

Living with illness is about living with vulnerability. It is just like life, only more so. In this series of personal essays, Dana Snyder- Grant shows how to face illness and other life challenges with hope, humor, and wisdom.

*Just Like Life, Only More So
and Other Stories of Illness*

In this excerpt, we have included the opening pages, and one set of essays called “Culture and Stigma”
Find out how to buy the complete version of this book at <http://justlikelifeonlymoreso.com>

*Just Like Life, Only More So
and Other Stories of Illness*

Dana Snyder-Grant

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This book is dedicated to the 2.5 million people around the world who have multiple sclerosis.

We tell stories because we can't help it. We tell stories because they save us.

— James Carroll, “The Communion of Sinners”

Acknowledgments

Thank you to my family for always being there.

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Thank you to my community of friends and neighbors for showing me the deep meanings in connection.

Thank you, RC, for walking this road with me.

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This book would not have become a reality without all of you.

Introduction

When I woke up on December 1, 1981, my world was spinning. The walls and ceiling moved like a merry-go-round; when I sat up in bed and looked at the apartment building across the street, I saw windows jumping. Any movement of my body, however slight, left me feeling nauseated and dizzy.... I inched slowly along the wall of my apartment to go to the bathroom and then returned to bed. Shattered by the loss of security in my orientation to the world, it was only when I lay down with my eyes closed that I felt safe. But I was scared...this was not like the pins and needles sensations that had taken over the left side of my body for a few weeks in September. That had been scary but mostly it had been annoying. Now I felt horribly ill and...I couldn't see.

— “Red-Letter Day”

One week later, I was diagnosed with multiple sclerosis. It's been twenty-five years since that day.

Living with illness is about living with vulnerability, about being susceptible to loss and hurt. It's just like life, only more so. For we all have vulnerabilities. Your friends earn more money than you do, you have a weight problem, you divorce, you lose your job, a loved one dies. My stories of illness can be generalized to other stories of living. We are all susceptible to loss, all the time, to the losses that come with being human.

I don't mean to say that it's all the same, that living with the unpredictability and disorganization of serious illness is just like other losses. We live in a different world, those of us with unpredictable bodies, deformed bodies, ungainly shuffles. We are more at risk of infirmity and early death. We are stared at, left out, underemployed. But my stories can apply to your life even if you don't live with illness; they can mean something to you.

Please don't withdraw from me out of pity or fear. I want us to stay connected. My story isn't so different from yours. When I am dismayed at myself because I have no balance and use a walker, you judge yourself for not being smart enough or good-looking enough. When I must give up knitting because I no longer have hand coordination, you give up tennis because you have bad knees. When I feel insecure because I am unable to work at a job for many hours, you lose your job during a recession. When I rest instead of attend the party, you work late and miss the festivities. We both have a choice here. You can't determine your work load, but you can control how you manage it. I can't control my illness, but I can control how I respond to it. Illness can make me vulnerable, but your exposure in the world can hurt just as much.

When we're vulnerable, the illusion that we are safe is shattered. It may be a cliché, but vulnerability teaches. It teaches me to appreciate the moment, to value human connection, to cherish the ease of simplicity. I tell my tale to make sense of my illness.

I wrote these essays over the last ten years, many as newspaper columns, to explore issues and events along the way. While editing the essays to create this book, I discovered that I kept returning to a few central themes. So I've organized the

book into chapters for each theme, such as the medical journey, loss and change, cultural bias, letting go, nature, and community. But most of the essays address multiple themes. For example, when I write about cultural bias and stigma, I'm often also writing about coping with the loss of physical functioning, hopes, and dreams, all influenced by my own and society's expectations. And in the process, I'm writing about letting go.

The theme of community surfaces throughout my stories. For more than ten years, my husband, Jim, and I have lived in the New View cohousing community in Acton, Massachusetts, with two dozen other families who know and care about each other. My neighbors don't hold the cure for my immune system gone awry, but they provide the support and connection that form my lifeblood, whether I am ill or well.

In various essays, I touch upon my work as a clinical social worker specializing in chronic illness and disability. That work is part of my regeneration, a way to create meaning from what I've been dealt. I devote my final chapter, "Portraits," to a client's story and to the tales of others in my life who have faced illness.

I have dated each essay to indicate when it was written, but I have not put them in a strictly chronological order. This is because the illness journey is not a linear process, but a cyclical one. Grief, accompanied by anger, despair, and acceptance, has always traveled near me, stopping by when I least expect a visitor.

