



# SEVERE ME/CFS:

## Caregiving Webinar Resource Guide

October 9th, 2024



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### **Kyle Kitzmiller (husband to woman with severe ME/CFS)**

I've written way more than I intended to here. And it's dense. I hope it's still accessible to you all. I've tried to share the things I've learned that made the biggest difference to me. Honestly, most of it is around mindset. There are concrete things you can do to make your life better, but caring for someone with severe MECFS is unbelievably difficult no matter what you do. Here's how I do it.

#### **Here's what made/makes my life better as a caregiver**

- **In the beginning, imagine you are someone else.** When I started to bathe and toilet Dianna, it was a huge and immediate shift. I couldn't process it. So, I imagined I was a medical professional. I would put on gloves and do my job, then remove my gloves and go back to being a husband. I did this until that stuff just became normalized.
- **Listen to music.** This sounds small but makes a huge difference to my quality of life. I spend a lot of time cooking and cleaning, and fun music changes that experience a lot.

- **Plan RECURRING activities with friends.** This makes it so you have to cancel to not do something. It'll get you doing activities and relationships more.
- **Make a daily schedule for food and meds and hygiene and try not to deviate.** This is the single biggest thing that impacts my daily life. I don't have to think about what to cook, what meds to give or when, it's all on a list. Everything was so complicated in the beginning that creating lists was the only way I didn't lose my mind.
- **Keep a symptom log.** If you don't keep a symptom log, it's impossible to spot trends. Emotions are all over the place, and we need an objective measure of how the patient is doing. I find it best if my partner keeps the log, rather than me, because she can more accurately record how she's doing. Having a set of numbers like "PEM 7; MCAS 8; TV time: 20min; etc. goes a long way in letting us see more objectively what's happening. Otherwise, we end up arguing over if she feels better or worse than a month ago.
- **Make a long-term treatment plan.** And having a plan of what treatments to do next keeps me from fixating on that - I know what's coming up and don't spend all my time scrolling through reddit or reading research papers.
- **Slow down.** Treatments normally take a long time to see results. Doctors' appointments can take many months to schedule. Crashes muddle any data you're gathering. The only way to make it through is to slow down. Have your treatment plan lined up, but don't be in a rush to get through it. REST is the most critical factor in recovery, and that's hard to do when rushing through treatments.

## These are different mental techniques and paradigms I've adopted:

- **The Stockdale Paradox**

This is a mindset that has proven incredibly valuable for both me and Dianna. Stockdale was a prisoner of war, and his mindset for getting through that experience overlaps with what is needed as both a caregiver and a patient. My version of the Stockdale paradox has 3 main components: 1) Maintain the faith; 2) Confront the facts; 3) Don't fall into the optimist's trap (aka the optimists died). I also added a 4th note that better aligns the paradox with my life values.

- **Maintain Faith** - *Have unwavering faith that you can and will prevail in the end, regardless of difficulties.* Prevail does not mean cured. Prevail means what we want it to mean. "Cured" doesn't exist in any disease - because it means we would revert back to how we were before this happened. We can't go back in time. We can see improvements, but any experience large or small has a lasting and permanent impact.

- **Confront the facts** - *Have the discipline to confront the most brutal facts of your current reality.* Severe ME/CFS is unimaginably horrible. You MUST look directly at that horror. Avoiding it does not change the reality of what's happening to your partner, all it does is make you unable to respond because you are blind to it. Yes, it is painful to look at it and acknowledge everything, but the horror is there either way. You must be unbelievably brave, beyond what you thought possible.

