CHRONICALLY HAPPY

Joyful Living in Spite of Chronic Illness

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DIAGNOSIS

You watch as your doctor's mouth moves, but the words coming out just don't make sense. You feign understanding with an occasional nod, but inside you are tumbling head to heel, trying to unravel the sentence he spoke when you first sat down. "Me? I have a chronic illness?" Over the next few weeks, the shock will wear off, but a range of other difficult emotions awaits you. I'm here to tell you can and will get beyond these feelings and live a fulfilling life. Your life is not over; it's just begun.

What lies behind us and what lies ahead of us are tiny matters compared to what lives within us.

—Oliver Wendell Holmes

I DON'T REMEMBER the first time someone said to me, "You have a chronic illness." I was a toddler at the onset of my disease, but through the years, my family has repeatedly told the story of the winter day my mother rushed me to the hospital, my temperature surging and stomach bloated. It is the retelling of this story that has created my memory.

The year was 1968, and I was two years old. I hadn't eaten in two days, and despite submerging me in cold baths, my mother hadn't been able to bring my fever down. She took me to Sunrise Hospital in Las Vegas, where the medical staff was so baffled by my symptoms they didn't know how to treat me. I was growing sicker

by the moment, so they promptly sent me to Children's Hospital in Los Angeles, which was better equipped to deal with serious ailments in children.

After a battery of tests at Children's, the specialists pinpointed the problem: complete kidney failure. At the time, the cause was a mystery, but, in later years, they diagnosed me with hemolytic uremic syndrome, a disease brought on by *E.coli* bacteria.

The medical team hooked my twenty-two-pound frame up to a dialysis machine, which, to me, looked like a modified washing machine. The contraption pulled my blood out, cleaned it, and then pumped it back in. The treatment kept me going for several weeks—until the day the tubing burst, and I nearly bled to death.

Ironically, this mishap ended up saving my life. As the blood drained out of me, so did the *E.coli* bacteria, relieving the stress on my kidneys, and enabling them to work again.

My diseased kidneys fought off dialysis for ten years, but wreaked havoc in other ways on my body. Mainly, they caused my blood pressure to rise uncontrollably, which made brain damage and stroke continuous threats.

Medications and a restricted diet controlled my blood pressure until I was twelve years old, living in Florida with my mom. It was here the medications and diet stopped working. Since I didn't have access to the specialists I needed, my mom took me back to Children's. With no money, my mom and my cherished black poodle, Pepi, and I packed up our gold-colored Oldsmobile and started the trek across the country. I was on my way to hear one of the most difficult diagnoses I would ever receive.

Propped up in the front seat of the Olds, I was going downhill fast. I couldn't lie down and breathe at the same time. My mom would drive all day and I would

sleep with my head on the window. At night I would sit up in the hotel room and watch television. I learned later I had been in congestive heart failure.

When we arrived in Los Angeles, we drove immediately to the hospital. My kidneys were failing again, and I had to go on dialysis right away. I underwent an emergency operation so the medical team could access my veins for dialysis. Sometime later, they removed my kidneys altogether.

During the following twelve years, I lived through dialysis treatments, three transplants, and two rejections. Each transplant brought renewed hope; each rejection would send me reeling. It took me years to learn how to manage the feelings that came along with the constant diagnoses, the seemingly endless stream of bad news.

Even after my successful transplant in 1990 when I was twenty-four years old, the diagnoses didn't stop. Since then, I've been treated for arthritis, osteoporosis, renal failure, and, I learned recently, I will likely have to have a hysterectomy. After years of taking immunosuppressant medications, I'm at a high risk for uterine cancer, and having a hysterectomy is the best way to rid my body of the precancerous cells.

In short, I have felt the way you may be feeling, swinging from anger to sadness, from "I'm going to beat this!" to "Why me?" I've been crushed in the vice grip, battling with depression, grief, and hope-shattering medical statistics and prognoses. I'm here to tell you that you can and will get beyond these feelings.

The first step is to acknowledge and deal with them; understanding what these feelings are and anticipating when they will surface are key steps in rebuilding your hopes, your future, and your dreams.

FACING THE EMOTIONS OF A CHRONIC ILLNESS

No More 'Untimely Ouches'

During my many medical procedures, I've had to endure hundreds of needle pricks. When I was younger, I would never complain about the number of sticks the nurses made. Consequently, they repeatedly told me what a good patient I was. In reality, those needles hurt! I wanted to cry and scream at the person who kept poking me. Most often I was silent and tried to be as accommodating as possible.