I'm driven to make sense from the MS. Maybe because I've been spared the worst, I want to give back to the world. As a psychotherapist, I bear witness to the stories of others. As a person with MS, I write and speak about illness to discover its meaning. Come with me on my journey.

CULTURE AND STIGMA

The She That Is Me

June 2003

It is July 1983. I live in Waltham, Massachusetts, and teach history at a private high school.

One night, I wake up and start walking towards the bathroom. I feel intense tingling sensations in my feet as I totter out of the bedroom. I worry that this is another exacerbation of multiple sclerosis, the illness that has startled me for the last two years. Or am I just groggy and out-of-it because it's three a.m.?

I wobble back to bed but have trouble falling back to sleep. What is going on inside me? I obsess about my body — I want to control it — but finally cry myself to sleep.

The next morning, my fears are confirmed. When I try to get out of bed, I can't feel my feet on the floor at all. I don't know where my body is in space. Close to nine o'clock, I call my neurologist and make an appointment. She will see me that afternoon and confirm that this is MS. I have lost my balance. I have lost my innocence.

That night, I cry myself to sleep again. I am terrified. Friends have brought me dinner and helped me to laugh, but still, when they leave, I am alone, in a body estranged.

The next day, I start to compensate. I hold on to furniture in my apartment, the first floor of a two-story house. I call the local chapter of the MS Society. Three hours later, Debra, the support services director, comes over to loan me a walker. It will help me balance and get around, if I'm willing to use it.

Debra's visit and generosity warm me. As she leaves, I finally notice that outside my door, the sky is a cloudless blue. I

want to get out of my house and not let my body imprison me. I step onto the porch and gingerly go down the stairs, grabbing the porch railing with one hand and dragging my walker with the other as it bumps down the seven steps. When I had looked for an apartment the previous year, it hadn't occurred to me that I wouldn't be able to navigate stairs.

I stand in my driveway and face the road with my walker in front of me. I discover that I am trembling. It is my self-image, not trust in my physical ability, that is shaken. I fear what others will think of me. What do I look like, holding on to this walker for balance? It disgusts me. Twenty-seven years old, I'm supposed to be in fine health. Aren't people who use walkers either elderly or mentally retarded? I am dismayed to recognize my assumptions and prejudices. Young teens walk by my driveway and gaze at me — or is it through me? Do they see me or the freak I believe I am? They laugh as they easily walk on. Don't mistake me for a retard, I want to shout. Then I gulp with shame for such thoughts. An older couple walk by and also stare, but then they nod and smile, acknowledging my presence. Later, it occurs to me that they might understand, because they also know human frailty. They are not as afraid as I imagine the teenagers are, or as I am.

Slowly, I walk down my driveway to the road. Lift the walker and my foot, move them forward, place them down and step. Balance! If I ever get it back, I will cherish it.

I reach the sidewalk and take a left, aiming to go around the block. Slowly, I pass the Catholic church. Its stoic silence encourages me to pause. Then I continue to lift and step. I am getting the hang of this walking.

I see my reflection in a store window and stop suddenly. I am outside myself, looking in. Seeing myself so starkly,

needing the walker, I feel pity. I don't want to see this vulnerability.

I am back at my driveway, exhausted. I lift and step on the drive. When I get to the porch stairs, I look around but see no one. I sit down and push myself up the stairs, again dragging the walker with me. I stand, lift, and step through the door into the living room, and collapse on the couch.

That day, I begin a course of Prednisone. This is my third MS exacerbation in five months. In March, my legs felt heavy and stiff; I walked like a robot — gingerly, yet mechanically. In May, I lost my coordination; with my hands feeling huge and clumsy, I couldn't tie my shoes or hold a pen. Those symptoms have remitted almost entirely, but I am overwhelmed by this constant onslaught. My loss of balance has uprooted my identity, the person who I believe I am.

I call my brother in New York. I cry and ask him what I did to bring on this exacerbation. I have turned my fear and anger at this illness against myself and into self-blame. Adam reminds me that the illness is not my fault; this flare-up is probably due to the position of the constellations in the sky. Skeptic that he is, his humor helps me to test my reality and to reconnect with some vital part of me. I am reminded that relationships sustain me.

The next week, my balance begins to return in more ways than one. I can move around my apartment with greater ease, although I still use the walker when I venture outdoors. Now, I smile at others on the street. I notice the trees and the birds, more than what strangers may perceive.