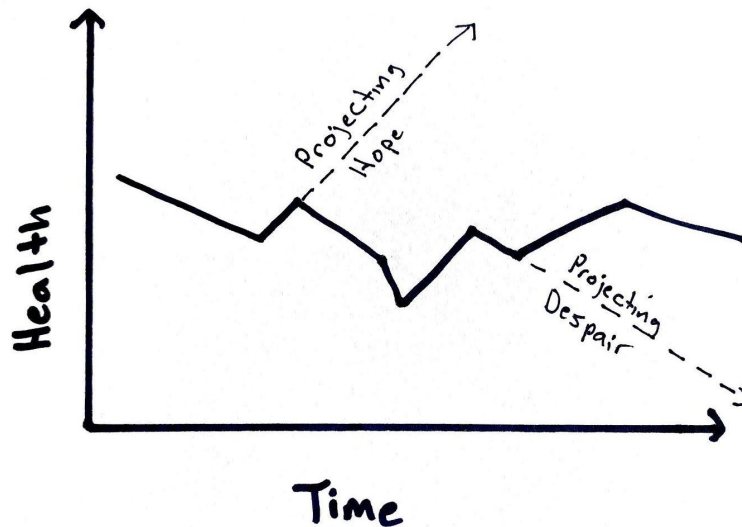
- **Don't fall into the optimist's trap** - *The ones who didn't make it out of the POW camps were the optimists. They died of broken hearts.* They would set dates that they'd be released (i.e. "get better") and those dates would come and go. They would be psychologically broken, their health would fail, and they didn't make it. This is the optimist's trap: thinking is always going to get better. I fell into the trap many times in the beginning, so I made this into an explicit rule: **DON'T SET DATES!** I am an optimist through and through, and I find it makes my life better, even now. But the key is to avoid concrete expectations. In other words, maintain the faith.

- **Kyle's addition** - *Have the discipline to confront the most brutal and beautiful facts of your current reality.* For me, the Stockdale paradox (as commonly quoted, he may discuss this elsewhere) is missing this fact: Just as there is horror before us, there is beauty everywhere you look. This is the yin-yang of the human experience. It's been talked about for thousands of years and in every culture. But in severe ME/CFS you must become an expert at it. You must see the beauty in the small things your partner does, in the things you do for your partner, in a simple walk around the block, in the smell of your morning tea, in singing while making pancakes in the morning.

### **Avoiding Projections and Create Space Between Emotions**

- Living with or around severe ME/CFS requires us to be extremely in tune with our emotions - unless we want to go off the rails every day. We are so tuned into our partner's state, and we strive to anticipate their needs so that we may provide them comfort. That means that we quickly become hypersensitive and habitually predict what's going to happen. While this is a useful skill on short timelines (knowing your partner will need an extra dose of medication, or that they need their ankles rolled) it is extremely problematic on longer time scales.
- When we take how our partner is feeling now, and project that into the future, we quickly become emotionally unstable. In life, we can project onto other people, but we can also project onto situations and our idea of the future. I find projecting onto the future to be a very natural but extremely destabilizing thing. When we see health increasing, we feel good, and project that positive feeling into the future. And the same thing happens when we see health failing.
- The important thing to do is recognize when this happens and create some mental space there. I often say to myself, "I feel good (or bad) about the future right now, but I don't know what will happen, so I won't get attached to it." From there, I can either enjoy the relief that comes with improvement, or I can sit with the sadness that comes with decline, knowing that these are not permanent states, and do not reflect the future.

- Here's a nice picture of what I mean by a projection:



- In this picture, our partner's health stays about the same over time. But there are ups and downs. If we project the hope we feel during positive times into the future, we will inevitably be disappointed. And then comes depression, despair, etc. Conversely, if we latch onto the negatives, we will immediately be launched into a frantic depression, and life goes into chaos thinking everything is ending right now.
- I've done both of those many times, and now I've learned to recognize when I'm projecting my hopes or fears onto the future. Your mind will do this automatically, it's designed to latch onto patterns (even when none are there). So, step back, create a bit of space, and then remember that you're on a journey. Look at the good and the bad, the yin-yang of your life, and then decide who you want to be in that moment. You may choose to lean into the depression, or joy, or to comfort your partner, or maybe just tune out completely, but at least you have the choice. If you don't create the space, you automatically follow your projection and then end up suffering more than the facts of your situation warrant.

