

paddle as quickly as you can, power filling your arms, your heart racing as you save your life by avoiding the waterfall. That is the mental and emotional urgency you need right now to radically alter your life for one month. Look like a fool for one month. Inconvenience your friends and family for one month. This will benefit you just as much as them, if you can keep your loved one from needing around-the-clock care like my son, James.

Ron Davis, PhD, Director of the ME/CFS Collaborative Research Center at Stanford University, shares this:

"My student, who came down with ME/CFS and became bed bound, got this theory that it was the crashing, and it's easy to do when you're bed bound. Crashing can make you worse and it's crashing that keeps you in the disease. She said she went for about a year and never crashed, and then she got over it. Now, that's all correlational, and we don't know for sure that that's the case, but she's a very, very smart scientist and she is totally cured."

Once someone is moderate or severe, it takes much less to crash. For James, he was mostly bed bound, but able to wheel himself to his bathroom on his desk chair... until he over-exerted himself — crashed — one time too many. That fateful night, I was sleeping on an air mattress in his living room and he didn't want to wake me up. All he did was lean over the side of his bed to pick up something he'd dropped, then pull himself back onto his bed again. After that one exertion, his baseline lowered.

Then, I had to wheel him around his apartment in his desk chair. I'd get him into his bathroom, but he could still get onto the toilet and back into the chair on his own. He could brush his teeth from his desk chair. He could climb from the desk chair onto the shower chair in the tub, but he could no longer bathe himself. With a hand towel over his privates, I leaned in and

bathed him in the shower. At this point I knew I had to move him to live with me in South Carolina.

Incremental losses, generated by an incident of some kind, were each one step lower for his baseline. From 80% to 90% to 100% bed bound and unable to even lift his arms, we can remember most of the events that robbed yet another ability from him.

Back when James was moving from mild to moderate, we had no idea what ME/CFS was. We weren't cooking nor cleaning for him, as we should have, nor helping him much at all, though he constantly complained about being tired. He crashed regularly, but no one realized what it was. First he had to stop cleaning pots, then he could no longer use a microwave nor rinse out a cup. Incremental losses compounded.

Other, non-physical exertions that can cause a crash are: strong emotions like anger, arguing, crying, or grieving; stress from pressure, a threat or a difficult situation; and mental exertion like reading too much or thinking too hard to solve a problem.

My first and best advice to you?

PREVENT A CRASH AT ALL COSTS.

DYING TO LIVE, Unflinching witness to Severe ME and Long Covid is the working title of Galen Warden's forthcoming book chronicling James Strazza's decline from the Epstein Barr virus to 100% bed bound, unable to tolerate light, sound, or communication, due to Severe Myalgic Encephalomyelitis (ME/CFS). ME can develop from Dengue Fever, Covid19, and myriad other illnesses.

As millions face a similar rapid decline from Long Covid following a Covid infection, Galen shines an urgent, unflinching light on the potential for suffering from poor medical advice and misguided referrals to psychiatric treatment.

Find excerpts, including this chapter, in blog posts at: galenwarden.com, or use the QR code.

CRASH PREVENTION

BY GALEN WARDEN

From the forthcoming book, *Dying to Live*

The most urgent thing you can do to prevent someone with Mild ME/CFS or Long Covid from becoming as severely ill as my son James, who is 100% bedridden, is to let them rest. Only extreme, radical rest will allow their bodies, their cells, to regroup and recover.

A universal symptom of ME and Long Covid is Post Exertional Malaise (PEM). The body just seems to give out after exertion. If someone with mild ME or Long Covid is unusually tired at the end of a day of work, or from cleaning their home, going shopping, climbing stairs, attending a party... things they would normally have had no problem with... listen to them. Encourage them to stop, to get in bed and rest, and to stay there except for doing necessary things that won't exert energy.

Don't take my word for it. Sure, we all get tired sometimes. Test it. Think of some kind of physical activity that you're very familiar with. If you ride a bike, then go for a ride. See how you feel after a normal ride. In the past your muscles may have been a little sore, you'd be sweating and collapse with a cold drink. But you'd feel energized, accomplished, satisfied with your effort. You get up after your cold drink, shower off, and make dinner.

