Living with anxiety

Jonathan Gingerich

I grew up in a middle-class Mennonite home in Goshen, Indiana. I had access to opportunities that many children don't get. My father is a physician and my mother stayed home with my younger brother and me until I was twelve. I was a bright and curious child, and while social skills have never been my strongest suit, I got along with others and had close friends. I breezed through my schoolwork, played violin and chess and soccer, and was, I think, a healthy and well-adjusted—if sometimes intense—child.

I spent my late teens and early twenties chronically unemployed and socially isolated. I lived in community housing for people with mental illnesses, was on food stamps and Medicaid, relied on walking and my parents and public transit to get everywhere, and generally struggled with basic tasks and activities of daily living. I lived with severe anxiety.

I am now employed full time as a software developer, having graduated from college summa cum laude with degrees in math and computer science. I am in a stable long-term relationship with a lovely woman, am close to my family, and enjoy the company of friends and a variety of pursuits. I still live with anxiety.

This is my story. I offer it—without any illusions that my experience is generalizable—in hopes that it nevertheless can be helpful to others who live with anxiety and to those who love us.

Onset

I'd always had performance anxiety, but it didn't reach debilitating levels until 2001, when I was a freshman in high school. During Thanksgiving break, with extended family in town, something inside me snapped. I remember sitting on a bed in the basement of my childhood home, crying—my parents sitting next to me, trying to understand what was going on. I felt confused and ashamed about my behavior and frustrated by my inability to explain myself or communicate how I felt.

When break was over, I just couldn't make myself go back to school, and it became clear to those around me that my difficulties went beyond normal teenage angst. I was diagnosed with depression and started taking antidepressants. The medicine helped my depressive symptoms, but my

irritability and anger got worse, and I was still suffering from debilitating anxiety. I didn't want to leave the house. I wanted to hide.

For the next three years, I would start school in late summer in a modestly hopeful frame of mind and crash in late November. In December of my sophomore year I saw a psychiatrist who diagnosed me with bipolar

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I had a couple stints as an inpatient in the local community mental health center and an overnight stay in juvenile detention. I had weekly appointments

with a succession of therapists and monthly appointments with a psychiatrist. We tried many different combinations of meds in a variety of dosages. I had side effects from the medications. Worst was the drowsiness.

My memory of high school is foggy and full of gaps. I slept a lot in school. When I got there, it was usually because my friend Benji, who lived down the street, would stop by and play Mario Kart with me for ten minutes and then walk to school with me. It wasn't something we talked about; he just did it, day after day. With his support and the help of an understanding special ed. teacher who ran a lot of interference for me with other teachers, I managed to graduate from high school, with a bare minimum of credits and mediocre grades.

At church it often felt like all those middle-class professional white people had their s**t together, and being with them was a reminder that I did not. Everyone was Mennonite polite, but it was hard for me to know whether that was sincere. I'd miss a few Sundays and then would be convinced that people had noticed and pitied or judged me. I felt like I was letting my family down, and I still didn't have the words to articulate what I was struggling with. And I was constantly at risk of falling asleep in the middle of worship or Sunday school, which led to more anxiety.

After high school

After high school, I knew I couldn't handle college, so I signed up for Service Adventure. The program entailed living with several other young adult volunteers for a year, participating in the life of the sponsoring congregation, and working for a local not-for-profit organization. I was

naïve to think that Service Adventure would be less stressful than college. After three months, the anxiety of a forty-hour work week and my new surroundings was too much for me to handle, and I dropped out of the program. Another fall, another crash.

Distressed, I moved home and got a part-time restaurant job washing dishes. Spring turned to summer and then fall, and I just couldn't get myself to work. In the meantime, an apartment in government-subsidized housing for people with persistent mental illnesses had opened up in nearby Elkhart, and it was a godsend for me. My relationship with my parents was full of frustrations and conflict. The new housing arrangement gave them much-needed space from me, and I got much-needed room to explore and fail without the stress that came with failing under their watchful eyes. They could give up their well-intentioned but unhelpful efforts to reason with and provide structure for me, focus on providing love and moral support, and continue to do the work of releasing their expectations of their under-achieving child. And I could begin to disentangle myself from those expectations and start working with my own hopes and fears.

