

#LiveLikeME

for one day

May 12th is World M.E. Day. M.E. (myalgic encephalomyelitis) is a debilitating chronic illness that affects every part of the patient's body. Persons with ME experience symptoms such as brain fog, muscle pains, sensitivity to sensory input (like light, sound, scents), and - crucially - post exertion malaise (PEM; flu-like symptoms that are triggered by activities that seem so normal to many people, such as going out to buy groceries).



Very few persons with M.E. can work fulltime, and most cannot work at all. There is no cure and no treatment. All we can do, is apply pacing. This means that we divide our energy relatively evenly throughout the day and take many moments of rest in between small activities. If we are planning a more tiring activity, we need to rest the day before and we know we will probably still get PEM afterwards.

M.E. was officially recognised by the World Health Organisation already in 1969, and there are millions of patients around the world (more even than people with AIDS). However, there is still very little recognition of the disease by both the public and by medical professionals. Research on M.E. is still scarce, and it takes multiple years for most patients to be diagnosed (for me, it was 'only' 2.5 years after I started to experience PEM).

This is why I need your help. While you obviously cannot cure me, you can help me by raising awareness of M.E.. To do so, I have set up an awareness sheet for healthy people to live one day like I have to live every single day. This helps to show you and others how very much unlike a vacation it is to spend one's days in bed without having to work.

Another way to help is to fund research into M.E. The Open Medicine Foundation (OMF) does exactly that. If you decide to participate in this awareness campaign, you may consider also donating to OMF. You can even ask people to sponsor your day of #LiveLikeME, so you can donate even more!

To donate, you can either follow the link on my website, or you can contribute to my fundraiser on Facebook. Thank you so much in advance!

