WHAT DOESN'T KILL YOU



A Life with Chronic Illness — Lessons from a Body in Revolt TESSA MILLER

Chapter 4 OUR GRIEF

In *The Year of Magical Thinking*, Joan Didion wrote, "Grief turns out to be a

place none of us know until we reach it." Grief is different than any other

feeling. Maybe it's a bunch of feelings jumbled together in a confusing stew.

Maybe it isn't a *feeling* at all, but rather an unfamiliar building that you

wandered into and can't find your way out of. Some of the rooms make you feel

afraid, exhausted, hopeless; but every so often, one of them surprises you with a

most mysterious joy. By the time you've found the building's exit, you feel a sort

of fondness for the time spent inside.

Grief is also irrational. When Dad died in 2008, I spent several weeks

believing that the only way I'd ever understand him was to quit college, become

an alcoholic myself, and drink until I died. I thought that recreating his death

would give me closure. I can see, now, why that's nonsensical—but at the time,

it made complete sense. Still, I miss something about those months of wild grief.

I was in such a heightened state that some days it felt like I could reach across

the ether and grab Dad's hand. My grief was consuming, drowning out sounds

and making my world—because I created my own little spinning planet to

mourn in—seem separate from the greater one. I couldn't believe I ever existed

in that *normal* world, where everyone was alive. The death of someone you love

splits your timeline in two—before and after. "I'm afraid I will go about for the

rest of my life in this one long day, beginning with the day you died," I wrote in

my journal on February 22, 2009. As months and years went on and my grief

became less acute, I felt farther and farther away from Dad. Eventually, I could

go days without thinking of him and I could speak about him without sobbing. I

was healthily moving on, but it felt like forgetting.

But grieving *yourself* when you're diagnosed with a chronic illness is different. The emotions might be similar to those felt when mourning a loved

one—anger, sadness, numbness, disconnection from reality—but the process of

"moving on" is more complicated. Whereas the loss of a loved one has a sense

of finality, the loss of self from chronic illness can feel neverending. Most

chronic illnesses work in patterns of flare-ups and remissions, where the disease

has an active period and a less active or dormant period, over and over again for

a lifetime. I've reached remission twice since my diagnosis, including my

current remission, and there was this feeling like, "This is who I am forever now

la dee da dee da!" I so desperately wished to feel better, longterm, and forget

how bad things were at my sickest, despite knowing the unpredictability of my

disease and the cruel fact that remission is fleeting. I wanted to pretend, even for

a little while, that I was okay again. Denial was sweet but dangerous.

In a 2019 survey of 1,084 people conducted by WebMD and the National

Opinion Research Center at the University of Chicago, 1 24 percent of people

who'd experienced serious illness said they were "still intensely grieving"

beyond one year when asked how long their most intense grief lasted. (Eighteen

percent of people who'd lost a loved one said the same.) In the same survey,

people dealing with a serious illness were most likely to indulge in negative

behaviors such as abusing drugs or alcohol, eating too much or too little, and

maintaining unhealthy relationships. I didn't turn to drugs, alcohol, or food after

my diagnosis (though food became confusing and fearinducing), but I did fall

back into a toxic relationship with a boyfriend named Jimmy. Being with Jimmy

tethered me to life pre-diagnosis and let me exist in denial, which for me came

with a lot of anger. And when I tried to squash the anger, it led to panic—at its

worst, that meant panic attacks that caused me to black out. I didn't recognize

then that what I was feeling, among other things, was grief. It should have been

familiar to me, as death wiped out an entire side of my family in less than a

decade. But mourning Dad and his brother and his parents, all of whom died in a

seven-year span, had some sort of order. According to the Way Things Work,

they were *supposed* to die before me. Even though I lost them too early, the laws

of nature weren't broken, and that allowed me to make some sense of a thing

that, at its core, will never make sense. But when I got sick and learned there

was no cure for my disease, it was *myself* who'd been lost, despite continuing to

wake up each day. I was still here, and yet I wasn't. It took a long time to realize

I was in mourning.