Towards the end of July, I visit Adam and his wife in upstate New York. The rest and relaxation and the support of loved ones soothe my body and soul. I start to let go of judgments of myself and my body. I talk and cry about my

losses and fears. I begin to admire the cane that a carpenter-friend has made me. Over and over again, I'm learning what I can control and what I can't.

I've begun to grieve. Running away from my grief that summer day with the walker estranged me from myself. I was fighting the MS, not learning new ways to respond to the illness. In my attempt to deny my own negative self-judgments, I imagined that others had those biases. I have to let go of my own and society's prejudice in order to accept myself.

The next year, I decide to attend social work school. I want to help others deal with the loss and vulnerability that encompasses life. My studies and psychotherapy help me to understand myself. I read *Stigma* by Erving Goffman, the renowned sociologist, and see the interplay between my own self-image and society's projections. I continue to grow up.

Twenty years later, I tell the story of how my prejudices dared to challenge my self-image. I skirted dangerously close to self-loathing on that summer day. When I walk past a store window now with my cane, the woman smiling back understands. I am no longer outside myself — she is me.

The Hierarchy of Disability

December 1999

The other morning, a reporter called me to apologize for a possible error of information in the newspaper. She thought she might have written that I had muscular dystrophy, instead of multiple sclerosis. My reactions surprised me. I thought, if I must have a disability, let me keep this one. MS is more romantic, more feminine than muscular dystrophy. Barbara Jordan and Joan Didion are my role models. Not that I want a chronic illness, but after almost twenty years, I'm used to MS.

I thought, what will people think of me if they believe I have muscular dystrophy? Isn't it worse than MS, more life-threatening? The need for a wheelchair more certain? They would think, "How unusual, it's rare for a woman to have MD." As a psychotherapist, I try to help clients to separate themselves from the thoughts and feelings about illness that dominate our culture, to accept their needs and develop a solid self-image, to reject the notion that "I am my illness."

Yet here I was, worrying about what people might think. I projected my prejudice and unfounded horror of an illness onto others, imagining that my thoughts would be theirs. The recognition of my actions gave me empathy for my clients who struggle with the attitudes of friends and family. I could also now understand the able-bodied who anger me, because I, too, had perceived people with an illness as pariahs, outcasts. Ironically, I labeled and feared those with MD, trying to put myself above them, as if there was a hierarchy of disability. Even I was trying to maintain emotional distance from illness, running away from my fear and vulnerability.

The irony is that some might fear multiple sclerosis more than they do other illnesses. Yet I've learned to manage my life with MS. My professional life grows from my personal experience. MS is an emotional challenge as much as a physical one. Fatigue limits my activities. I've lost coordination in my hands, strength and balance in my legs. Double vision pays a visit at times. The unpredictability of these symptoms is scary; I could become blind or paralyzed, temporarily or permanently. Or none of these things might ever happen.

What did I mean by thinking that one illness is "worse" than another? That it makes one less happy? Receive a kind of pity that is unwanted? Does the fear of life in a wheelchair stem from the dread of dependency in our culture? Does the burden of illness and disability make our lives less valuable? Or do we offer others the opportunity to learn about intimacy and vulnerability without running away?

There was no error in the newspaper. The article stated that I did, indeed, have multiple sclerosis. But I learned some things. Even those of us with disability compare ourselves to one another. "At least, I'm able to walk" can give me a false sense of superiority. Someone else might look at my life and say, "At least, I have the energy for child-rearing."

The hope is that we can witness and honor the experience of others, whatever that may be. After the diagnosis those twenty years ago, I immediately went to the home of a good friend to tell him I had multiple sclerosis. He responded, "Oh, now you'll be one of Jerry's kids!" His attempt at humor relaxed us, but I remember thinking, "No, that's muscular dystrophy. My experience is going to be of MS and let's understand that."

So the other day, prejudice reared its ugly head. I saw first-hand how fear and ignorance can develop into negative

attitudes. And I'm supposed to be above all that, considering my personal and professional experience. Ha! I understand more fully now how confronting biases can go a long way towards overcoming prejudice.

Not Always So Black and White*January 2001*

The story of Casey Martin, a golfer with a disability, has captured my attention. Because I so understand his predicament. A federal appeals court ruled last year that Martin was entitled to use a golf cart rather than walk the course on the PGA Tour. His right leg is so atrophied and weak from a circulatory disorder, Klippel-Trenaunay-Weber syndrome, that walking the length of a golf course is impossible. The PGA Tour, which has a no-cart rule for its circuit, responded by taking its case to the Supreme Court.