If you have mild ME/CFS or Long Covid, you'll easily recognize a difference. There's no energized feeling, just exhaustion. You're not up to making dinner. Even



the shower, which always refreshed you, just adds to your exhaustion. All you want to do is get on the sofa, limbs feeling like lead, and lie there for as long as it takes to feel like moving again. This is Post-Exertional Malaise (PEM). It's one of the clearest signals that you could have ME/CFS or Long Covid.

If this is you, if you feel overly tired after what should be a normal physical activity, don't dismiss it. Don't push through it. Immediately consider that there's a possibility you have a medical condition that is causing your fatigue.

Once you've tested and proven to yourself that you, or someone you love, has an unexplained onset of fatigue, weakness or tiredness, after strenuous activity, the time to take urgent and radical action is now. Crash prevention can save them from continuing to get worse.

Reach out to family and friends and create a support system right away, before things get worse. Arrange to have food dropped off, their place cleaned for them, their pet cared for, and their bills paid for the next 30 days. Plan one month of radical rest. Meanwhile, search for an ME specialist in your area to evaluate them.

Radical rest, early on, is the easiest and least complicated way to help someone with a mild condition recover. But because their condition is mild, it's mentally and emotionally very difficult to stop the train of life and get off for a month.

Your job may not understand, so I'll help with a memo you can use. You feel guilty, you want to justify what you're feeling with the usual suspects, "I'm under stress at work," "I'm just not sleeping well," "I'm fighting a cold."

It's embarrassing, uncharacteristic, against your nature, and a bruise to your pride. But so be it. Swallow that pride and take radical action now. Right away.

Be alarmed, even though no one else is. Even if your friends think you're overreacting. Be the irrational nut to them. Radical rest is the early response that can save you from losing your job altogether, losing those same friends because you can't socialize any more, losing everything you love to do.

Because you probably can't justify this extreme response to "a little fatigue," I'll provide an analogy that might help.

It's a sunny summer day and you're on vacation. You're enjoying some great recreation in a canoe on a river. You're soaking in the sunshine, little birds are flitting by. There's a turtle on a log by the shore. You're more relaxed than you've been in months. You take a deep breath and rest back on the seat cushion behind you, letting the current carry you along for a little while. Looking up at the sky, you see animals in the shapes of the fluffy clouds floating along. It's a little hot, so you hang your arm over the side and dip your fingers into the refreshing water. You feel the gentle pressure of the current against your hand.

Suddenly you hear someone on the shore shouting. You sit up and turn toward them. You can see they're waving their arms at you. You yell back, "What?" Now they're shouting louder and you can clearly make out what they're saying, "Get to shore! Get to shore! Waterfall!!!!"

Adrenaline rushes to your whole body and you feel a surge of power as you grip your oar and paddle like crazy to get to the bank of the river as quickly as you can.

You have not seen the waterfall. You don't have any proof that there's a waterfall. Your sudden rush to shore might be unnecessary. Maybe this is a jokester. But, seriously, why would a perfect stranger go to all of that trouble, seeing you on the river, having a nice relaxing canoe ride, to urgently plead with you to get to shore?

I'm that stranger.

That waterfall is the end of life as you know it. Only a radical move now, extreme rest, will keep you from tumbling over that waterfall into a life of suffering you cannot imagine. You could not have known about the waterfall on your own, not from where you are, so I'm waving my arms and shouting at you to save you from it.

If your ME/CFS or Long Covid condition is currently in the Mild category, being basically bed bound for one month might actually recover you fully. Do it now, while it's a choice, because you're not really bed bound. Unlike James, who is truly 100% bed bound, you can still walk around, use a toilet, get a drink of water and live a normal life. But planning and taking steps now to accommodate extreme rest will make all the difference. You can prevent a steady increase in your fatigue and worsening of your condition.

Take one month off of exertion of any kind. Have someone get you a shower chair so you can rest in the shower. Don't drive for a month. Don't do your own cooking, laundry, dishes, or housework. Have friends or family stock your freezer with one-serving baggies of stew, shepherd's pie, chicken with rice in gravy... anything that freezes well. Or they can buy frozen entrees you like. Your new best friend is your toaster oven or microwave.

Drag a chair or stool into your kitchen. Use it while you wait for the microwave, or to sit at your sink to rinse a dish. Have someone rent a wheelchair and push you around if you absolutely can't miss an activity.

I get it. You don't have to do these radical things at this point. You can stand at your sink and wash dishes, or stand at your stove and cook a meal. But you just shouldn't.

Remember the canoe: the surge of adrenaline to