See, chronically ill people grieve two versions of ourselves: the people wewere before we got sick and the future, healthy versions that don't exist (or, at

least, look much different from what we'd imagined). There's no guidebook for

this kind of ongoing self-loss. No Hallmark card that says, "Sorry you'll never

be yourself again." When I found out Dad died my junior year of college, the

day before winter break, I spent the next month on Mom's couch wondering if I

should go back to Northwestern or just kill myself. But when I got sick, I wasn't

overcome with sadness. I was enraged—at everything. I was angry to be stuck in

a malfunctioning body, that I had to adjust my life around this *thing* I never

asked for while my career suffered because of it, and I was pissed at an

unpredictable future without anyone who could understand me. I was so mad all

the time that I had to consciously squash the hot, rising ball of rage that lived

somewhere between my stomach and my throat just to get through regular

human interactions. I thought my pain was more valid than anyone else's

because it was *mine*. And getting angry felt *good*, even for a few seconds, until eventually it didn't anymore.

Prior to my diagnosis, I didn't know how to deal with anger. It was an

emotion that frightened me. Dad's cause of death was liver failure due to alcohol

abuse, but I think a lifetime of toxic anger exacerbated his demise. He was scary

because he was angry, and so when grief-laden rage bubbled up inside me, it

made me afraid. I didn't know where to put it or how to direct it, so I did what I

always did when facing something uncomfortable: I squashed it. I thought about

feeling like I thought about hunger: If you ignore it long enough, it'll fade away.

But, similar to hunger, if you ignore feeling for too long, it'll kill you. Panic

attacks were a furious physical reaction to what I was trying hard to stuff away.

The grief was forcing its way out, as much as I tried to fight it, through my

trembling hands and pounding heart.

Here's what I wish I had known then:

Control is an illusion.

Paul Chafetz, PhD, is a veteran Dallas-based clinical psychologist who

specializes in helping adults through life's most difficult transitions, which

includes long-term illness. I've interviewed Dr. Chafetz before for my work at

the *New York Times* and *New York Magazine* and found him to be warm, honest,

and infectiously optimistic. He told me that letting go of the idea of control is

vital to the grieving process—easier said than done for most humans, who are

built to relish order and sense rather than chaos. "We go through life with an

illusion of safety, guaranteed health, even immortality," he said. "Acquiring achronic illness pierces this illusion, and this is a loss. Grieving this loss is an

integral part of adjusting to the illness. But where is it written that we're

guaranteed good health? Assuming that this was promised was an illusion all

along. Realism hurts, but it's the more mature choice."

Dr. Chafetz was spot-on. I held on to anger, even when it burned me up

inside, because I'd lost control of my body and because I'd assumed good health

was my right. This wasn't entirely my fault. There's very little public dialogue

about chronic illness—we're brought up to believe sickness either goes away or

kills you. But what about that space in between, where it does neither? Six in ten

Americans exist within that space, living with at least one chronic condition, yet

it's rarely talked about outside of doctor's offices or *hush-hush* support groups.

Kathleen Gilbert, PhD, is professor emerita at Indiana University and a veteran

grief researcher. She's spent the better part of forty years studying different kinds

of loss and has published several papers, books, and studies on everything from

husbands who've been widowed to how grieving morphed in the age of the

internet. "I once interviewed a rabbi whose son had progeria [a rare genetic

condition that speeds up the aging process in children]," Dr. Gilbert said on the

phone. "He spoke a lot about grief. Eventually he came to the point of: 'Why *not*

me?" There's this myth that young people don't get seriously ill, but as I

mentioned before, the age of diagnosis for autoimmune diseases like mine tends

to be under thirty-five, and 80 percent of Americans who live with an

autoimmune disease are women. Had I known any of this before I got sick at

twenty-three, maybe it would have been easier to cope—or at least get to that

point of "why not me?"

Letting go of control allowed me to release the undirected rage I was

carrying around. I'm still angry—have you seen the world?—but not at myself,

nor at passing strangers whose lives I silently judge as better or easier than mine.

