensure that adults, children, young people and families living with M.E. are supported during this unprecedented time, and beyond.

Over the past 35 years, Action for M.E. has worked to improve the lives of people with M.E., taking action to reduce the isolation experienced by many and working to create change.

# 10 key things to remember when communicating about M.E.

- 1 Do use Myalgic Encephalomyelitis (M.E.) or ME/CFS rather than just Chronic Fatigue Syndrome (CFS).** The NHS may diagnose ME or CFS or ME/CFS.
- 2 Don't refer to people as "M.E. sufferers".** Adopt a more person-centric approach and refer to 'people with M.E.' or 'patients with M.E.'
- 3 Avoid labelling conditions as "mild".** Many people with M.E. take exception to being described as having "mild" M.E. – even the "mildest" cases still result in the loss of at least 50% of usual capabilities.
- 4 Avoid reference to "tired" when describing symptoms.** Fatigue is just one of many symptoms and "tired" underplays the severity of the condition. 25% of people with M.E. are so severely affected, house or bedbound and unable to care for themselves.
- 5 Don't use the term "high-achievers" for those experiencing M.E. but are able to function more 'normally'.** This is inaccurate as M.E. can affect people differently. It also has negative connotations and perpetuates negative stereotypes of people with M.E. as it embeds misplaced views that the disease is a psychological condition.
- 6 Be careful about the use of imagery accompanying an PR/Article.** Too often imagery accompanying articles can be insensitive or inappropriate. Examples include displaying people with M.E. with a hand to their head or undertaking physical activity. Action for M.E. are always happy to provide journalists with imagery that has been consulted on with a focus group of people with M.E.
- 7 Be careful about referring to recovery from M.E. e.g. referencing that person "had M.E."** without providing the full context of the condition. While some people do recover from M.E., many more do not and many relapse repeatedly.
- 8 Do consult as widely as possible with Action for M.E. and people with M.E. before drafting an article/PR.**
- 9 Do think about the impact of what you write on people with M.E.**
- 10 Don't be afraid to ask Action for M.E. for advice and assistance.** Contact us on [media@actionforme.org.uk](mailto:media@actionforme.org.uk) for advice and assistance.

This guidance has been prepared for and with the M.E. Community.