What happened to the feelings boiling inside? I would vent them in other, nonrelated ways. I would cuss out drivers on the way home from the hospital, or I would snap at my mom.

Later, I learned that I had been disassociating my feelings. It was as though someone stepped on my foot, and I would yell, "Ouch!" two weeks later. My compliant attitude had been a survival tool, one that was hurting me. By not expressing my true feelings, I was telling myself that my physical or emotional instincts were incorrect and should not be trusted. I consequently had a hard time expressing how I really felt.

To deal with the problem, I learned that when an emotion came up, I had to consciously ask myself, "How do you feel, Lori?" and then I had to acknowledge it immediately. "No more untimely ouches!" became my motto.

This is my challenge to you. Address your hurts as they arise. If you have been recently diagnosed with a chronic illness or are dealing with one in a long list of diagnoses, it is critical that you identify your feelings so you can cope with them.

Research has shown most people go through similar emotional stages when they are met with severe loss, such as the death of a loved one or the diagnosis of a severe illness.[1] Through my many diagnoses, I've noticed that I first go through a shock phase, then I slip

into denial. These feelings are followed by anger and fear, grief, and sometimes depression. Only after I've passed through the gamut am I able to reach the final stage—acceptance, where I find a way to live with the diagnosis, pick up and move on.

This book will talk mostly about picking up and moving on, but before we get into strategies for living with chronic illness, we have to sort through the difficult emotions that can be brought on by the diagnosis itself.

Life appears to me too short to be spent in nursing animosity or registering wrongs.

—Charlotte Brontë

Shock: This Can't Be Happening

Some of you may have struggled with unexplained symptoms before learning what ails you. This often happens to people who have less-understood diseases for which there is no test, such as chronic fatigue syndrome. For you, a diagnosis can be a welcome relief. It carries the promise of treatment and potential recovery.

Others, however, such as those with HIV or cancer, may have few noticeable symptoms before being diagnosed. In these cases, the news can result in life-halting shock.

Lance Armstrong, champion cyclist and winner of the Tour de France, recalls his feelings after learning he had testicular cancer in his biography *It's Not About the Bike: My Journey Back to Life.* After an initial consultation, the doctor who diagnosed Armstrong scheduled surgery for the next day. Here's what happened when Armstrong left that appointment:

> For the first time in my life, I drove slowly. I was in shock. I drifted through the streets in first gear, without even the energy to press the gas pedal. As I puttered along, I questioned everything: my world, my profession, myself. I had left the house an indestructible twenty-five-year-old, bulletproof. Cancer would change everything for me,

> I realized; it wouldn't just derail my career, it would deprive me of my entire definition of who I was.[2]

Denial: This Isn't Happening to Me

Many people find it difficult to accept they have an illness, before and after diagnosis. In Armstrong's case, denial prevented him from acting on his symptoms.

> [Cycling] is a sport of self-abuse. Everything hurts. Your back hurts, your feet hurt, your hands hurt, your neck hurts, your legs hurt, and of course, your butt hurts. So no, I didn't pay attention to the fact that I didn't feel well in 1996. When my right testicle became slightly swollen that winter, I told myself to live with it because I figured it was something I had done to myself on my bike.[3]

Some level of denial, like Armstrong's, is natural. Why would Armstrong, a world-class athlete, believe he was sick? Some denial after we hear the diagnosis is also understandable. It can be protective, acting as a buffer between ourselves and a harsh truth we are not yet prepared to face.

If the denial goes on, however, it can be harmful. The longer you refuse to face the truth, the longer it will take to work around the losses and map out a new future. If denial delays necessary treatment, it can be disastrous. Denial will not make the illness disappear or the raw feelings go away.

Matthew Dubiner, a retired teacher who taught science for thirty-five years, was diagnosed with a form of dementia after several seizures. He describes his feelings after hearing the news of his illness:

> Have I been given a diagnosis? Yes! Do I dispute my doctor's diagnosis? Yes! When I was told, I was filled with a fierce anger and an agitation that could not be calmed. Why me? This is not fair! This left me emotionally splin-

> tered. My reaction, in the face of all the evidence, was total denial. By employing an elaborate set of rationales, I was able to deflect reality. Despite my protestation that I was as capable as ever, those around me, especially my wife, saw more than I did, or maybe, more apropos, saw less of me.

