

ME is not just 'fatigue'

You don't just feel tired - you feel **ill!**

It affects people in different ways.

Post-exertional malaise and flu-like symptoms, unrefreshing sleep, pain, digestive symptoms, memory and concentration difficulties, tender lymph nodes, sensitivity to light and sound.

Symptoms are made worse by physical or mental exertion. Reaction can be delayed for days. Relapses can last days, weeks, months or years.

ME sufferers can look well outside but they only go out when they are well enough and you don't see them afterwards *when they pay for their exertion.*

For more information go to



<http://mefmaction.com>



<https://www.facebook.com/MEFMAActionNetwork>

Myalgic Encephalomyelitis

(used to be known as Chronic Fatigue Syndrome and "the yuppie flu" but those names trivialize the symptoms)



ME is an incurable neurological illness where symptoms worsen after exertion.

It affects 580,000 Canadians*

25% are severely affected: house or bed bound for years.

*From the Canadian Community Health Survey 2016

Questions to ME Patients

What do you do all day? It's similar to what you do with the flu. Often I'm trying to relieve symptoms but I do get spurts of energy at unpredictable times.

Why don't you exercise more? My energy doesn't replenish properly. Studies took patients with ME and depression and a healthy sedentary group. They cycled 10 min on 2 days. The vitals of the ME group worsened on Day 2 of cycling whereas the other two groups improved. Further, the ME patients took days or weeks to recover.

You don't look sick. This is an invisible illness. You'll have to ask how I feel to really know. During good moments, I feel like my former healthy self. But other times even doing light chores or taking a shower can flare my symptoms.

You should go out more. I too want to do so much more than I can. But if I push beyond my signals, I get a flare-up (or crash) that can impair me even more. But if I stay within my energy limits consistently enough, my stamina can get longer.

I'm uncomfortable seeing you this way. Indeed, I've grieved for losing my old lifestyle, but I am learning to still have a quality life within my limits. Your support makes my life better. Some people have stopped all contact or worse, tell me it's all in my head or assume this is all my fault somehow.

"I have been treated like a hypochondriac for years before a proper diagnosis"

ME sufferers cannot live a normal life.
They are often isolated. Many live in poverty.
Even those well enough to work
must ration their energy to avoid a relapse.

How can I help?

If you know someone with ME:

1. **Believe them.** It is a complex disease, not just a periodic inconvenience.
2. **Refrain from giving treatment advice.** What works for one person may make another patient worse.
3. **Ask them:** "Can I do anything to help you?" Or during an activity "Do you need a break?" Even enjoying a visit uses up their limited physical and mental energy.
4. **Be flexible.** They may have to modify an activity or cancel plans at the last minute. They can suffer setbacks if they push past their boundaries.
5. **Share** this information with someone. Though famous, Laura Hillenbrand, Pema Chödrön & Morgan Fairchild have hesitated to share their diagnoses due to common misperceptions.
6. **Donate** to a Registered Charity. Research funding for ME is very low compared to other chronic illnesses.

"It's a kind of tired that sleep can't fix"