

19 Things People With ME/CFS Wish Others Understood

Have you ever told someone about your ME/[CFS](#), only for them to respond, “I understand, I’m always tired, too”?

Though friends and loved ones may be well-intentioned, it can be frustrating and hurtful when they just don’t “get it.” The reality is that ME/[CFS](#) is not well understood and unfortunately comes with a lot of misconceptions.

ME/[CFS](#) ([myalgic encephalomyelitis](#), formerly called [chronic fatigue syndrome](#)) is a serious, chronic and debilitating disease that can affect people of any age. According to the [Solve ME/CFS Initiative \(SMCI\)](#), it is estimated that between 17 and 24 million people worldwide live with the condition. Still, there is no diagnostic test, FDA-approved treatment or cure for ME/[CFS](#).

Some of the [most common symptoms](#) of ME/[CFS](#) include:

- Post-exertional malaise (PEM), meaning extreme exhaustion made worse by even minor physical or mental effort
- Unrefreshing sleep or other sleep problems

- Concentration and cognition problems
- Muscle pain, joint pain, headache
- Light and/or sound sensitivity
- Abdominal issues, including stomach pain, bloating and nausea
- Sinus/nasal problems, swollen glands, tender lymph nodes, sore throat

While the illness may often involve extreme fatigue or exhaustion, it's not the only symptom people with ME/[CFS](#) experience – and it's certainly not the same as regular tiredness. Mighty contributor [Hayley Green](#) [explained](#):

This illness is so much more than fatigue. Fatigue is just one of the multitude of symptoms a person with ME may experience. In some cases, such as mine, it isn't even the most prevalent one.

Many people may say, 'Oh, I get tired, too.' This may well be the case, but imagine being so 'tired' you can't even lift your arms above your head to tie your hair. Imagine having to lay down and rest after a bath because it's left you completely wiped out. Imagine being so ill you can't leave the house for weeks, and when you do, you experience tremendous suffering for days afterwards.

It seems almost unfathomable — but to people with ME, it is very real. And there is no respite.

Although others may never fully understand what it's like to have ME/[CFS](#) unless they have the condition themselves, it's still important to raise awareness and speak out about how the illness can affect people. This can not only help friends and loved ones support people with ME/[CFS](#), but can hopefully lead to more research, funding and treatments for the illness.

To challenge misconceptions and provide better support and understanding for people with ME/[CFS](#), The Mighty worked with the [Solve ME/CFS Initiative](#). We [asked our Mighty community](#) and [the SMCI community](#) what they wish others knew about life with ME/[CFS](#).

Here's what our communities shared with us:

1. "'Resting' does absolutely nothing to 'fix' how exhausted we feel with CFS. There is literally nothing that makes it better. I know, because I've tried pretty much everything. Defending ourselves is even more exhausting." – Laura G.
2. "It's so hard to socialize or be spontaneous. Activities take planning and rest ahead of time. So many things need to be taken into consideration: location, travel time, amount of walking/standing required, seating types and availability, noise levels, smells, lighting (no strobe lighting please!). It takes so much energy to appear 'normal.' Even a short event can lead to a crash that can last for days or weeks." – roberta.peters

3. "It's debilitating even in its 'mild' form. It takes a lot of effort to manage the condition symptoms and appear to have a relatively 'normal' life. Just because we are seen to have fun on social media and raise a family and work full-time, does not mean we are well, we just 'manage.' Conversely, what you don't see is when we can't manage, function or cope. We don't flaunt that, that happens behind closed doors." – Emma J.H.
4. "I'm trying my best. Even when it seems like I'm not doing as well as everyone else it's my best or I have to cancel plans. I'm always trying my best." – Clare E.
5. "I can't 'pick and choose' when I'll have a good day and it's not an excuse/lie I use to get out of things. People will be like 'but you went to xx event last week and you were fine' which is hard to explain that every day is different and I never know what my energy levels will be like in advance." – Nicholle U.
6. "I understand everyone's life is tiring, but please don't try and make it a competition. I would be over the moon to wake up one day feeling only tired. When I say I'm tired, it's complete exhaustion. Please understand that I would never wish this level of fatigue on anyone, especially not my friends. And on that, don't make me feel worse by saying, 'Well I'm tired but I'm still going out' or 'everyone's tired' because it's just not that simple and we don't have the energy to explain it to you every time." – Deayana-Mai B.