Some commentators have said that the sports world should be exempt from protections for people with disabilities. Despite the increased visibility of women's sports, the athletic arena does have a tradition of being a macho world; inclusion is not its top priority. If you combine this with the fact that golf is a sport that cherishes rules and tradition, then Martin loses out. But the fact is that, disabled or not, Martin is a star. He has a strength that calls for recognition. He is not a very good walker, but he is a great golfer.

It is possible that you doubt Martin. It may be hard to understand how he can swing a golf club with expertise yet be unable to walk to the next tee. You might also wonder how Martin can stand and flex his knees without problem but find walking so difficult that he must ask for this exception. His talents might make you question the severity of his condition. Illness and disability might scare you so (because none of us is immune) that you just don't want to believe Martin. If he had a

significant disability, could he really compete in sports with the able-bodied?

But disability is not always so black and white. We had a president who used a wheelchair, even if he and the world tried to hide that fact. Sometimes disability is invisible. People who “look so well” with lupus or multiple sclerosis may function quite well at work or home, but they can’t help but be affected by the fatigue in their bodies. Even with MS for the last twenty years, I can climb mountains with my cane, but I use a wheelchair in museums to avoid the pain and exhaustion that come from standing. I understand how Casey Martin can move his body perfectly to play golf but not to walk.

What often harms people with disabilities is not their “handicap,” but the world’s attitudes. If Casey Martin is such a great golfer, why not let him use a cart? Let’s use the Americans with Disabilities Act (ADA) to level the playing field.

Martin’s case reminds me of the debate in the Appalachian Mountain Club about whether to make their White Mountain huts in New Hampshire accessible. Some think it ridiculous to build ramps and have accessible bathrooms on mountains that are five thousand feet high. I did at first. But there are hikers in wheelchairs who, with assistance and a lot of determination, have made it to the top in glory. Haven’t they earned access to a warm bed and a tasty meal?

Martin was dealt a lousy hand (or leg) of cards, but he plays it well. We may want to peg him into the stereotype of “the hero who can overcome anything.” But Martin, a former golf champion at Stanford University, only wants to continue to compete in the sport that he has played all his life. Requiring him to be a hero is hurtful to him and the thousands with

disabilities who live life as best they can. It is unjust to demand a standard from them of constant courage and heroism.

These cases confuse me, however. Right and wrong are not clear-cut. Do we use limited financial resources to make places accessible in remote locations? If only one person in a wheelchair gets to the mountaintop, does that warrant an accessible entrance? Is it fair to use the ADA to alter the terms of a sporting competition? Is the twenty-five miles that golfers have to walk fundamental to the game? If it is, then why do golf carts exist? Perhaps to make the game more equitable for all. Here is the irony.

People want sports to be a simple story without the complexities and ambiguities of everyday life. They want golf to be about Tiger Woods, not Casey Martin. But Woods and Martin played together at Stanford University. Why can't they play together in the PGA?

Illness, Lies, and the Television Version

May 2001

I share a chronic illness with the President of the United States. President Bartlet, of TV's "The West Wing," has multiple sclerosis. In remission for the last eight years, he has kept silent about his illness.

When I first watched this story unfold, I was stunned. That MS, an illness about which many are misinformed, could be portrayed with accuracy to the television public was remarkable. MS is often depicted as an illness that "strikes victims" who "end up in wheelchairs." That the illness varies widely from person to person — there are progressive, moderate, and benign courses — is often overlooked. Nor do the ambiguities of MS for those who "look so well" but feel so lousy get attention. It may have been unrealistic that someone who works long hours and has the most stressful job in the world could have an illness whose primary symptom is an exhausting fatigue. But it was exciting that millions of viewers could receive a fine education about illness, and life, from this drama.

I began to watch "The West Wing" with regularity. MS did not often figure in the weekly plots. The illness was important, but it was not a big deal. I became engaged with the characters on the President's staff. I was proud of C.J., his press secretary. A confident and personable woman, she was a role model for all female viewers. I was enamored with Charlie, the President's personal aide. He was the epitome of cool, not batting an eye at the President's idiosyncratic demands for the perfect Thanksgiving carving knife. When the character of Joey Lucas,

played by Marlee Matlin, was introduced, I was tickled. A presidential pollster, Lucas happened to have a serious hearing impairment, as does Matlin. Again, we were given the message that disability does not have to dominate one's life.