## **My secret to maintaining a relationship: Un-define your relationship.**

- A lot of people talk about re-defining a relationship when a partner gets sick. I think that you need a step before this: un-defining a relationship. In other words, taking away all of the definitions we have in our minds of what a relationship is. This is critical, because unless we've spent a lot (and I mean a lot) of time thinking about this, our concept of a relationship is pretty much entirely driven by society and what we've been told. Consequently, it's not defined by the intrinsic needs and wants of the people in it - which it should be! For more on this, I highly, highly, highly recommend watching this video: [our conception of love is messed up](#).
- To summarize a few key points, love in our society is often viewed as an exchange of value - we get something from our partners, they give us something, and we want the exchange to be roughly of equal value. But who's doing the valuing? For most of us (for me for most of my life) the valuing was done by an idea of what I'm "supposed" to be getting in a "normal" relationship.
- Well, congratulations, if you're in the world of severe ME/CFS you are now mostly outside of society, and certainly you're operating outside of societal norms. So, if you hold up your relationship and examine it through that lens, you're going to feel like you're losing. Like you're getting an unfair exchange of value. And if you cling onto that feeling, you will feel resentment, anger, frustration, lots of stuff that will create distance between you and your partner.
- A relationship with a severe ME/CFS patient requires us to undo 20, 30, 40+ years of being told what a relationship is, all while our partner is going through hell and our lives evaporate around us. It's really, really hard to do.
- In order to have a loving and meaningful relationship in this context, you have to define what YOU need from your relationship. And also, not to view it as an exchange. You can love, and give, and not get much back in return, and that in itself can be valuable. Saving a life is rewarding, and that's exactly what you're doing every day. Only our society doesn't value it. Doctors get paid lots of money to save lives every day, but when you do it in a relationship you are

operating outside of the capitalist envelope, so you get no support. And because of that people will judge you, they will wonder why you stay and support the way you do, because they can't understand how you can do so much and get so little in exchange. In these situations, I do my best to stand for what I believe in - love, care, support, and that I can choose what brings value to my life better than society can.

**Finally - you're going to mess up. It's ok.**

- I've basically just summarized two years of philosophy that I've developed, discussed and worked on with professional help. I've had the privilege to be able to do that and have a ton of support, including caregivers and family, therapists and life coaches, and I still messed up in every way imaginable.
- I've grown frustrated, I've been mean, I've given up, I've made poor medical decisions for Dianna. But (yin-yang again) I've been understanding, kind, resilient, I've pushed for both of us when she could not, and I've made excellent medical decisions for her. I've done it all, good and bad and beautiful and ugly, and you will too.
- In these times, when you feel like you're failing, remember who you want to be, and be that person again. Take a few minutes and imagine the version of yourself you want to be, and then give it a shot. Slow down and show your partner and yourself some extra love.

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**Amy Mooney, MS OTR/L (medical professional and mother to a teen daughter with severe ME/CFS)**

Amy created the following two summary sheets that she uses with her daughter and occupational therapy patients. It helps to track symptoms, functional performance, and keep general information in order. Amy reviews the information over time to analyze the progress and see how interventions may have helped or hindered functional performance. These can also serve as documentation for providers to show functional impairment and may be supportive in disability applications.

- [Health and Functional Performance Summary](#)
  - [Symptoms and Functional Performance](#)
  - The following is a list of terms to use when searching online for supportive resources. When searching on Google it is recommended to include “near me” within the search.
    - home/mobile: labs; phlebotomy; blood draw
    - home/mobile infusion services
    - home/mobile nurse, dentist, teeth cleaning, eye exam, ophthalmologist
    - virtual eye exam
    - virtual nurse, immediate care, doctor
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**Kim Moy, (Founder of [caregivingwisdom.com](http://caregivingwisdom.com) and wife to a husband with severe ME/CFS)**

- [Severe ME Caregiving: Lessons Learned](#) slide deck
- [Caregiver Wisdom](#) supports ME/CFS, Long COVID, and other infection-associated chronic illness caregivers with content, community, and coaching. [Offerings](#) include a free monthly support group, a weekly newsletter, an online community that’s off social media, and a blog with helpful posts. Paid services include a group course and 1:1 coaching. [Sign up for the newsletter here.](#)

**#MEAction has two monthly support groups:**

1) The support group for all caregivers takes place on the third Saturday of each month at 12:30 p.m. PT / 3:30 p.m. ET. To be added to the email list, contact Denise at [caregiver@meaction.net](mailto:caregiver@meaction.net).

