

## Insights into My Chronic Illness

### Intro:

It is *hard* to know how to support others when their health becomes compromised. It can leave you feeling powerless and unsure of what to do. It is *even harder* when your loved one is afflicted by an “invisible illness.” One where there isn’t a cast around their arm, or a blood test to reveal exactly what “it” is.

Myalgic Encephalomyelitis (ME/CFS), fibromyalgia (FM), dysautonomia, postural orthostatic intolerance syndrome (POTS), and Long COVID are just a few chronic illnesses that present with complex ambiguities. As a part of human nature, we don’t like ambiguity. We prefer concrete evidence and proof. However, not every chronic illness allows for this. So, when you and your loved one are confronted with such a journey, start at a place of compassion and validation. Next, cultivate a sense of understanding and acceptance.

The following explanations aim to provide insight into what your loved one may be experiencing. They are written from the perspective of an individual with chronic illness.

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### To my loved one,

#### This is Scary

I know something is wrong. Something is “off” in my body-but the blood tests, and endless hours of medical diagnostic procedures continue to come back NORMAL. I am scared.

There are so many thoughts running through my mind: What are they missing? Am I crazy? They have to keep running tests because they will eventually find something, right?

There is no biomarker (measurable substance indicative of the specific disease) for what I have. The endless dead ends, and “normal” test results, lead me to doubt myself. Labels of depression, anxiety, hypochondria are being thrown around because my physician does not believe in my disease. I am being told that I am, “healthier than most patients,” but what they don’t see are my bad days. They don’t see what my body will succumb to after I get home from this visit.

I am beginning to distrust myself and question if my symptoms are real. It is scary to not have the words to describe my symptoms in a way that others can understand. It is also scary when medical providers don’t know how to manage my symptoms because they aren’t sure how to find the cause of my illness.

Loved One, please know that if I am moody or unkind, it’s because I am scared. I am not sure what to do and my brain fog and fatigue are making it difficult to advocate for myself in my journey to find help and answers. Please believe me and validate my experience.

#### I Need Extra Support

Without the support of my medical providers, I need even more from you. It is very difficult to be my own advocate when I don’t feel well. It is also hard to put all of the pieces together, when I don’t have a doctor that fully understands my illness. My brain fog gets in the way of my ability

to recall events, tests, timing, etc. Please go with me to my doctor appointments. Help me by being another set of ears and advocate for my health with me.

### **Please Don't Blame Me**

It is tempting to assign blame to someone or something when we don't have a definitive cause to what is happening to my body. I too want to find a place to put the blame. I feel like I need to say "this is my fault" but we both know that isn't true. This just "happened" and I need your support when I start to feel guilty or place blame on myself.

I also need you to know that I am still me. I may make some bad choices or decide to push myself when I know I shouldn't; but this is still my body. Please put yourself in my shoes and meet me with empathy and understanding.

### **Be Okay with Ambiguity**

Our culture struggles with ambiguity. We want black and white answers, and we want to know exactly what is happening and how to fix it. Unfortunately, this is not the case with my illness. Please know that the ambiguity is challenging for me as well. Accepting this will allow you to help me through my journey.

### **Trial and Error – It Can Be Expensive**

Due to the unknowns of my illness, I will have a lot of medical visits. Many things will not be covered by insurance. We may try a new medicine and it may work for a period of time, or it may make me even more ill.

I will want to try new interventions in an effort to grasp my life back. This too is an expense. There will be times when I am open to trying new things, and other times when it will feel too difficult to build the hope for success. I need you to respect where I am at in my journey.

### **I Am Not Lazy**

I want to be able to do all the things I once did. I want to help with chores, errands, cook, wash my hair, run around with our children. I want to work out, be in shape, eat all the right things, climb mountains, be able to drive, sit in the sun, listen to music without earplugs. I want all the normal life things.

It is incredibly frustrating to be trapped in a body that will not give me the energy or health to do so. Please don't call me lazy.

