Pick one of these 3 emails, edit and personalise and email to meconnect@meassociation.org.uk

To whom it may concern,

I am writing as a person with ME who has supported your organization for many years. My sister has raised money on your behalf, and our story has even been featured in your magazine. However, I am formally withdrawing my support due to the appalling letter by your chairman published in the recent ME Essentials magazine. I strongly believe he should step down, and I urge you to release a formal statement addressing this matter.

I am utterly shocked that someone representing your charity would insinuate that people with ME choose to stay in bed. Those of us living with this condition understand that movement, where possible, is beneficial. Of course, we would get out of bed if we could and I don’t know a single person with severe ME who doesn’t repeatedly try and do more, often suffering severe consequences! Such a statement shows a complete lack of understanding and compassion.

INSERT PERSONAL STORY

I have been severely affected by ME for the past two years. I lost my ability to walk precisely because I tried to push through, walking to the bathroom daily until I crashed so severely that I could barely move my legs or lift my head, let alone walk. This was not a choice. I am not afraid of movement—I physically cannot do it without devastating consequences. I have even had a chairlift installed in my home, but I remain too unwell to use it.

Before becoming severely affected, I worked as a veterinary surgeon despite having mild ME. I loved going on walks, spending time outdoors, and baking. Why on earth would I choose to stay in bed if I had any other option? To suggest otherwise is deeply insulting and dismissive of the realities faced by severely unwell people. It makes a mockery of those of us who have not only lost our quality of life but now must endure such baseless accusations from someone who is supposed to advocate for us.

I would like to understand how this individual was appointed chairman and what qualifications he holds to represent people with ME. It is clear he lacks a basic understanding of the condition, particularly severe ME, which affects 25% of us. This group, the most severely impacted, needs the greatest advocacy and research—not belittlement or harmful rhetoric.

I look forward to your response and hope you will take this matter seriously.

Sincerely,

Alternative E-mail

To ME Association,

I'm writing as someone who has been severely affected by ME. This charity was the first place I turned to when I needed support and information when first diagnosed.

I'm so disappointed in a letter that was published in the most recent ME magazine by chairman, Neil Riley. I can see it was carefully worded to point out that the letter is his view and experience, however I believe it could cause a lot of harm to patients if their family members read it and think their loved one with ME just needs to force themselves out of bed to get better. Neil is representing your charity, and I believe it's your responsibility to release a statement addressing the harm it could cause and why you felt it necessary to publish the letter in the first place.

Perhaps only a few complaints about this letter have been raised so far, but please bear in mind many ME patients cannot write or form a complaint.

ME charities are supposed to educate, spread awareness, and destigmatise an already severely stigmatised condition. The letter Neil wrote and you published does the complete opposite. For Neil to insinuate that people with ME haven't already tried getting out of bed and pushing themselves every day is absolutely ridiculous. He said "I think it's worth a go." No, it absolutely isn't worth a go when people with ME are very aware of their limits and not pushing themselves to be even more unwell.

As a charity, you've fought and written about so many misconceptions, dangerous treatments, inaccurate articles written in newspapers...but in one letter from a chairman, this has all been undone.

Please consider writing a statement or replying to my email to address this.

Sincerely,

Dear Editor,

I am compelled to express my profound disappointment in light of the deeply misguided and damaging letter from your chairman published in ME Essentials.

The assertion by your chairman that individuals with ME would choose to remain in bed is not only appalling but demonstrates a fundamental misunderstanding of the physiological complexities associated with this condition. ME is characterized by significant metabolic abnormalities, as evidenced by the two-day cardiopulmonary exercise testing (CPET), which reveals a marked reduction in exercise capacity and a distinctive physiological response to exertion. This testing highlights the debilitating nature of the disorder, where even minimal exertion can lead to severe post-exertional malaise, exacerbating symptoms and reinforcing a cycle of tissue hypoxia and mitochondrial dysfunction.

<u>INSERT PERSONAL STORY HERE</u>

It is critical to recognize that movement is not a source of fear for those of us with severe ME; rather, it is a process our bodies can no longer tolerate without severe repercussions. Such comments from your organization trivialize the lived experiences of those battling severe ME and reflect a disturbing lack of empathy and understanding from leadership expected to advocate for our community.

I strongly believe a retraction and an apology is necessary here., it is imperative that your organization embodies respect and accuracy in representing our community. Please reassess your leadership to ensure that those in positions of influence possess a comprehensive understanding of the complexities inherent in this condition and to ensure that severe pwME are always thoroughly represented and that no further harm regarding exercise and movement is ever promoted by the ME association again.

Sincerely,