How anxiety feels

Anxiety makes the simple things hard and the hard things agonizing. It makes you doubt yourself. It's difficult to get other people to understand what you're dealing with. And fighting to get them to understand brings its own anxiety. It's stressful to try to explain yourself. It's stressful to feel like you're a burden. It's stressful to constantly feel like people are judging you and to constantly judge yourself for the difference between where you are and where you "should" be. As the English essayist William Hazlitt famously said, "Man is the only animal that laughs and weeps; for he is the only animal that is struck with the difference between what things are, and what they ought to be."

People who haven't experienced debilitating anxiety seem to think the issue is irrational fear. Fear is concrete. Fear is immediate. Anxiety is generalized and pervasive. Fear is a response to a clear and present threat. Anxiety persists, and at least for me, tends to revolve around uncertainty and the unknown.

As I write these words, I'm anxious because I've had this assignment on my plate for six months and I feel like I'm letting people down. I'm keenly aware that I still have potentially debilitating anxiety, and I'm not sure where it might strike next. I wasn't expecting writing this article to

be so anxiety provoking. I'm anxious because this subject is important to me and deeply personal—because I want to make every word count and I'm not sure I will.

When my boss schedules a meeting with me for tomorrow afternoon and doesn't tell me what's on the agenda, I am anxious. I wrack my brain: Did I do something? What am I forgetting? I know I do good work and that he hasn't expressed any concerns about my work or conduct. I know that every other time this has happened, the meeting has been routine,

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no problems. And yet I'm anxious. What if? My anxiety isn't proportionate to the risk present in the situation. In fact, it exists despite my understanding of what's likely to happen.

It's easy from the outside to think of anxiety as a result of not understanding what's likely to happen. But the problem, at least with chronic anxiety, is rarely one of education or information. What's more, when those around me

treat my anxiety as an educational challenge to be tackled, it only makes my anxiety worse. In addition to what I was already struggling with, I now feel judged and misunderstood by those around me, and like I'm wasting their time and they're wasting my energy.

The same principle applies when those around me try to help me by addressing something other than the root cause of my anxiety. When I'm struggling so much that I'm not eating, showering, or sleeping regularly, the last thing I need is a someone trying to explain to me the importance of sleep, food, and hygiene. I know how to eat, sleep, and bathe, and I know how I should be eating, sleeping, and bathing.

So what has helped?

Remembering that we're doing the best we can. I think it was easy for those close to me when I was sickest to forget, in the heat and frustration of the worst moments, that I was my biggest critic and that I was trying hard. And it was easy for me, even on my better days, to forget that those around me were also trying and that they were human too.

My parents have told me that a couple events shifted their way of interacting with me during this time. One happened when a therapist speaking to their Sunday school class observed that it's usually a good idea

for people dealing with friends or family members with mental illness to assume that their loved one is doing the best he can. Mennonite theology and middle-class values tend to focus on will and decision and discipline and effort, and my parents' formation had made it hard for them to understand the extent to which my anxiety and mood instability impaired those functions. My problem was not, in the first instance, a failure of will. I can't overstate the significance that change in their posture made in our relationship.

Recognizing the gap between perception and reality. Accepting the fact that I had a mental illness involved recognizing that my perceptions aren't always aligned with reality. This shouldn't be any great revelation; to be human is to have that mismatch from time to time. But what do you do when that mismatch is no longer an occasional inconvenience

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but omnipresent and debilitating? What do you do when your mind and thought processes, the tools you've always used to solve problems and to distinguish right from wrong, truth from falsehood, reality from imagination, are themselves the problem? Recognizing this dynamic may mess with some of our usual ways of thinking about faith and ethics; for me it presented an existential problem.

To look at this from another angle, let me ask you, Reader: How do you figure out what to do in a situation? What process do you use to make your deci-

sions? I'm guessing you analyze your possible options. You weigh their pros and cons. You weigh their potential outcomes and the likelihood of each outcome. You consider your feelings. You consider the feelings of others. You consider the impact your decision would have on your life and the lives of others. And then you make a choice. I assume that's basically how you approach decisions, even when the steps are not always conscious and discrete. Now every one of those steps involves a complicated mental process. Would you trust your assessment of a situation if you knew you couldn't trust your perceptions? Would you trust your emotions on something if you knew they were often distorted? Would you trust your perceptions or emotions if you couldn't reliably differentiate between times when they were appropriate and times when they weren't?

