



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. This has led to a degree of prejudice on people's perception of M.E.

At the same time, there have been ineffective and potentially harmful treatments recommended such as graded exercise therapy, 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.

Case Study

I like to use the battery analogy: I have a smaller battery than other people and it takes longer than other people's to recharge (sometimes days). My main symptoms are exhaustion, "brain fog", muscle discomfort and spasms, poor temperature regulation and slurred speech.

Symptoms mean that I am only able to work part-time, and I enable part-time work by restricting the other activities I do mid-week. For example, I batch-cook meals at the weekends and reheat food during the week, so I don't have to work and cook on the same day.

Symptoms also have an effect on how much I am able to socialise; I often only see friends once a week (usually at the weekend). In order to prevent my symptoms getting worse I balance any activity I do with regular periods of effective rest, during which I can recover and reset ("recharge" the battery)."

- Imogen

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.



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 debilitating and persistent exhaustion, associated with post-exertional malaise (PEM), 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.

Whilst M.E. presents similarities in symptoms to long COVID, the two terms should not be used interchangeably.

In 2021, NICE published further [guidelines](https://www.nice.org.uk/guidance/ng206) on M.E. and is a useful place to find out more information. (<https://www.nice.org.uk/guidance/ng206>)

“Post-exertional Malaise, or PEM, is the most commonly associated symptom of M.E. It is the worsening of symptoms following minor physical or mental exertion, and can flare up from 12 to 48 hours after activity. For some people with M.E. PEM can arise from even simple daily activities such as cleaning, cooking, or showering. It can be extremely debilitating, with the effects lasting anything from several days to weeks at a time.”

Professor David Strain
Chief Medical Advisor for Action for M.E.

Use of language

DO	DON'T
DO refer to the disease as Myalgic Encephalomyelitis (M.E.). The NHS may, however, diagnose M.E. or CFS or ME/CFS.	DON'T refer to the disease as 'Chronic Fatigue' or 'Chronic Fatigue Syndrome' as this ignores many other symptoms and their severity.
DO refer to 'people with M.E.' or 'patients with M.E.'	DON'T refer to people as 'M.E. sufferers'.
DO explain the wide variety of symptoms that people with M.E. experience. Focus on core symptom criteria of the 2021 NICE Guidelines.	DON'T refer to 'tired' or 'tiredness' when describing symptoms of M.E. Fatigue is just one of many symptoms.
DO be careful about referring to recovery from M.E. Only 5% of people with M.E. are currently in remission from M.E. and many relapse.	DON'T reference a person having 'had M.E.' without providing the full content of the condition.
DO consult as widely as possible with Action for M.E. (media@actionforme.org.uk) and people with M.E. and refer to the 2021 NICE Guidelines before drafting an article/PR.	DON'T rely solely on service websites for (eg. NHS) as patient experience is crucial when accurately portraying M.E.
DO refer to M.E. as a physical disease whose symptoms can be measured in tests.	DON'T suggest M.E. is psychological or that behaviours, thinking patterns or mental illnesses can lead to either the development or recovery from M.E.
DO talk to a wide range of people with M.E. and make your interview process accessible by providing lengthy turnaround times and allow interviews by email not just by phone or in person.	DON'T just talk to people with M.E. at the less severe end of the spectrum or default to interviewing just white individuals. M.E. affects people of all races and ages.
DO use terminology such as 'wheelchair users', 'walking aids', 'daily living aids', 'ambulatory wheelchair users', and 'mobility scooters', when referring to 'mobility aids'.	DON'T use negative or reductive terminology. Mobility aids are not a tragedy or a negative thing to avoid but a tool to enable people to do things they would not be able to do otherwise.
DO use the terminology such as 'chronic illness', 'chronically ill', 'invisible illness', 'disabled', 'disability', 'energy limiting chronic illness'.	DON'T use the terminology 'crippled', 'handicapped', 'invalid', 'differently abled' or 'special'.

Key Facts and Figures

FACT	SOURCE
DM.E. is defined as a 'disability' under the Equality Act 2010	Office for Disability Issues, May 2011 Equality Act 2010: Guidance on matters to be taken into account in determining questions relating to the definition of disability
M.E. affects 250,000 people in the UK	Radford G. and Chowdhury S. ME/CFS Research Funding; commissioned by CMRC (2016)
The quality of life for people with M.E. is below that of patients with some cancers	Hvidberg et al. The Health-Related Quality of Life for Patients with (ME/CFS) (2015)
People with M.E. are six times more likely to die by suicide compared to the general population	Chang, Hotopf et al. Mortality of people with CFS (2016)
M.E. is more prevalent in socially deprived families	Crawley, E. The epidemiology of chronic fatigue syndrome/myalgic encephalitis in children (2017)
One in four people with M.E. are severely affected, leaving them house- and/or bed-bound	Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness (2014)
Studies have shown over 80% of those suffering with M.E. suffer from other conditions in addition to M.E.	Castro-Marrero, Jesús et al. Comorbidity in CFS/ ME: A Nationwide Population-Based Cohort Study (2017)
Recovery rates from M.E. are not clear	Adamowicz JL et al. Defining recovery in chronic fatigue syndrome: a critical review. Quality of Life Research 23 (9): 2407–16 (2014)
80% of people with M.E. have to stop work	Action for M.E. No-one written off: problems and potential solutions for people affected by chronic fluctuating conditions (2008)
Less than 10% of people with M.E. are in full time work	Action for M.E. M.E. time to deliver (2014)
Research into M.E. represents less than 1% of all active grants given by UK mainstream funding agencies	Radford G. and Chowdhury S. ME/CFS Research Funding; commissioned by CMRC (2016)
M.E. affects twice as many people in the UK than MS, however MS receives over 7 times the funding in the UK	Radford G. and Chowdhury S. ME/CFS Research Funding; commissioned by CMRC (2016)
78% of schools have failed to demonstrate that they have a medical condition policy for M.E.	The Health Conditions in Schools Alliance, 2017
Less than half of NHS organisations have a specialist M.E. service	https://www.actionforme.org.uk/uploads/pdfs/spotlight-on-specialist-services-july-2017.pdf

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 M.E. or CFS or M.E./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 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.
- 4 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.
- 5 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. (<https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/chronic-fatigue-syndrome-cfs>)
- 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. (<https://www.mecfs.de/stockphotos/>)
- 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 for advice and assistance.

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