Denial isn't always so obvious. A chronic illness is just that—chronic. The "chronicity" of the disease is a breeding ground for denial because of the way it slowly changes your life and behavior patterns. An example is my arthritis. Renal disease causes bone loss, which contributes to arthritis. It has been part of my life much longer than I dared to recognize.

When the symptoms first started, I made excuses for no longer playing sports. "I'm too busy," or "I'm too tired," I'd tell my friends, rather than admit quick movements were just too painful. I agonized over the cold weather arriving because, "I don't like the cold," not because my joints ached. I gave up my high-heel shoes for flats because, "Flats are more practical," not because the heels shot spikes through my legs with each step.

I did not want to believe I had another problem related to my kidney disease. Had I addressed the arthritis head on, I may have ended up in better shape today. For one, I know now I could have continued to exercise (under the supervision of a trained specialist) despite the pain. By slowing down, I may actually have made the problem worse.[4]

As you can see from my situation, the first step to living with an illness is to acknowledge you have one. By denying you are ill, you could be giving up valuable time for medical treatment, as well as physical, psychological, and spiritual adjustment. Don't take the gamble!

Anger: Yes, You Got a Raw Deal!

Anger is an inevitable part of the unsavory package when you're diagnosed with a chronic illness. There's no way around it. You got a raw deal! You have sustained a devastating loss of health, which must be acknowledged, felt, and grieved. The tricky thing about anger is it will not go away if you ignore it. Anger, left unaddressed, can negatively affect you and your relationships. My friend Maria Hsieh recalls how she discovered she was deeply angry over her diagnosis with renal failure:

> I was shopping at JCPenney. A clerk almost ran into me while I was walking down an aisle looking for a pair of sunglasses. I did not even realize how angry I was. Even though I knew it was an accident, she was in the wrong place at the wrong time and became the prime target for my anger. I just lost it, saying, 'You better watch it,' with a look that would kill, something totally out of my character. She quickly moved and got out of my way. After this incident I realized how the anger was bottling up inside of me. Inappropriate comments were a way of releasing the anger. My anger was projecting on other people and pushing them away. This was the first time my anger surfaced noticeably, and I could see if I didn't address the feeling, it would certainly take over my life and alienate my friends and family.

We all have something to be really angry about it. It's appropriate to let out those feelings, but it's equally important to be mindful of how you do it.

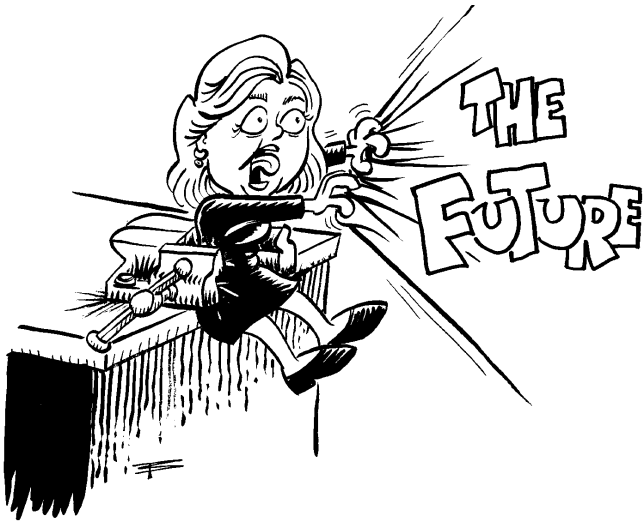
If your anger persists, I suggest you be clear with your friends and family: "I'm not mad at you; I'm mad at the world. This all feels so unfair." By showing your loved ones your vulnerability, rather than growling at them, you'll create a safe place to talk about your feelings. Such an approach is more likely to lead to the kind

of reception you need: one of listening and understanding, not frustration.

Pinpoint the Cause of Your Anger

It is also helpful to get to the root of the anger, then work it out. I was furious when my physician recently broke the news that I would likely need a hysterectomy! When I looked closely at the situation I realized, yes, I'm angry that I may never give birth to a child. What got me really upset, however, is that I've lost the freedom to make the choice. By homing in on the reason for my anger, I began to conquer it: I may have to give up the choice to have a child, but I am not giving up the choice to live a happy life.

