

Chronic Illness: What I Want You To Know

Chronic illness is a roller coaster ride for everyone experiencing the disease. This includes the individual living with the disease, loved ones, care partners, friends, and anyone within the care circle of individuals with multi-system chronic complex diseases *(msCCD).



It feels good when you take the time to learn about my disease to better understand what I am going through.



I feel included when I'm invited. But understand my illness may prevent me from attending or even result in a last minute cancellation. Knowing you thought of me matters.



I may not always be able to communicate with words or in sentences when in a *crash. Please work with me to use communication cards or help make our own communication signals.



Ask about my food sensitivities and be aware they may change over time.



Don't take my disease experience personally, even if that means I'm able to attend activities one day but not the next. These diseases are unpredictable.



Planning ahead is helpful for you and me. A resting place where I can lie down with limited sensory stimuli is appreciated. This can include a car, a back room, office space, etc.



I may look okay today, but chances are I will pay for the energy expended. I must pace to remain within my energy envelope to prevent a worsening of symptoms in the days and months following the activity. You can also help by understanding post exertional malaise (*PEM) and pacing.



Even though my body operates in a different way now, I am still a person with ambitions. I long for a life of wellness.



Be flexible with your expectations. My symptoms and their level of severity can change quickly.



Support and love me where I am.

*msCCD refers to diseases such as ME/CFS, fibromyalgia, long COVID, etc.


*Crash is a term used when the individual is experiencing PEM or a flare/exacerbation of symptoms.

*PEM is the body's inability to recover normally following physical, cognitive and emotional effort, as well as orthostatic, environmental, and sensory stress. The onset of PEM is often delayed in presentation, occurring 12- 72 hours after the trigger(s), and can last hours to weeks and even months at a time depending on the severity of the energy insult.




My Specific Insights


My pre-crash/pre-flare symptoms include:




When I am in a crash or flare episode you can help me by:



My most common symptoms when I am crashed or in a flare are:



I also want you to know:



Name: _____

Date: _____

Resources

Insights into My Chronic Illness



<http://bit.ly/3YG6p60>

Crash Survival Guidebook



<https://bit.ly/34nh5yX>

Communication Cards



<http://bit.ly/3YG6p60>