



25% M.E. Group

Support for Severe M.E.

This year marks the **25 year anniversary of the 25% ME Group**, the only charity concerned specifically with the needs of the severely affected.

They have a wealth of experience and as such are

generally seen as an authority on Severe ME. The charity has been active in campaigning for better diagnosis, treatment and care of people with Severe ME including being a stakeholder in the NICE review, supporting use of ICC, undertaking surveys about various aspects of Severe ME, disseminating information, etc, and being a respected voice for people who are the most affected by ME.

<https://25megroup.org/about-us>



As part of their 25 year celebrations, and to mark **Severe ME Awareness Day on 8 August**, 25% ME Group have invited members of the charity and the 25% ME Facebook group to participate in a project to make Severe ME visible. They have been asked to submit **Stories and Images** of their lives with Severe ME.

<https://25megroup.org/severe-me-day-2020>

Sneak peak at some excerpts from **Stories and Images** of lives with Severe ME

- ❖ *“I became ill so many years ago, back in the 1990’s. We thought I had a really bad case of flu to start with, but I just didn’t get better. I couldn’t believe how ill I felt. What was this mystery illness? I eventually had to go back to work, but I wasn’t able to do anything else and my health was getting worse and worse. And no one seemed to care! I looked well, but I certainly wasn’t well. Turns out I originally had mild-moderate ME, but due to being constantly advised to just try harder I became more and more ill and now I have Severe ME. I still look well, people don’t see the PENE (post exertional neuroimmune exhaustion) cos I’m hidden away in my bed, having to reduce my interaction with others, being looked after by paid carers. I was originally told by doctors that everyone got better from ME, that I was the only one who hadn’t got better. Then I heard about 25% ME Group. I learned that 25% of ME sufferers remain long*

term ill and are severely disabled. The doctors were wrong. I was not alone. I would never be alone again. I was so happy to find the 25% ME Group and its members”

- ❖ “My life has changed dramatically since I developed severe ME. I used to be extremely active and had a good career and social life. I was fit and healthy, I was a keen sportswoman and assumed I would always be like that. But severe ME changed all that. I’m now almost bedridden. I can’t care for myself. I’m lucky because I have kind carers. They try to make life more comfortable for me, but I have to discourage visitors because they exhaust me too much”

How does ‘Severe’ Myalgic Encephalomyelitis differ from less severe forms?

Those with severe Myalgic Encephalomyelitis are either bedbound and/or virtually or completely housebound. They require unique care due to the tendency for the illness to be exacerbated by everyday stimuli such as light, noise and movement. They are often too ill to use a wheelchair, or can only do so to a very limited degree. Many need to spend their time lying flat in silence and darkness to avoid deterioration. Some are tube-fed, incontinent, unable to communicate, allergic to medications, and unable to move.

Those with very severe Myalgic Encephalomyelitis experience profound levels of suffering and extreme symptoms, which can be life-threatening. Life may be reduced to basic survival, struggling moment by moment to breathe, eat, and drink, while enduring extreme pain.

<https://25megroup.org/me/management>



There are approximately 200,000 people in the UK who suffer from M.E. Some do recover. However, approximately 25% of sufferers remain long term ill and severely disabled by the disease. Many are left isolated, housebound or even bedbound by the effects of the illness. It affects people from all walks of life, all age groups and can strike when you are least expecting it.

The 25% M.E. Group exists to support all who have the severe form of M.E. and those who care for them. This includes people who are housebound, bedbound and wheelchair users

You can support 25% ME Group by becoming a member. Full membership is for those who have Severe ME and their carers (UK and non-UK memberships are available. Associate membership is for anyone with an interest in Severe ME, again UK and non-UK memberships are available

You can see full details of membership benefits and fees at

<https://25megroup.org/memberships>

You can join the [25% Severe ME Group News Page](#) on Facebook to learn more about Severe ME and those with Severe ME can find out how to join the hidden, private 25% ME Group