In the last few weeks of the second season, the President's staff found out about the MS. Some felt betrayed; a few showed concern for Bartlet's health. All were anxious about the public's reaction. In the season's final episode, the President disclosed his condition to the world.

Did the President lie to the public through a sin of omission? How much of this politician's life did the public have the right to know? Did he have the right to keep private about an illness that can be degenerative in some, but that in him has been quiet and only a nuisance? It's a big deal to have a serious illness, but is it a big deal if you can still live a full and productive life? Sixty years after F.D.R., we still debate whether or not to acknowledge Roosevelt's wheelchair.

Truth and honesty are central subjects in American politics. The interpersonal complexities of hiding the truth parallel the political ramifications of keeping secrets. People with chronic illness often face the issue of disclosure. Some, living with invisible symptoms, choose to hide illness from friends and colleagues. They fear the loss of their companions or their jobs. But in shutting down this part of themselves, they lose the intimacy that genuine connection brings, and they deny a part of themselves. In this fictional drama, the President's pollster assessed the public's reaction before the disclosure. People overwhelmingly responded by rejecting a politician who developed a serious illness, demanding that he step down. Would this, in truth, be the case if the fictional scenario actually happened? Is it an irrational fear of the unpredictability of some illnesses that is at play, or is it a rational response to the

restrictions that illness imposes? Can the lessons in compassion and living with limitations override the possibility that the illness might progress?

What I appreciate about how the MS has been handled in “The West Wing” is that it has not been the central issue of the show, even though it has been a serious matter. It is just part of life. Politically, the MS has highlighted issues of honesty and privacy. Spiritually, the show has confronted issues of loss and vulnerability. The second season’s final episode also showed the President in mourning for his beloved secretary, who was killed by a drunk driver. The story went beyond the fears that can be raised by a single focus on the random nature of ill health. The President railed against God about the unfairness of haphazard events in the world. And doesn’t such randomness confront us all?

To Tell or Not to Tell*March 2004*

Last month, a colleague asked me to speak to a breast cancer support group about disclosing illness. Who do you tell — family, friends, colleagues? What do you tell — the details or the bare minimum? When do you tell — now or later, if the illness becomes more visible?

And how does it feel to tell? Do you feel guilty, that you have somehow done something wrong to deserve this, or do you feel ashamed, that you are tainted in some way? Does that shame affect who, how, and when you tell? Or do you feel angry at our culture, which makes it difficult for you to accept the illness, for shunning you in order to allow the able-bodied to keep their eyes closed? Or do you feel relief because the secret is out? Clearly, the issue of disclosure has many layers.

I still give thanks to my first neurologist, who helped me skip over any shame. She made it clear that I had done nothing wrong to bring on multiple sclerosis, that it was likely caused by a virus that had lain dormant in my body for years. The stress of teaching may have been the trigger, but no one really knew.

I told everyone that first year, 1981, including family, friends, and colleagues. It wasn't my style to hide from others and I wanted — no, needed — the support. Back then, you could be fired just because you were ill or disabled. It was just as well that I was naive; it allowed me to be myself. Holly, another teacher, gave me a hug when I told. I described the illness and explained that it was unpredictable, but not fatal. Telling others about the MS helped to make it real.

Of course, not everyone was warm and fuzzy. When I first realized that I couldn't control people's reaction to the MS, I felt powerless and angry. I remember telling one friend that my interest in social work school stemmed from a desire to help others who faced difficult life events. She was concerned that this meant that I was focused on the MS to the detriment of the rest of my life. I was hurt by what felt like an unsupportive response. It was a few weeks before I began to wonder if her fear and discomfort with illness had affected her reaction.

When I began to use a cane a few years later, I started to hide. I had learned that serious illness frightened people and that first impressions mattered. So sometimes I would wait to tell people about the MS, even hiding the cane on a first visit.

I was particularly uncertain about the issue of disclosure when I entered the dating scene. Since being diagnosed at age twenty-five, I had not dated. My close friends accepted my MS, but I was not ready for the exposure that dating would entail. I feared rejection, imagining that men would only see the MS, because that was all I saw. As I slowly integrated MS into my identity, I recognized that I was so much more than the illness. I realized that a guy's response said more about him than about me. Did his discomfort reflect an unease with difference and vulnerability? If he couldn't embrace the entire Dana, was he the man for me?