Another event my parents point to as marking a shift in their way of interacting with me happened at a routine appointment with my psychiatrist. I was describing something, and Mom and Dad jumped in to set the record straight. Dr. K. looked at me and asked, "Do they often gang up on you like that?" They were totally taken aback, chagrined—and learned, with some coaching, to respond to me on such occasions with something like "Hmm. That's not the way I remember it. But we're unlikely to convince each other, so let's not argue about it." That response tended to reduce conflict between us around these perceptual differences, opening a way for more fruitful interaction. And my growing self-awareness about my perceptual gaps also helped de-escalate things between us.

Tackling manageable bits of uncertainty in safe places. When I'm feeling anxious, my first impulse is to try to control my environment: to suppress anything that will make things worse, to isolate myself in a bubble. When you're afraid of the unknown, what better way forward than to remove from your life as many unknowns as possible? But there will always be unknowns. I started to make real progress when I began to tackle manageable bits of uncertainty in safe places. It wasn't a smooth process; there was progress followed by setbacks. But it turns out that having setbacks and coming out the other end intact helped reduce anxiety. And success bred confidence, making it easier to tackle the next unknown.

Several years after I finished high school, a friend from church invited me to visit a Clubhouse in Fort Wayne, Indiana, to learn about this place where people with mental illness could rebuild their lives as they form meaningful relationships around meaningful work. The program was inspiring, and we began to lay the groundwork for the formation of a Clubhouse in Elkhart County. I spoke to church groups and service clubs, to anyone who would listen, and in time we formed a board and hired an executive director and bought a beautiful Victorian home, and a strong program developed. Telling my story and making the case for a local Clubhouse was a profoundly healing experience for me. It gave me confidence that I could manage my anxiety and contribute to my community. And in time, that confidence led me to college and work and a full life—a resurrection.

Focusing on what's getting in the way. I know it's hard to be on the outside looking in, able to see what the person you love just doesn't

¹ For more information, see https://en.wikipedia.org/wiki/Clubhouse_Model_of_Psychosocial Rehabilitation and https://www.ecclubhouse.org/.

seem to be able to see. It's just as frustrating to be on the inside, experiencing things that people you love just don't seem to feel. I know it's tempting from the outside to nudge-even push-the person with anxiety to have that breakthrough. In my experience, the desire for change needs to come from within if it's going to be lasting. Pushing often made my anxiety worse, because it left me feeling like I was letting those around me down and not living up to their expectations. Rather than thinking about how to incentivize the behavior you'd like to see in your loved one with debilitating anxiety, or how to disincentivize the behavior you think is counterproductive, focus on what obstacles are getting in the way of what she would like to do. Ask: What are her goals? What are her dreams? What's getting in her way? And how I can help remove those obstacles?

Looking for patterns. In the years after high school and before college, when I lived in government-subsidized housing for people with persistent mental illnesses, most of the forty or so people living there had a primary diagnosis of bipolar disorder, schizophrenia, or schizoaffective disorder, with secondary diagnoses ranging from anxiety to addiction to obesity. Nearly every resident was chronically unemployed, and many were socially isolated, with no community to belong to.² The year my housemate turned forty-eight, he got one card for his birthday. Almost a year later, it was still on the mantle in our living room. It was the only thing in our whole house that he displayed with any kind of pride. In fact, it's the only thing I ever saw him display with pride. That birthday card—the only birthday card he got—was from the pharmacy that filled his prescriptions. I realized how fortunate I was to have good medical care and a supportive family and friends and congregation.

One of the first things I noticed in this new community was how stuck so many people seemed. Some did the same things over and over again in the hope that they'd get different results. Some had the hope beaten out of them by relapse after relapse, setback after setback. Some would believe they'd turned a corner, only to have the rug ripped out from under them by their disease. Some had given up hope and consigned themselves to living the same day over and over again for the rest of their lives.