I'm not even mad that I'm sick. Rather, the powerful, vibrating fury in my belly

is directed at the politicians who are itching to take away chronically ill folks'

already paltry health care. Insurance CEOs getting rich off our suffering.

Employers who won't hire us. Employers who fire us.

Infrastructures that aren't

designed with us in mind. Doctors who don't believe us. An economic system

that sees no value in sick or disabled bodies. When it has a purpose, anger can be

righteous. Anger can be fuel.

You are *not* doing it wrong.

You've surely heard this before, but I'll write it here anyway: There's noright or wrong way to grieve. No two people do it the same way. The stages of

grief—denial, anger, bargaining, depression, and acceptance—popularized by

the psychiatrist and end-of-life researcher Elisabeth Kübler-Ross in the late

1960s, aren't law—and over time, they've fallen out of favor for a more fluid

grief model. (One mental health professional I interviewed even said, "No

research has ever documented that the [five stages] exist.") My point is:

Whatever you feel while grieving is valid, in whatever order, at whatever time.

"The Kübler-Ross model articulates a meaningful description of various

elements of grief, but many times the stages don't happen in order," Matt

Lundquist, LCSW, MSEd, a New York-based therapist and the founder of

Tribeca Therapy, said via email. I've interviewed Lundquist twice before about

chronic illness and mental health, as well as news cyclerelated PTSD; his

nondiagnostic, creativity-focused approach to therapy is highly suited for the

times we live in. "Some stages are more meaningful than others, harder than

others, and some less of a challenge for certain folks. I've also found that the

idea of stages of grief connotes a picture that's more peaceful than reality, which

often involves a fair amount of yelling and screaming and agony," he said.

"I used to lecture about the grief process of those who'd lost their ability to

communicate—in some instances, permanently," Dr. Gilbert said. "A teenager

with brain trauma was experiencing aphasia [loss of speech], and being an

adolescent and all, he didn't want to be 'weird.' His speech pathologist could tell

him that he was making progress and that all his feelings were normal, but what

really helped him was hearing from *other patients* that his feelings were

normal." Grief makes you feel utterly alone, but it also presents an opportunity

to connect with other chronically ill people in meaningful ways through in

person and online support meetings, fundraising events, volunteering, or

however else you can (and that you're comfortable with). When you share

stories with each other, you'll come to realize that there's no proper way to

process the tremendous loss that comes with chronic illness. It's a great relief to

recognize you aren't "doing it wrong," even if your feelings are not represented

in the popular culture grief model.

Acceptance in particular is misleading as a "final" stage because it indicates

some sort of conclusion—but for chronically ill folks, that may never exist.

(Keep in mind that the stages of grief are based on *terminal* illness.) Karen

Conlon, LCSW, the founder of New York's Cohesive Therapy, a cognitive

behavioral therapist who began her therapy career working with IBD patients atMount Sinai and a specialist in the psychological impact of gut disease, told me

this: "Acceptance comes in stages and tiers. You don't go from not accepting to

accepting every aspect of living with your disease, and you may not have the

same level of acceptance forever." What's more important than total acceptance

is *flexibility*, and a willingness to adapt to the needs your illness requires. "I ask

patients to think about what they love to do," Conlon said. "Can you

accommodate some of that with the changes to your body? Will this be an

opportunity to discover a new skill or a new chapter of your life? New likes?"

Conlon is right: According to the Anxiety and Depression Association of

America, acceptance for people with chronic illness comes from a combination

of three things: "Recognizing that something cannot be changed, consciously

working to adjust expectations, and actively seeking more satisfaction and

meaning in the things you can do." 2

Rather than searching for big, sweeping acceptance, then feeling like a

failure when it doesn't come, chronically ill folks can enact small, empowering

steps, such as taking our required medications, learning everything we can about

how our diseases work, seeing doctors regularly and being prepared for

appointments with a list of questions, advocating for our needs and wants,

figuring out which foods make us feel good, and going to therapy and/or

connecting with a support group. "Acceptance doesn't mean that you get over it,

or that you're even okay with the loss that comes with becoming chronically ill,"

Claire Bidwell Smith, LCPC, a writer and grief counselor, said on the phone

from her home in South Carolina. "It simply means you're learning to live with

the idea and knowledge of it, while holding space to grieve." Though there's no wrong way to grieve, you should still keep an eye out for

signs that indicate you need extra help navigating the loss that comes with

chronic illness. I think everyone can use professional help while they're

grieving, even if they're handling it "well." Mental health care shouldn't be

reserved for crises only. But below are the telltale indicators that you need help

putting the train back on its tracks.