In 1987, a man I was dating asked me, "Do you want to go for a bicycle ride?" We had been on only one date, but we had talked easily. It wasn't love at first sight, but that was a good sign. Falling in love quickly often meant that I was falling in love with a fantasy, not a real person.

Now, he had called me for another date. "I don't ride bicycles much," I replied. "How about a walk in the woods?" he tried again. I gulped and said, "Sure, that sounds nice," and we

arranged to walk around a local reservoir. I hung up and realized that this guy might find out about MS sooner than I had planned. I loved the outdoors and walking, but MS reduced my stamina. I did what I could, which some days was more than expected; other days, my legs demanded rest.

As we began our walk, I took my cane, collapsed like a tent pole and secured with a rubber band, out of my purse. I released the rubber band and the cane dramatically fell into place. “Meet my cane,” I declared. “Oh, what’s that for?” my date asked matter-of-factly. “I sometimes have trouble walking,” I replied. “I have multiple sclerosis.” I told him about MS, that symptoms could come and go for years, that my doctor was optimistic. We had walked about three-quarters of the way around the reservoir and sat down on a bench. “How are you doing with all this?” I asked. “It brings me down to earth. And you?” he asked. I talked about my nervousness, how I didn’t mean to tell him so soon, but this was just my life.

Disclosure is a personal decision and a different one each time. It was scary to tell that day, but I’m glad I did. Seventeen years later, my husband and I still walk around ponds and ask each other, “How are you doing?”

Soft Tissues for the Rough Times

March 2005

Walking home one evening from a neighbor's house, I was oblivious to the frigid winter air, though the need to blow my nose was obvious. I got home and, sneezing, I scurried to find a box of tissues. This couldn't be the beginning of a cold, because mine always began with a sore throat and there was none of that tonight. Sure, my husband had a cold the week before, but I wasn't going to get sick. I was above all that.

The next morning was Saturday. I awoke with a stuffy nose and a headache. I told myself to take it easy. MS, an autoimmune disease, can get triggered when the body is fighting an infection. I didn't want my immune system to attack my nerve linings instead of the cold germs.

I was sluggish all weekend. I read a good mystery and avoided walking outdoors. My headache eased, but my need for tissues did not. I still didn't have a sore throat, not even a cough, so I started to think that the congestion would abate quickly. On Monday, I stayed home and wrote. As the week progressed, I left the house to see psychotherapy clients, and the headache returned. At night, my sleep was interrupted — the worst side-effect of all — by nose blowing, sneezes, and restlessness.

My MS symptoms of eye pain, spasticity, and fatigue intensified by the end of the week. I got scared. I realized I wasn't doing anybody any good by working and by denying my need to take care of myself. I'm usually good at taking it easy when I'm tired. But this time, I wanted to be strong and invulnerable to the world of illness. Weren't these the distorted

thoughts and beliefs that I helped my clients to question? I thought that by now I had learned to ignore our culture's message that getting sick was one's fault. Yes, we have a responsibility to take care of ourselves as best we can. But no, part of me had fallen into the belief that if I were tough, I could ward off this cold. That vigor and health equaled strength. So was it weak to be sick?

It was this type of thinking combined with my diminished energy that took away my resilience. First, a reader criticized my writing. Then, I couldn't seem to help a client's depression. Who was I to think I had so much power, anyway? I did a good job of finding my failures and stewing in them.

The cold lingered into the following weekend and the headache returned, all exacerbating my MS symptoms. I stayed prone and did little on Saturday, and then started to feel human again on Sunday. My head cleared. I felt as I did when coming out of an MS flare-up. The world was a beautiful place. I was good to myself. I bought only "ultra soft" tissues for my sensitive, now-chapped nose. I scheduled a massage for Monday afternoon.

I wrote my friend and colleague Tracy, who also has MS, about the self-criticism. She could relate. "There's something so insidious and invisible about how a little bit more of illness or strain depletes what we are able to handle," Tracy wrote back. "And then we blame ourselves, when actually there's a very good reason, that has nothing to do with us, for feeling so horrible. When my body ails, it's not really ME that's failing: it's my body. And that I can forgive."

I thought about how we blame ourselves for illness, whether it is MS or a cold, in an attempt to control its origin and outcome. I have come to believe that there are aspects of illness that we cannot control, that have a life of their own. Some days,

even when I feel rested, my legs still feel “gimpy,” a word I use to describe my clumsiness and loss of coordination and balance. But I can control how I respond to the illness and to my self-perceptions.

