

## WRITTEN BY YOUNG PEOPLE, FOR YOUNG PEOPLE



### WHAT DOES HAVING M.E./CFS FEEL LIKE?

Having M.E./CFS 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 M.E./CFS AFFECT YOUR DAY TO DAY?

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

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

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

### SUM UP HAVING M.E./CFS IN ONLY A FEW WORDS:

OVER-WHELMING

EXHAUSTION, FEAR AND HOPE

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 M.E./CFS".**

### WHAT DOESN'T HELP YOU WITH MANAGING M.E./CFS?

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

**People who think M.E./CFS is a mental illness, or think this condition is just an excuse for laziness.**

People telling me I'm being dramatic.



### WHAT HELPS WITH MANAGING YOUR M.E./CFS?

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

**"Pacing and planning".**

"Regular rest/sleep".

**"Reading and music".**

**NEED SUPPORT? CALL US ON 0117 927 7551**

## WHAT BETTER SUPPORT DO YOU NEED IN YOUR EDUCATION?

"More awareness about M.E. overall would be the best way to fix systemic issues with how education systems deal with M.E".

"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 M.E./CFS 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 M.E./CFS 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 - M.E. 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

M.E./CFS is not a mental illness and the main goal of someone with M.E./CFS is to become as well as possible - M.E./CFS is not a choice.

"Everyone is different".

That M.E. is a chronic condition, and currently there isn't a cure, so the best thing a doctor can do is help individuals to manage it in the best way possible.



**M.E./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 M.E./CFS, remember there is an awesome community out there to support you and you are not alone!

## ANY ADVICE FOR OTHER YOUNG PEOPLE?