You're having trouble doing daily tasks, like bathing and feeding yourself

and/or your children.

You're skipping work often.

You're sleeping too much or not enough.

You're eating too much or not enough. You're using alcohol or drugs in an attempt to numb your feelings.

You're isolating.

You're falling into destructive behaviors.

You're having thoughts of self-harm or suicide.

If any of these statements ring true, it's time to reach out for help from a mental health professional. There is *no shame* in this. (If you're not sure where

to begin, flip to Appendix II, "How to Find a Good Therapist," in the back of the

book, as well as Appendix III, "Mental Health Resources.")

Anxiety is part of grief.

If you think about anxiety as your brain trying to distract you from trauma, it

makes sense that it would pop up in the wake of chronic illness. After all, being

diagnosed with a chronic illness is trauma. Experiencing the symptoms, *the*

physical pain, that come along with chronic illness is trauma. Being hospitalized

and subjected to invasive procedures is trauma. Not being believed about your

illness is trauma. Losing work and any sort of financial anchor due to illness is

trauma. Relationships falling out because of your illness is trauma. Losing

autonomy or the ability to do things you love is trauma. Your brain doesn't want

to unpack all of these traumatic realities because it hurts.

Anxious thoughts and

behaviors serve as a distraction, a protective mechanism of sorts. Worrying or

feeling afraid, occasionally or even often, is pretty normal.

After all, these

feelings are important protective mechanisms and do serve a purpose to alert us

to and keep us from harm. "Humans are hardwired to be vigilant for danger—

always looking forward and anticipating," Dr. Chafetz said.

"'Anxiety'—a word

people often use for when they're feeling fear—is anticipating a future event and

feeling a strong need to prepare."

But anxiety becomes disordered when you worry excessively for months on

end, and that worrying impacts your life, work, and relationships. 3 (For more

about anxiety, flip to Appendix IV, "Chronic Illness and Anxiety.") Don't

dismiss changes in mind or body as par for the course or a "normal" part of

chronic illness—talk to your health-care providers.

Whatever's going on, you

deserve to feel better. "Your brain is a unique organ, just like your stomach or

your heart," Conlon said. "If you're willing to take care of those organs, then

why not treat your brain? Our daily function relies on it."

I'd battled anxiety for most of my life—and continue to—but after my

diagnosis and first hospitalization it made itself undeniable through panicattacks. Turns out, I learned through therapy and chronic illness support groups,

that a lot of other people experience anxiety as they grieve. Claire Bidwell Smith

wrote an entire book about it called *Anxiety: The Missing Stage of Grief*.

"There's a multitude of emotions that come with grief. They can come up

quickly and that can be scary," she said. "People often tamp those feelings down

and that's one of many reasons anxiety pops up."

The solution? Allow yourself to *feel*. Sounds easy, doesn't it? Well, if you're

like me, it isn't. Vulnerability wasn't rewarded as I grew up and feelings were

not spoken aloud. Dad's emotions were all over the place—more so when he was

drunk, which was, eventually, all the time. Sometimes he'd be screaming about

the world wronging him, and other times he'd be sobbing over cheese fries about

"the light" going out in a hunted deer's eyes (which happened at a Steak 'n

Shake when I was fourteen). Turbulent feelings scared me, and I came to think

of *all* emotions as unsafe. I put off going to therapy for so long partly because I

was afraid to cry during a session. (I did cry. My psychiatrist handed me a box of

tissues. The world kept turning.) Allowing myself time and space to *feel*, even

for an hour-long therapy session, seemed indulgent at first. But those thoughts

subsided as I began to unpack why I felt that way, and as I started to see and feel

real progress from therapy and medication.

