

Illness Isn't Your Fault; Joy Isn't a Reward

Let's turn toward a community model of care, writes brain cancer blogger Adam Hayden.

June 20, 2024 By [Adam Hayden](#)

Pop psychology has us wondering why bad things happen to good people; combine this with the pervasive notion that everything happens for a reason, and we end up in a situation where circumstances have to be rationalized, justified, or explained away. This is where we hear things like our illness is a part of a larger plan that we can't comprehend for this reason or that.

I've always said, if the plan includes giving me brain cancer, that's a bad plan.

Still, I understand the appeal because I understand the alternative, which is this. We don't have a firm grasp of the cause of many serious illnesses. It's easier to point our fingers to some cause for suffering, even if it is mysterious or supernatural, than to admit the reality that many of life's most difficult situations arise from chance and probability.

An even more threatening notion is to hold people themselves accountable for their illnesses. You may think this is pretty far out, but spend a little time around so-called wellness influencers and you'll get the impression that if you don't eat organic, or avoid GMOs, or cut out sugar, then you get what's coming to you. Even if not made explicit, that sort of rhetoric suggests at least some blame on the person who's ill for failing to follow the current diet fad or exercise trend. This is not to dismiss nutritional science out of hand; in fact, just the opposite. We should seek medically vetted information, but Instagram isn't always a repository of peer reviewed science.

Though, as someone who makes a lot of short form video content, I'm a huge proponent of leveraging social media for information dissemination and building community. It's with a keen eye and a skeptical mind that we ought to approach the internet. Also, we can look to platforms like my friends at [Roon](#) who are harnessing the best lessons from short form video creation and pairing that with a growing team of licensed clinical practitioners to produce content that is user-centered, empathetic, and medically vetted.

At any rate, the sugar substitute in Diet Coke or eating a burger with the bun didn't give you cancer. Illness is not your fault.

But I don't want to stop there because many of us who are living with illness struggle in ways that are likely opaque to those who have not had this experience. I've noticed something about myself

recently; something insidious. During this period of active treatment with chemotherapy for my cancer recurrence, we set up a Meal Train to help us out a couple nights each week during chemo cycles because I'm the primary cook at home, and between the chemo and the new tumor in my brain, I've not had my full strength.

I'll take this chance to express my gratitude for everyone who has so generously prepared meals for our family or sent along Door Dash gift cards! It's truly been a huge help and a gift of rest to me when I can take a few nights off from cooking during chemo weeks.

Here's the thing I noticed after only a week or two of receiving these meals: I feel very self-conscious. I wonder if I'm sick enough to deserve this special attention. It's not productive thinking, but I'm speaking honestly. I wonder if other patients feel this way?

I mean, I imagine people thinking, if you feel okay, why are you getting all this help from others? This is an evergreen discomfort with illness and disability, especially "invisible illnesses." We get in our heads that being sick has to look a certain way. I actually wrote a post at the beginning of June about [that](#). Sometimes sick people get sick, and that's OK, but "sick people" aren't always sick. This is the flipside of the coin. A lot of days, I can shoot hoops with the kids, kick the soccer ball, sit outside and laugh with the neighbors, and there is this nagging feeling that if I'm well enough to do that, then I'm well enough to cook our own damn meals, or work as much as is possible, or turn down help from others.

But here, too, this misguided thinking is rooted in the same premise that maybe your illness has at least something to do with you, and not by an act of chance. If we are somehow complicit in our illness (what an absurd notion), then what right do we have to enjoy ourselves? The way that I feel insecure about playing with the kids outside when you drop off dinner is part of the overall thinking that illness is something punitive. Who are you to be enjoying your life when outsourcing needs to others? I'm not defending this thinking, only describing it.

I'm here to remind us, illness isn't your fault, and guess what, joy isn't a reward that you have to earn and neither is it part of life that becomes off limits when you get sick. If we can break out of the notion that individuals are responsible for their lot in life, we can turn toward a community model of care. Rather than prizing as the highest good our own self-sufficiency, we can embrace the strength in our collective interdependence. I need you and you need me. Thinking this way, illness isn't a you problem, it becomes an us problem, and not a problem, but a responsibility that we owe to each other. Thinking like this, we no longer need to fear illness or rationalize it away to immunize ourselves from it (pun). Rather, we can feel safety and security in the knowledge that we have each other's backs. Here, illness is natural, but so is community, so should illness knock at our door, we'll have our whole community behind us. Then we may have the strength to shoot hoops with the kids because our community has taken a couple of other responsibilities off our to do list, like preparing meals two or three times each week.

Joy isn't a reward and neither is it restricted to the well. Joy is the outcome of trusting each other and that's open to all of us. Indeed, that's what community is all about.

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