I focused on reaffirming my life by setting my body in motion. I went for a walk. I took a trip to the local ice rink and watched the kids slide and fall. I soaked in the sensation of the cool air and upbeat music. It reminded me to enjoy what I have right now—and let go of the things I can't have. I got informed. I spoke at length with my gynecologist, Dr. Josephine Hall. She told me I have more choices than I think. For one, she said, I can



LORI'S TOOLBOX
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PEN AND PAPER: *Write a List of What You CAN Do*

Throughout this book, you'll find several references to what I call Lori's Toolbox. This is a metaphorical kit filled with useful devices to help you push past barriers or slog through unshakable funks. The first, and possibly the most indispensable, instruments in your box are pen and paper. I'm a big believer in writing things down, and you'll find several exercises where I encourage you to jot your thoughts on paper. Doing this has a magical way of making ideas realities, keeping us focused on goals, and making us realize how far we've come.

With a chronic illness, it's so easy to concentrate on the negatives. With the following exercise, I'd like you to recognize the things you CAN do, despite your loss.

find a surrogate mother. This gave me hope. I don't know if I'll take this route, but it is uplifting to know I have options.

There are many books on anger and how to get through the hard times, including *The Anger Workbook*.[5] If we carry anger inside of us, it can slowly eat our souls away. Or, as Ralph Waldo Emerson put it, "For every minute you remain angry, you give up sixty seconds of peace of mind."

Fear: Don't Get Paralyzed by the What-Ifs

Fear is a powerful emotion, one that can leave us doe-in-the-headlights panicked. When Franklin Roosevelt said to Depression-weary Americans in his 1933 inaugural speech, "The only thing we have to fear is fear itself," he was talking about this kind of paralysis. He was urging Americans to get on with their lives, to

Here are some ideas to help you get started.

Can You Read?—Perhaps you could learn a new language, join a book club, or increase your formal education through correspondence courses.

Can You Write?—Compose a poem, send a note to someone in need of a good word, or make a new friend via e-mail.

Can You Work with Your Hands?—How about woodworking, painting, or sculpting?

If all you have energy for today is talking on the phone, write that down and count it as a victory—and in the meantime, take the opportunity to bless someone's life with encouragement, support, and a listening ear. As you are reminded of more things you can do, add them to the list, and take daily encouragement that you now have written proof that life is far from over.

muster up a little "irrational exuberance" so the economy would get moving again. I think his famous words would have been more accurate if they read: "The only thing we have to fear is fear itself—and an unskilled IV nurse."

When you are diagnosed with a chronic illness, it's easy to become mentally stuck by the terrifying what-ifs. "What if I can't work?", "What if I end up in the hospital?", "What if I lose the ability to walk?"

It helps to get educated about your illness and to create a game plan should your worst-case scenario become a reality.

By visualizing the worst thing that could happen and seeing yourself continuing to create value in your life, you take the power away from the fear. I used this strategy with my knees. I kept thinking, "What if my knees go? I just won't want to live!" The more I fretted, the

more trouble they gave me. The mental gymnastics were out of control, and I decided it would be healthier to take action, rather than sit around and worry.

I did everything I could to keep my knees in the best possible shape. I determined that if, despite these efforts, my knees were still going to give out, then "Damn the torpedoes!" I would just do more with my mind and my hands. Guess what happened after I stopped dwelling on my knees? They felt better! No, my knees are not perfect, and they still give me pain. I just don't give them the power to wreck my day or my plans for the future.

Franklin's wife, Eleanor Roosevelt, said this about fear: "You gain strength, courage, and confidence by every experience in which you really stop to look fear in the face. You are able to say to yourself, 'I have lived through this horror. I can take the next thing that comes along.' You must do the thing you think you cannot do."

Grief: It's Okay to Be Sad

Believe it or not, I started to learn to grieve in my early twenties when a teacher in a singing class asked me to

IT ISN'T YOU, IT'S THE MEDS

As you sort through your postdiagnosis feelings, be aware of how your medications may be affecting you. Many people with chronic illness take a laundry list of drugs that can intensify feelings of anger, frustration, agitation, and depression.

I know firsthand what a common anti-inflammatory steroid can do to your mind. While taking it, I felt as if I were on an emotional roller coaster with no way to get off.