Chronically ill people spend a lot of time wishing for the past and worrying

about the future, but very little brain space is given to the present. "This is part

of grief," Lundquist said. "That you thought your world was going to look a

certain way and now you not only have to change how you see your life, but also

rethink how you go about constructing hope and finding meaning." This is

where mindfulness comes in. "Mindfulness" is one of those words that's become

so popular in recent years that it's lost some practical value while simultaneously

becoming an extremely profitable industry. But for us chronically ill folks, it

simply means to be present and aware of the moment we're in, be it through

meditation or something else. You don't need to pay for an app or a book or a

class unless you want to.

"Mindfulness must be tailored to the individual," Caryl Boehnert, PhD, a

longtime clinical psychologist who specializes in chronic illness and chronic

pain, told me on the phone from her office in Minnesota. Dr. Boehnert's

postdoctoral fellowship in health psychology set her on the path to focusing on

acutely and chronically ill patients, which is what she's been doing since the

1980s. "[Mindfulness] can be the standard breathing exercises to manageautonomic responses, but it can also be sketching, examining a photograph and

staying still in the moment with that image, or listening to music or other

beautiful sounds," she said. I tried the whole eyes-closed-counting-my-breath

thing—I even took a class and downloaded several apps—but I never grasped it.

Mindfulness for me comes when I'm writing. Sitting alone searching for the

right words, putting thoughts and ideas and memories to a page, hearing the

clicks of the keys, feeling the *zap* from my brain to my fingers—that's when I

feel the most *in* my body.

Mindfulness is whatever ritual grounds you in the present.

Even if it's just a

moment to take a few deep breaths and thank your chronically ill body for

getting you this far, that's mindfulness. "Working through anxiety requires

people to come back to the present," Conlon said. "Anxiety is fueled by fear of

the unknown or fear from the past—like a medication previously failing or

having an accident in public. Understand that that might not happen again in the

future. You aren't a fortune teller!"

In therapy, you'll learn and practice many tools to cope with anxiety. Conlon

recommended a simple mindfulness-based one called GLAD that I quite liked

when I tried it. You can do this mentally or in a journal. Either way, it only takes

a few minutes and is an easy trick to separate your brain from an anxiety spiral

and refocus it elsewhere. Here's how it works:

G: Gratitude. Think of one thing, no matter how small, that you're thankful

for *today* (keep it focused on today). "I'm thankful that my pain level was a

three instead of a five," for example. Spend some time in that feeling.

L: Learning. Name one thing you learned today. Again, it doesn't have to be

a giant lightbulb moment. "I learned that eight hours of sleep is the right

amount for me," or "I learned that raw vegetables increase my abdominal

pain." Appreciate your ability to learn new things every day.

A: Reflect on an accomplishment. One thing you accomplished today, like "I

took my medication on time" or "I ate foods that don't cause me any pain" or

"I discovered a good anxiety-management exercise."

D: Jot down or think about a delight. One thing that pleased you today, like a

cute dog in your neighborhood or a delicious cup of coffee. This can be silly,

adorable, funny, whatever! Honor the happiness that brought, no matter how

brief. Re-create that joyful feeling by playing it again in your mind, noticing

how cool it is that we have the ability to recall stuff that makes us feel good. **Guilt is a part of grief, too.**

I don't know *anyone* with chronic illness who hasn't struggled with guilt. We

all think we could have done something—many things—differently to prevent

getting sick in the first place, and then we feel guilty about needing to rest, not

working longer hours, being a "bad" parent or partner, losing relationships,

skipping social events, needing extra support and care, and on and on. Guilt and

anxiety are friends. They both let us go down the *would have* should have could

have rabbit hole, which is an easy place to get stuck. "Guilt is the appropriate

emotion when we believe we've done something wrong—violated a rule or

commandment or when we believe we've been 'bad,'" Dr.