I'm an analytical person, but it's generally my gut that tells me I need to analyze. When you've lived your whole life operating under the assumption that you can trust your feelings, it isn't easy to make the transition

² Recent studies suggest that social isolation has dire effects on health. See https:// www.nytimes.com/2016/12/22/upshot/how-social-isolation-is-killing-us.html.

to figuring out how to live in a world where you can't. I had a choice: I could consign myself to a life with few risks and little hope, or I could take advantage of my situation—very little to lose and no-one counting on me—and try to figure out a way forward. One of the things I noticed about so many of the people I was living with was that they didn't see the setbacks and relapses coming. I also noticed in my own life that there were signs when I was heading into mania or depression. One of these signs was anxiety.

The first step in handling anxiety is recognizing anxiety. If you operate under the assumption that anxiety is a response to environmental stimuli,

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it's a short jump to trying to find patterns in the environment, identifying the things that provoke that anxiety. Why did I stay up all night? Why have I been eating all day? Why are my nails chewed to the quick? Why do I have the runs? Why didn't I take a shower today? Why am I irritable? None of these behaviors necessarily mean that I'm anxious, but for me they tend to be good indicators of anxiety, especially when they show up together. As I got better at identifying when I was anxious and when I wasn't,

it became easier to figure out the impact that anxiety had on my functioning. Recognizing that I was anxious also gave me the opportunity to figure out what I was anxious about. As I got better at identifying when I was anxious and the environmental sources of that anxiety, I could start to pick those sources apart and avoid them or manage my responses to them.

Budgeting time and energy, harnessing motivation. Another strategy that I have found helpful in living with anxiety is to think about the resources at my disposal in terms of budgeting. Each day I have a certain amount of time; in a day there is a certain amount that I can do. Likewise, there is a certain amount of anxiety that I can handle at any one time; if I cross that threshold, I tend to shut down. And I have a certain amount of energy each day. Even if I have plenty of time and my anxiety is manageable, I can still run out of energy. And then there's motivation. In my resource model, motivation isn't its own resource; it functions as a multiplier on energy. If I'm motivated to do something, it takes less energy and often less time. If I'm not motivated, it takes more energy and more time.

If I can evaluate my upcoming schedule in terms of the time, anxiety, and energy cost, then I can stay within my budgets. I can often trade time for a reduction in anxiety (for example, by playing video games). Time spent this way is often labeled as escapism or avoidance and looks unproductive from the outside, but when I engage in it intentionally as a tool for reducing anxiety (rather than as a coping mechanism), I've found that it can be very useful. Tackling my day-to-day life using this framework has helped me keep my anxiety at manageable levels.

Finding companions. As I look back, I realize that even now, when I'm feeling anxious and like I don't have control over something that I really want to have control over (usually my feelings!), I tend to focus my frustration on unrelated things that I do have control over. This venting leaves me feeling bad, and it leaves whomever I took out my frustration on feeling some combination of hurt, anger, and confusion. When I was at my worst, this venting was frequent enough and extreme enough to effectively isolate me. That said, I have always had people who loved me even when they didn't understand me. There were friends who suspended judgment and accepted me, despite my erratic behavior. People from church cared, prayed, visited, brought cherry pie, and sent care packages. My family loved me unconditionally. And Grandpa took me out to Subway every week during the worst years, until heart disease limited his mobility. The day he died was one of my hardest—in addition to losing his gracious presence in my life, everything I valued most had just been stolen from my room. And it was November. But it was the first November in years that I didn't crash, and living through that loss gave me courage to begin rebuilding my life. During my college years a family friend treated me to dinner at every good restaurant in Bloomington and listened with interest to my musings about anything and everything. And now I am blessed with satisfying work, and a dear companion, and people in my immediate and extended family who stay in touch. And then there's my old lapdog, Buddy, whose affection I can always count on.

Life-even with anxiety-can be very good. And I would not trade what I have learned from living with mental illness for a life free of its complications. The Light shines in the darkness, and the darkness has not overcome it.

About the author

Jonathan Gingerich lives in Madison, Wisconsin, and works at Epic Systems.