



“My dad’s death made me mourn my own”

Losing a parent is devastating. But as 26-year-old writer Emily Rekstis shares, it’s even harder to cope when you know you have a good chance of dying from the same disease.

My dad couldn’t carry a tune, but man, did he love to sing. He would lullaby my sisters and me at night and belt out songs during chores. He sang with all his heart, a trait passed down to my youngest sister. My other sister inherited his compassion. I received his old-man taste in music and history. And we all have one thing in common that came from him: a strong chance of being diagnosed with Huntington’s Disease (HD), a fatal disorder that causes a breakdown of nerve cells in the brain.

I learned my dad had HD a month before my high school graduation. Over the next few years, I watched him struggle with involuntary movements, slurred speech, weight loss, and forgetfulness. When he could no longer swallow, he moved into an assisted-care facility, where he passed two days before his 58th birthday.

Like a haze floating over my grief, selfishness settled on me. You see, if you have a parent with HD, you have a 50 percent chance of inheriting the gene that causes the disease. I’ve chosen to not get tested: If I discover I don’t have it, I’ll stress about my sisters’ chances; if I learn I do, I’ll be left to race against a ticking time bomb.

Even though my decision is firm, my own mortality shifted into the spotlight after my dad was gone. The future I had planned seemed to slip

away: climbing the corporate ladder at a magazine (I wouldn’t have time to enjoy being at the top), traveling (what’s the point if I can’t walk to the sights?), writing stories as a wisecracking woman (my brain could turn to mush by the time I’m 40). Then again, maybe I will be able to do all of this. Perhaps I won’t get HD. It’s that “maybe” that adds a layer of complexity to the already complicated idea of death.

I’m a work in progress, but I’ve come to appreciate certain aspects of my situation. Ruminating on my years to come alongside my dad’s past helped me identify what is most important. Now, I write more often about topics I care about; I prioritize time with loved ones and let go of toxic relationships. Navigating my circumstances has made me the loyal, risk-taking, passionate person I don’t think I would otherwise be. It’s these newfound qualities that make me feel equipped to embrace my life, no matter how long it is.

Dealing With Uncertainty If a family member has a condition with a genetic link, you may be at higher risk for the same illness. But don’t let that scary possibility overwhelm you. Support groups or specialized care centers can help you cope. Or maybe finally sign up for that pottery class: Discovering hobbies can help you manage your fear, as focusing on enjoyable interests will bring creativity and a sense of control to your life, says Tanya M. Bardakjian, a genetics counselor at Penn Medicine.