Chafetz said. "Then

we're ashamed to be a bad person. But in the vast majority of cases, that's just

not true. When there's no direct causation between behavior and chronic illness,

then [we shouldn't feel] guilt—we can feel regret, sure, or understand that it's

just a darn shame."

Dr. Boehnert offered three strategies that chronically ill people can use to

deal with this anxiety-guilt spinout. First, identify cognitive distortions (this is a

major part of the work done in cognitive behavioral therapy). "We all have errors

in thinking that are left over from childhood," Dr. Boehnert said. "Bad

forecasting. Catastrophizing. Looking at the future with only grimness. Thinking

you could have done something better, that you shouldn't feel tired, that you'll

never get over something, that you'll die miserably."

Identifying patterns and

figuring out why you think about things the way you do can be the first step to

changing those thought patterns. To help you organize this process, I recommend

buying a CBT workbook and dedicating a bit of time to it every day. (This isn't a

replacement for therapy, but it's a good place to start.)

Next, try an exercise called thought blocking. "This is a technique that

people can learn to do once they identify the unhelpful things they're telling

themselves," Dr. Boehnert said. "For example, most women have told

themselves at one point or another that they're fat, ugly, or stupid. We start with

counting how many times per day you're using those words. Once you're

actively recognizing the word or thought, you can 'block' it by substituting in a

healthier, more positive word or thought." Many chronically ill folks believe

they're a burden on their loved ones, so this exercise could be useful every time

that thought pops up. Change "I'm a burden" to "I have value" or "I am loved,"

for example. Noticing your internal dialogue *at all* is progress, so give yourself

credit for that.Last, schedule a time to worry. It's unrealistic to tell chronically ill people to

stop worrying entirely; after all, a lot of our fears are valid. "If you can't stop

worrying, then schedule a time to worry," Dr. Boehnert said. "Say, from 7:00 to

7:30 a.m., that's the *only* time I will allow myself to worry about this thought. A

lot of my patients are, despite chronic illness, very highfunctioning people

who've scheduled the rest of their lives, so why not schedule a worry time? Set

an alarm. Once the clock rings, you stop until the next scheduled session." You

can incorporate a worry journal into this practice, too, Dr. Boehnert said.

Worrying—if done right—can be constructive for chronically ill people. "It's

okay to worry about the future. It's what human beings do," Conlon said. "But

you have to focus on things you can control. Shift the focus from worrying to

planning." For example, yes, it's possible that your medication might fail. You

can't control how your body will react, but you can plan for what you'll do if it

does fail. Talk to your doctor about what happens if you need to switch

treatments. Know which medication you'll try next. Figure out if you need

insurance approvals. Be prepared for new side effects. That's *active* planning,

not passive worrying.

"I suggest people shift their word choice to *if-then*, so they can take more

practical steps," Dr. Chafetz told me. "It's helpful to identify the fearful event

and then apply *if-then*." For example: If my medication stops working, then I've

discussed the next option with my doctor. If I need surgery, then I'll research

everything I can about it and be sure I choose a skilled, trustworthy surgeon. If

I'm treated as a drug seeker, then I can have my doctor put a pain contract in my

patient file. A pain contract, also called a pain treatment agreement, lays out

why, how often, and at what dosage a patient takes opioids; it can be helpful to

have on file if you're chronically ill and require frequent or occasional pain

management via ER.

Don't try to rush "meaning."

During an interview on *Ellen* in November 2019, the iconic Julie Andrews

said that one of the hardest things she'd ever been through was the loss of her

singing voice. She'd tied up her entire identity in that voice and when it was

fractured (due to throat surgery gone wrong), she felt an immense amount of

grief. Her daughter, a writer with whom Andrews has coauthored several books,

finally told her, "Mom, when you write, you're still using your voice. You're just

using it in a different way." Andrews said that as soon as she heard that, her grief

lifted. She wasn't harnessing her voice in the same way, but she was still using it—and that gave her purpose. She found new meaning. That doesn't mean that

she's okay with the loss of her ability to sing or that she doesn't miss doing a

thing she loves, but she *can* move forward. Andrews said it took her several

years to get to that place, even with the help of therapy.