### **Chronic Illness is a Roller Coaster**

My illness is a never-ending roller-coaster ride-so, buckle up. Perhaps one of the most annoying aspects of my disease are the times when I get a glimmer of hope. I feel good. What does this mean? Am I cured? So...I do things. I help out, shower, clean, or even go for a walk. Then the next day my energy stores are completely depleted, and I can't get out of bed for days Please know that there will be good days and bad days. Some hours of the day I may have the ability to do things, and others I will not. My sensitivities will fluctuate (noise, light, heat/cold, chemicals, food intolerances, etc.). There will be interventions that work for a period of time, and then suddenly don't. Unusual symptoms may randomly appear.

Know that I have spent mounds of time and energy trying to figure out the “whys.” Please buckle up with me and stay by my side through the ride.

### **Be Flexible with the Roller Coaster**

I know it can be frustrating that I can't always make plans ahead of time, but please know that this is part of being on this roller coaster with me. Don't take it personally if I cannot fulfill a duty or attend an event at the last minute. I will try my hardest, but there are just times when the roller coaster is on a down- even when I wish (with all my heart) that it was not.

### **My Spoons Are Precious/Honor How I Use Them**

*Spoon theory is a metaphor used to describe the amount of mental or physical energy a person has available for daily activities and tasks. A spoon represents a unit of energy allocated to each exertion. I must use each spoon (unit of energy) wisely so that I don't run out before the end of the day.*

Because things are such a roller coaster, this can affect my mental health. It can sometimes feel like my life is out of control because I cannot control my own body and what it decides to feel on any given day. Depression and anxiety tend to be higher in people with chronic illness. Because of this, there is a balancing act between trying to take care of my physical needs and emotional needs.

It is helpful when you can help take care of my physical needs, so that I can focus on meeting my emotional needs. For example, when you offer to drive or do the dishes, you just saved several of my spoons so I can use them elsewhere in my day. My spoons are my lifeline. Please support me in how I use them.

### **Have Grace/Withhold Judgment**

Please know that when you come to my space and it is not as clean as I would like to be, or I have not paid my bills on time, or I am wearing sweats because I can't tolerate any other material against my skin...I am doing my best.

### **Communication is Key**

Please don't assume you know how I am feeling or what I can or cannot do. It changes constantly, and if we maintain a safe and open place to talk about what's going on, we will better understand how to support one another through this. If you are unsure how to help, just ask.

### **Be Curious & Put On Your Research Hat**

It can be incredibly exhausting both physically and emotionally to explain all that is happening with me. While I appreciate you asking to better understand, it can be insightful to do your own research. Spend time looking at scientific journals, join a support group with me, watch YouTube videos, etc. This will help me conserve my spoons and bring a greater understanding into my experience.

### **Take Care of Yourself and Have a Life Outside of Caregiving**

Please don't make caretaking your whole life. Make sure that you are doing the things that are restorative to you, and that make your life rewarding outside of me. And don't feel guilty doing them! You deserve to have an identity outside of this illness, and you will be a better caregiver to me if you take care of yourself.

### **Use Others to Support You as a Caregiver**

There is a "rings of trauma theory" and it says that you draw a circle with whoever has the trauma in the center, and you make degrees (or people) connected to the trauma going outward. Please "support in" and "dump out." This means that if you are addressing someone closer to the inner circle than you, the communication should involve listening, comforting and validating. If you are feeling stressed or overwhelmed and need to "dump" or share your emotional experience, do so with people further away from the inner circle than you are. Don't be afraid to find your own therapist or friend that you can "dump" to when you are feeling overwhelmed-we all need a place like this.

### **I Acknowledge that You are Going Through A Lot Too**

Even though you don't experience the same things as I do, **you are** "experiencing" chronic illness too. I acknowledge this.

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In closing, I appreciate what you do to love, support, and care for me.

Thank you for taking the time to read this letter!

Love,

Your Loved One