7. "Something I wish others understood about ME/CFS is just how complex the illness is, how it greatly affects so many systems in the body, and the known fact that it has the potential to be fatal." – nattieo
8. "It's lonely. I can pick maybe one or two activities a month otherwise I'm usually in my bed or couch. I wish more people would come visit." – Kelly A.
9. "It's an illness that like any other has many spectrums. Just because you know someone or heard of someone who had [CFS](#)/ME and was bedridden, and I'm (fortunately) not, that does *not* mean I am faking it. Some can work, some can't. Some can stay at home and do a few things. Others can't even get up and use the restroom. Understand that it can vary. Everyone is different. And everyone with this is different. And just because I am 'OK' to you does not mean I really am. I managed to graduate from university. But no one on the outside saw that that was *literally* all I could handle doing." – Alexandria B.M.
10. "It never goes away, I've been exhausted constantly for years. I always hurt, I'm always 'tired,' I'm always planning my now limited life around ME. People see me and think I seem fine, they don't see me collapse at home after minimal activity. I just don't like to be seen to complain or go on about it all the time. So I say, 'I'm fine thanks, how are you?'" – Jo G.
11. "The little things are big things to us, like going up stairs or even making tea." – Leanne E.

12. "It's almost completely invisible. You might think I look 'a little tired' or that I'm just a lazy person who walks slowly and exerts herself as infrequently as possible. But you don't understand how my body is screaming out in pain for every minute spent walking and standing without support. How there are unfallen tears of pain and frustration behind my smile and humor. How every step feels like there's lead in your veins and weights on your ankles. How it seems like you're looking through a window watching the life you want pass you by. You couldn't possibly understand completely until you've lived with it. And I would never wish that on anyone. But you can be mindful of people's time and precious energy if they tell you they [are] suffering. Support them and be kind, for they are constantly struggling even if you can't visibly see it." – Fatima H.
13. "It never goes away. Never. 24/7. 365. No matter how we look or act. It's there for every second, every feeling, every experience. It colors every moment of our lives." – tanyajane1.1
14. "I wish others understood that having ME/[CFS](#) is like having the worst flu you've ever had, *every single day*. And that our medical institutions are completely ill-equipped to understand and treat the people impacted by this devastating disease." – Eddie N.
15. "People often mistake us for being weak or lazy. They have no idea how much strength it takes to get through one day with this illness, never mind weeks,

months and years." – i.m.robie

16. "My feeling bad or having an *awful* day isn't an emotional thing, but a physical one. I have friends who'll say 'but I can still come over, we can just sit next to each other and I can give you a hug, I can just be there for you' and they don't get that that means I have to deal with more input in the shape of them moving, touching me, asking me questions (including simple ones like 'in which cupboard do you have glasses') and that is utterly unbearable. If I'm already crashing that's what's gonna tip me over the edge. It's too much. Paying attention to another human, having to adapt in even the smallest way, is just out of the question often, because it takes so much energy to process." – hannahthuva
17. "I'm not lazy. I'm not 'just tired.' I don't need to lose weight to feel better. I'm not exaggerating. My symptoms are not 'all in my head,' and it's not 'just anxiety.' This is really happening to me, and it shouldn't have taken eight years to get a diagnosis." – Becky B.
18. "When I say I can't do something it's not that I don't want to do it. Most of the time I do. It's because if I choose that thing it most likely means not being able to do the things I have to do. My entire life is about making choices I don't want to make." – Amanda K.
19. "Be a friend. A real one. Put your fast, busy, important life on hold for a bit. Come round my place. Accept me as I am. Make a cuppa. Bring your

favorite movie. Or a pack of cards. Sit with me. Join the slow lane for a bit. It will be exhausting for me, frustrating for you, but you will have been a friend." – Trevor H.

To learn more about ME/[CFS](#), check out the [Solve ME/CFS Initiative's website](#). You can also learn more about [how to get involved and become an advocate here](#).

If you are struggling with the symptoms or side effects of ME/[CFS](#), you are not alone. To read more about the illness from people who have been there, check out the following stories from our Mighty community:

- [24 Things to Know If You've Just Been Diagnosed With ME/CFS](#)
- [The Endless Cycle of Recovery and Relapse in Chronic Fatigue Syndrome](#)
- [11 Hidden Realities \(and 4 Hidden Gifts\) of Myalgic Encephalomyelitis](#)
- [What It Feels Like When I Experience a Chronic Fatigue Syndrome Crash](#)
- [4 Coping Strategies That Can Help in Life with ME/CFS](#)