Like acceptance, "meaning" isn't an end zone, and it may change or look

differently over time. "You're making meaning throughout the entire grief

process," Dr. Gilbert said. "People want it to be meaning with a capital M, but

really it's about finding an explanation for what happened that lets you move on

with life. For people who are chronically ill, that has to begin with forgiving

themselves for not being able to be the person they imagined themselves as."

You're (more than likely) going to need professional help.

I'll repeat this more times than is necessary: Good help exists for folks like

us, and there's no shame in seeking it. I'd argue that's it's not only okay to get

mental health help when you're chronically ill, it's required.

"Any therapist

worth their salt should be able to help with grief," Lundquist said. "What is

therapy but the activity of helping people grieve?"

Most therapy is so expensive that it's reserved for a certain class of people

who can afford it, and it's going to remain that way until our entire health-care

system gets a necessary overhaul. But we're also living in a golden age of

mental health access where you can connect with a therapist in more ways than

ever. (Keep in mind, though, that quantity doesn't mean quality. Just because a

lot of mental health options are available doesn't mean they're *good* or the right

fit for you. It can take time and effort to find the right match.) If you don't have

the physical or mental energy to research mental health professionals, ask a

trusted friend or family member for help. Reach out to multiple therapists or

counselors to find out what their approach toward chronic illness and grief is.

Make sure they take your insurance or offer sliding scale payment. Research

community-based mental health care through your local hospitals—sometimes

it's discounted or free. If you're a student yourself, take advantage of your

campus's mental health center; if you aren't a student but live near a campus

with a psychology training program, call and ask what reduced-fee services they

provide. If you're homebound, some mental health pros will come to you, or you

can do video or phone sessions. There are even reasonably priced therapy apps

now that connect you with a therapist via text. (Again, you can find more

information in Appendices II and III.)

Chronic illness often feels inescapable, and the desire to be free from a bodyin pain, a body that's lost control, is understandable. I've wished to leave my

body many times, even just for a few moments of relief. I get it. If your feelings

of loss are overwhelming and you feel suicidal, please don't suffer in silence.

Reach out to your therapist, your support group, a friend or family member you

trust, or call the National Suicide Prevention Lifeline. The hotline isn't robust

mental health care or a substitute for therapy, of course, but it's open twenty-four

hours a day, seven days a week at 1-800-273-8255. I called several years ago and

a very kind woman listened to me when I needed someone to *just listen*. No

judgment. I felt a lot better after that phone call. There's also an online chat

available

twenty-four

hours

a

day,

seven

days

a

week

at

suicidepreventionlifeline.org. Now read this sentence (and then read it again if

you need to): My life has meaning and is worth living, even if it looks different

than I'd hoped.

There's this grief analogy I think about a lot, which I first read in a tweet by

@LaurenHerschel. Grief is like a box with a ball and a "pain button" inside.

Every time the ball hits the pain button, it hurts. At first, the ball is so giant that

it hits the button all the time and the pain is inescapable. Over time, the ball

shrinks. It connects with the pain button less often. But when the now smaller

ball hits the button, it still hurts as much as it ever did. Along those lines, Dr.

Gilbert told me that grief is akin to a river: sometimes turbulent, sometimes

calm, even comforting.

Grieving makes you realize that two feelings—and three feelings, and four

feelings—can exist at once. "I had a parent who'd lost a twin in utero; the other

was born healthy. She became frustrated when people told her she should be

grateful for the living twin," Dr. Gilbert said. "What they didn't understand is

that this mother was grateful *and* grieving." Bidwell Smith said something

similar: "Finding a meaningful life doesn't mean you have to let go of grief.

People feel like they have to pick sadness or joy. But you can continue to feel

sad and create a meaningful, joyful life again." Hear that? You can feel sad and

create a meaningful, joyful life. You can feel sad and create a meaningful, joyful

life.