We learn about the meanings of health and illness at an early age. Recently, I had a conversation with an eleven-year-old neighbor who struggles with migraines. Jenna told me, “Every day when I wake up feeling well, I’m so happy. I congratulate myself for doing something right.” I understood Jenna’s glee. I’ve been there. But if we compliment ourselves for feeling well, how do Jenna and I avoid berating ourselves for feeling sick? By forgiving our bodies and ourselves, by learning what we can control and what we can’t. And by storing away a few extra boxes of those ultra-soft tissues for the next cold.

Take Back Your Time

November 2005

Did you know that the United States military has a Directorate of Time? And a director of the Directorate of Time? Fantasize for a moment about what you might do in this position. I would stop all clocks for a day. Without warning. Instruct everyone to take one day off to chill. Most important, I would add an extra hour, every afternoon, for everyone to take a nap. And it would be my department's job to make sure that we all don't just return to our crazy, hectic lives. That would be my greatest challenge.

I've been struggling with time lately, because I've had the luxury of feeling well. So I do more — more work projects, more community tasks. Then I forget appointments, lose files. Trip on my way to the bathroom. With my extra energy, someone asks me if I've considered more play. I ponder that.

This week I study time and I know I'm not alone. James Gleick, in *Faster: The Acceleration of Just about Everything*, asserts that "We are in a rush. We are making haste." He writes that "the blacks," those punctuations between television shows "when the screen fades momentarily to darkness," are disappearing. We've lost our down time. Gleick proposes that "our ability to work fast and play fast gives us power," and that "behind all our haste lurks the fear of mortality." I ask myself: Is it the baby-boomers who are rushing things for fear we will lose our influence and run out of time?

I wonder how our speedy culture affects us. We no longer wait for postal mail, which we rename snail mail. Tasks multiply as we email, speed dial, fax, instant message. Fast

forward, channel-surf. Ten seconds seems like an eternity. Does our impatience affect our health? Do we still make time for human connection? Have we become trapped in this electronic, overloaded world? Do we have more leisure time or more time to keep busy?

I connect with friends about their relationship to time. And I find solutions. I'm struck that it is those with whom I speak, not email, who help me the most. Yvonne, who says she's always "wrestled with time more than anything else in my life," finds it helpful that our culture is so fast now. She's more conscious of the pressure to speed up and more mindful to pace herself. Living in community, she uses a neighbor to help her account for time. They call each other in the morning, prioritize their tasks for the next few hours, and then check back with each other later in the day. "When I state my accomplishments, I own what I've done and feel less overwhelmed," says Yvonne. "I've taken back control and it slows me down."

Community helps me to pace myself, too. I run into my neighbor Beth one Saturday, and we spontaneously connect and take a walk. I leave my "to dos" behind at home and slow down over supper with friends in our neighborhood's common house.

Carol, who is recovering from open heart surgery, speaks with me about her lack of speed, a most difficult aspect of healing. "I have to adjust to how slow I am. I never had to pace myself before and I'm used to doing things quickly." She adds in an email, "I don't think I'm judging myself critically, nor do I think I'm wasting time. I'm definitely into accepting what is.... I'm trying not to use energy to change what I can't."

Living with a chronic illness in this fast, busy culture, it's taken me some time to accept that I must rest between tasks, lest I receive a visit from overwhelming fatigue. Like Yvonne and Carol, I realize that I can choose to reject our culture's pressure.

People with illness tell me that responding to the cultural call for speed is one of their greatest challenges. “The faster I do a task, the longer I have to lie down afterwards,” says Jean, who has chronic fatigue syndrome. Frank, who has Parkinson’s disease, says, “It takes so long for me to do things now. For a long time, I didn’t want anyone to see that.” Eating, dressing, or talking on the telephone are no longer simple tasks for these two. But Frank says that now, after five years, he appreciates his accomplishments like he never did. He also values the simple things — friends, family, relative health. Slowing down has allowed him to stop and smell the flowers.

If the director of the Directorate of Time doesn’t give me that day off, I’ll just take it anyway. It’s about time.

About the Author

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Living with illness is about living with vulnerability. It is just like life, only more so. In this series of personal essays, Dana Snyder-Grant shows how to face illness and other life challenges with hope, humor, and wisdom.

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In this excerpt, we have included the opening pages,
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