2) The support group for partner caregivers (please note all caregivers are welcome) takes place the first Sunday of each month at 12 p.m. PT / 3 p.m. ET. We focus on monthly topics and have small breakout rooms for closer community connection. To be added to the email list, sign up for Kim’s [email](#)



[newsletter here.](#)

### **Online support groups:**

If you are on Facebook, #MEAction has a Facebook group for caregivers. It has over 1,200 members from around the world.

<https://www.facebook.com/groups/meactioncaregivers>

There are other caregiver support groups on Facebook and Discord.

### **Caregiver Wisdom blog posts:**

- [Navigating Ambiguous Loss in Chronic Illness Caregiving](#)
  - [How to Explain ME/CFS or Long COVID to Others](#)
  - [How to Hire a Paid Caregiver](#)
  - [20 Ways to Support a Family Caregiver \(these are also ideas of how you can ask others to support you\)](#)
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### **Galen Warden (mother to an adult son with severe ME/CFS)**

- Like a good friend sharing a little wisdom they've earned the hard way, Galen shares what she's learned on her own path to mental wellness as the caregiver for her adult son with severe/very severe ME/CFS. Questions and empty space for notes turn this handout into a workbook for anyone pursuing their own mental health journey.
    - [Caregiver Mental Health Workbook](#)
  - [How to be a Demanding Diplomat](#) (PDF)
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### **Q&A**

- Bateman Horne Center references resources for a few questions asked at the webinar.

- How do we get doctors and caregivers to understand the true harm of pushing through PEM?
    - [Post-Exertional Malaise video series](#) is targeted for clinicians
    - [Occupational and Physical Therapy for patients with PEM video series](#) is targeted for OTs and PTs but the information is accessible to most viewers
    - [The Basics video series](#) is geared for patients and their loved ones
    - [Living with a Low Battery: Life with ME/CFS video](#) is geared primarily for individuals who may need help understanding what life is like for people with ME/CFS and Long COVID
  - I am a 55 y/o person with Long COVID ME - 3 years in. I am listening for my young adult kids who support me. They are 22 and 17. Any thoughts for very young caregivers of their parents?
    - Look into the following resources for your state: home and community-based waived services, Department of Health and Human Services, 211, VA for military families.
    - Medicare and Medicaid offer home health services through paid individuals
  - Doctors (and workplaces) keep saying that if there is no accepted medical evidence (i.e. approved test result, MRI etc.) to substantiate symptoms, the diagnosis of ME/CFS is not valid. Basically, if there is no approved test the patient is making it up. Any feedback on dealing with this?
    - [ME/CFS: Essentials of Diagnosis and Management](#) (Mayo Clinic)
    - [U.S. ME/CFS Clinician Coalition Testing Recommendations](#)
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## General Resources for Patients and Caregivers

- [Solve M.E. Patient and Caregiver Resources](#)
- [ER and Urgent Care Considerations](#)
- [ME/CFS Crash Survival Guide](#) (includes health information sheets, medication sheets, and communication cards)
- [AMMES Financial Crisis Fund](#)
- [Pandora Delivers](#)
- [Accessibility and Accommodation Resources](#) by Alison Sbrana
- [Disability and Accommodation](#) slide deck by Alison Sbrana

- National Suicide Prevention Lifeline: 1-800-273-8255 (TALK), Dial 988, Text ANSWER to 839863
  - Crisis Text Line
  - US and Canada text HOME to 741741
  - UK text 85258
  - Ireland text 50808
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