

From Me and My Friends, to You and Yours Myalgic Encephalomyelitis (M.E.)

What is M.E.?

M.E stands for Myalgic Encephalomyelitis. These 2 words can be broken down into the following:

My→Muscle **algic**→Pain

Encephalo→ Brain **myel**→Spinal Cord **itis**→Inflammation

M.E is a chronic (long term) neurological condition that causes a wide range of symptoms which can affect the entire body. M.E. affects an estimated 250,000 people in the UK, and around 17 million people worldwide. The condition has a spectrum of severities ranging from mild to severe all of which are life altering. The effects of ME are devastating enough to leave 25% of patients housebound or bed bound and a much larger number in part time work or education.

How is M.E. Diagnosed?

There is no diagnostic test for M.E. so doctors will do a range of tests eg. blood tests to rule out other conditions before coming to a diagnosis of M.E. They will take an in-depth symptom history, family medical history and conduct a physical examination. If nothing shows up that gives an alternative answer and your symptoms persist then a diagnosis of M.E. may be made by the clinician.

How Does M.E. impact my body?

Not everyone will experience the same symptoms so it's important not to compare someone who has M.E. to another person who has the same illness.

For me M.E. causes widespread chronic pain, severe fatigue, dizziness, nausea and brain fog amongst other symptoms. M.E. means I cannot stand or walk from long periods of time, so I use a wheelchair or power chair to help me get around sometimes out of the house. Normally I use my power chair as it gives me increased independence but you have to be certain degree of "well enough" to control it so sometimes having someone push me in a manual wheelchair is safer. I also struggle with sensory sensitivity so am more aware of noise, light, touch and smells than the average person- this makes busy social occasions tricky to navigate.

Another large part of M.E. is Post Exertional Malaise (PEM). This refers to the body and brain's inability to recover after expending even small amounts of cognitive or physical energy. This causes a reduction in functioning and a severe worsening of symptoms for a period of time after the exertion. PEM is also known as "payback".

How Does M.E. impact my mind?

It's hard to know precisely how much M.E. has impacted me mentally as I have struggled with anxiety for much longer than I've had M.E. But it has definitely created new anxieties for me, I find the unpredictability of flare ups particularly anxiety provoking, as you could be doing everything right to avoid a flare but one still may happen. M.E. has also made and continues to make me feel isolated from my peers at times as there is quite the disparity between what I am

going through in comparison to them. There are definitely times when I feel low about my disability but I'm learning now that this is normal from time to time and is needed sometimes to help you appreciate what your body is capable of. I had some psychology sessions after my initial diagnosis which really helped me to accept my disability as a part of me and I will be forever indebted to the psychologist who helped me realise that good health and happiness are not mutually exclusive.

How Does M.E. impact my life?

M.E. permeates every aspect of my life. I have to plan my days extensively so that I can maximise what I get done with the limited energy that I have. If I want to go anywhere I have to consider how much walking is involved, how busy the place will be, how long we will be out for etc. I also have to schedule in regular rests to help me manage my symptoms and pace myself. It means I have to be cautious about doing too many things in one week as I have to factor in the rest time before an event and the PEM after- this often leads to me missing out on opportunities. This really limits my ability to be spontaneous, doing too much can lead to a crash that will wipe me off my feet completely for days at a time so it's best to prioritise. M.E. impacts my relationships with my friends and family as I can't socialise for long periods of time as I find social spaces quite overstimulating from a sensory perspective. Sometimes my friends and family act more as carers when I'm in a crash and this impacts not only my life but their's as well.

What Can Friends do to help?

- Be understanding when we have to cancel plans at the last minute, we can't help it
- Don't pass judgement on how we choose to spend our limited energy, we know our bodies and the implications activity can have
- If we are out and about together it's always good if you can keep an eye out for somewhere to sit and rest for a bit
- Low energy catch ups like chilling at home and watching a film with a pizza can be much more accessible to us than parties
- But please don't stop inviting us to these things, let us decide what our bodies are capable of
- Being there to listen is always appreciated but I don't need you to try and fix me or give unsolicited health advice

More Resources

- <https://www.actionforme.org.uk/> Action For ME are a charity that provide a range of services for people with M.E. from the Young People's Forum to information resources its a real bank of valuable knowledge
- <https://meassociation.org.uk/> The ME Association is also a charity working to support people with ME, raising awareness for the impact it has on people's life as well as offering a range of information leaflets and advice.
- There is an entire Instagram community of people sharing their experiences of M.E. Some of my favourites include @cupsofteaplusme, @lifeofpippa and @thisthingtheycallrecovery

- Overcoming Chronic Fatigue in Young People- Katharine Rimes & Trudie Chalder-this book was recommended by my consultant. It has lots of useful advice about pacing and support you may be able get from your place of education.

About the Author

I'm Amber and I'm 19 years old. I was diagnosed with M.E. in late 2018 after 2 and a half years of declining health and medical investigations. I was then diagnosed with Fibromyalgia in late 2020. Currently I am a first year university student taking Education Studies.