

Written by young people, for young people



What does having ME feel like?

Having ME feels like something constantly needs repairing but you're never quite fixed.

It feels exhausting all the time and just wanting it to stop.

Waking up feels like you have already run a marathon with lead weights to your arms and legs.



What symptoms of ME affect your day to day?

"Severe fatigue, brain fog, nausea, aches/pain, headaches, sensory input and difficulty with thermoregulation".

"Dizziness, problems with sleep, feeling worse after resting and memory problems".

"Mainly pain and joint pain (and obviously fatigue)".

Sum up having ME in only a few words:

EXHAUSTION,
FEAR
AND HOPE

OVER-
WHELMING

FRUSTRATING

Letting people know the difficulties...

"It can be really difficult to maintain social contact, especially if seeing friends is too exhausting."

"Brainfog and tiredness can cause people to be unable to focus or perform a task well, no matter how hard they try".

"When fatigue is severe, moving can be unbearable".

"Tiny little things like lifting cutlery to eat are so exhausting - I think it can be hard to portray to healthy people that even barely significant things to them can be affected for someone with ME/CFS".

What doesn't help you with managing ME?

There is a misconception that the symptoms can be pushed through - this only intensifies the symptoms and can make you more ill.

People think ME/CFS is a mental illness, or think this condition is just an excuse for being lazy.

People tell me I'm being dramatic.



What helps with managing your ME?

"Having the love and support of family and friends who can bolster me up".

"Pacing and planning".

"Regular rest/sleep".

"Reading and music".



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What better support do you need in your education?

“More awareness about ME overall would be the best way to fix systemic issues with how education systems deal with ME”.

“Adjustments and accommodations with exams and schoolwork”.

“Having better systems in place for students who are too severe to attend school in person (e.g. online zoom calls)”.

“A better understanding of the illness and appreciate the difficulty of managing both education and a chronic illness”.

“ How would you explain the boom and bust cycle? ”

Trying to push through ME is like trying to run up an escalator that’s going down. You can try as hard as you can, but you will inevitably end up crashing down at the bottom. You can determinedly sprint up that escalator again and again but you will fall harder every time

It feels like you are taking a step forward but end up going two steps back.

It’s like you can’t stay awake or breathe without widespread pain.



How would you explain having ME to a friend?

“Imagine a really, really long lockdown. It can be really tough as they don’t see the daily challenges. Giving examples of everyday things - such as not being able to watch a long film without crashing - helps show how hard even little things can be”.

“It’s like the feeling you have after running a marathon and you have recovered a bit of energy, but you still lack a large amount of the energy that you started with - ME is like that, but the feeling doesn’t go away when you wake up the next day”.

“It’s like waking up and feeling the weight of everything and every step you take just makes it worse.”

Explaining ME/CFS to your doctor

ME/CFS is not a mental illness & the main goal of someone with it is to become as well as possible - ME/CFS is not a choice.

“Everyone is different”.

ME is a chronic condition & currently, there isn’t a cure. So, the best thing a doctor can do is help individual to manage it in the best way possible.

“ ME/CFS can be a debilitating illness and can take away many things, however, with friends and family to support you, it can be managed.

Prioritising activities that are most important to you is essential (e.g. choosing to limit social time to focus on exams, or focusing on physical wellbeing rather than schoolwork. Also, having the self-discipline to stop yourself from overdoing things is really important with pacing (this can be hard!) There is a lot of support out there, so to anyone with ME/CFS, remember there is an awesome community out there to support you and you are not alone!

Any advice for other young people?

