



action for m·e

# We asked, You said, **We did.**

After consulting widely with the M.E. Community, we are pleased to have published the final media guidelines.

We asked for views on our set of media guidelines, produced to combat the misrepresentation of Myalgic Encephalomyelitis (M.E.) in the media and online. The guidelines outline ten simple considerations for journalists to keep in mind when writing about M.E.

Please find a summary of the key themes outlined in the feedback received below, and our consideration of them in reviewing the guidelines.\* We believe the guidelines are reflective of the broad feelings of the community, and hope they will prove a useful resource for journalists, in tackling the misrepresentation of M.E. in the media.

<b>Can you expand on the definition of M.E.?</b>	Following feedback from several individuals, we have re-framed the definition of M.E. to consider conversations that people have had with people telling them the condition isn't real.
<b>Can you clarify the symptoms of M.E.?</b>	<p>We recognise there are many symptoms of M.E. and are trying to move away from 'fatigue' as the central symptom focused on.</p> <p>Following feedback, we have rephrased the framing of 'fatigue' in the about M.E. section. Given the number of thoughts on definition, we thought it was important to include a suggested description of M.E. from a member of the community, and have therefore included a case study.</p> <p>With regards to the inclusion of the severity of M.E., we have included a link to the NICE guidelines, so that journalists can find further information on the definition and symptoms if required.</p>
<b>Why do you refer to M.E. as both a condition and disease?</b>	We use the terms interchangeably, as other organisations in the sector do.
<b>Can you expand on the definition of Post-Exertional Malaise (PEM)?</b>	We recognise that although there are many symptoms of M.E., PEM is widely considered the most associated symptom. We have therefore included a medical professional's definition of PEM to address this.

<p><b>Why have you included information on Long Covid? Surely this is irrelevant to these guidelines and might create confusion.</b></p>	<p>Whilst we understand and have highlighted that M.E. can be triggered by a number of infections, not only Covid-19, we have seen an increase in media around Long Covid and post-viral conditions such as M.E. We want to avoid any potential for misrepresentation by addressing the connection directly and making it clear that the two conditions are not the same.</p> <p>We think there are clear lessons to be learnt on the treatment of Long Covid, from the M.E. community, who have experienced similar conversations in the past.</p>
<p><b>Why have you phrased myalgic encephalomyelitis as M.E., when other organisations and the NHS refer to it as ME, ME/CFS, CFS etc?</b></p>	<p>We have used the acronym of myalgic encephalomyelitis as M.E. and standardised this across the guidelines. This decision was taken to ensure that communication is clear on M.E. as its own condition, and avoids any focus on 'fatigue' as a main symptom of M.E.</p> <p>We do, however, recognise that there is history to previous definitions, and that other organisations will refer to the condition differently.</p>
<p><b>Can you add 'do' and 'don't' in the text box?</b></p>	<p>Following several suggestions, we have reformatted the 'Use of Language' table to include 'do' and 'don't' into each text box and made the font size bigger.</p>
<p><b>Can you include more information on the appropriate use of imagery?</b></p>	<p>We recognise there is still work to be done on the appropriate imagery of people with M.E. This is part of a wider ongoing project that Action for M.E. are exploring as imagery remains a contentious issue.</p>
<p><b>Can you expand on the resources available?</b></p>	<p>We have expanded the guidelines to include a short list key facts and figures that journalists can use covering a range of facts on M.E. This list should not be taken comprehensively, but we hope provides a useful starting point for data.</p>
<p><b>Can you change the phrasing of 'enforced exercise'?</b></p>	<p>We have changed this definition to 'graded exercise therapy' as we understand it is more accurate.</p>
<p><b>Why is this an Action for M.E. project?</b></p>	<p>Action for M.E. are proud to represent the voices of the M.E. community, and work with a variety of organisations across the sector. The guidelines are fundamentally a resource for better understanding around the condition, which ultimately better serves the community.</p>

\*We recognise that there will be individuals who are disappointed that some of their suggestions were not taken forward. We have spent a significant amount of time considering each point of feedback and hope that the guidelines capture the broad feelings of the community.