One day I would be sky-high and the next day I felt as if the world were coming to an end. I would cry over the silliest of things, knowing they were silly, but I couldn't stop myself. Daily tasks seemed overly complicated, and the simplest of chores agitated me.

The only thing that gave me comfort was confiding in a fellow patient. She said to me, "Lori, don't worry. It isn't you, it's the meds."

Read the side effects of medications before taking them. If you feel the treatment is causing a problem, you should speak to your doctor about finding a solution.

sing loud enough for her to hear. Despite her persistence, all I could manage was a whisper. Finally, she said, "Lori, you're not used to being heard, are you?" Her words released a wellspring of sadness in me, and I broke down and cried in front of the class.

I couldn't stop. I cried so hard I could barely breathe; something I had never experienced before. For the first time, I acknowledged that life had treated me unfairly and that it hurt, terribly. The painful episode marked a turning point. I learned I had to let out my sadness—or else it would overtake me.

Grieving is one of the most important steps in accepting your losses and moving on. The feelings build up and they have to be released, like a valve in a dam.

Throw Yourself a Pity Party

On a recent night, as I tried to go to sleep, all I could think about was how angry I was. My body ached, and I was tired. Why do I have to have a hysterectomy? Why do my knees ache? I exercise, I watch what I eat, but still the pain is there. What choices do I have?

I felt out of control, my blood was boiling inside. The physical and emotional pain of my chronic illness—and yet another distressing diagnosis—were slowly creeping in and robbing me of basic enjoyments in life.

My husband asked me, "Are you all right?" Tears were rolling down my cheeks.

"I worry about walking long distances," I told him. "Will my knees give out? I can't play tag with my niece and nephew anymore. It hurts to sit on the floor with them. And now I can't even make the choice of whether we will have children. I feel so inadequate. Right now all I can focus on is what I do not have."

This is called a Pity Party, and I needed it, badly. Pity Parties are okay if they do not last very long and you invite loved ones, like my caring husband Dean.

The world is full of suffering, it is true, but full, also, of the overcoming of it.

—Helen Keller

By the end of our conversation I had a trash can full of Kleenex. Once again my anger turned into sadness, then slowly into acceptance. I allowed myself to grieve my losses, again. No matter how many negative diagnoses I hear, I know I'll have to grieve each one.

Depression: If You Need Help, Get It

While grief can help us move on from difficult losses, depression can keep us stuck there. Mandy Gordon became depressed after acknowledging her chronic fatigue syndrome was not going to go away. For years

she had sought second opinions and went from doctor's office to doctor's office in search of someone who would "cure her." When she finally accepted she would not get better, the despair set in. "I got very depressed. I spent lots of time in tears. I was grieving for the person I was. Things used to be very easy," she recalls. "Things that I would fit into a day's work, like shopping or getting my hair cut, are now very hard. I felt very sad and hopeless."

Gordon worked through her depression, though she still occasionally struggles. Today, she is in the process of configuring her old life to the one that once was. "I just have to plan my days very carefully. I have to make sure I give myself a little target, something to accomplish each day. And however awful it seems having to get out of bed in the morning, I do. I know from past experience that if you do get up, get dressed, and get washed, the day looks a little bit brighter."

Symptoms of Depression

Research has shown that people with chronic illness have higher rates of depression. Some sources estimate the condition is twice as prevalent with the chronically ill as with the physically healthy,[6] and Lee Shirey, author of "Depression: A Treatable Disease," estimates 25 to 33 percent of people with chronic disease also suffer depression.[7]

The prevalence of depression is not a reason for you or your doctors to treat depression as "normal" and leave it unaddressed. In an article on depression and people with chronic conditions, depression specialist Dr. Arthur Rifkin writes:

> I believe that the most common misconception preventing correct diagnosis [of depression among the chronically ill] is that depression in such a situation is understandable and does not represent a treatable mental disorder. This notion

> is shared by patients and physicians alike. Disentangling normal feelings from symptoms of a mental disorder requires careful attention to details of symptoms, their longitudinal development, and historical details ... [Depression] should not be dismissed because it is 'understandable' in particular situations, but rather, it should be differentiated from overlapping symptoms of the physical disorder and treated.[8]

So how can you tell if you are reasonably blue because of this life-shaking news or if you are mired in a full-blown clinical depression? Talk to your doctor; he is trained to recognize the signs. There are many options these days for people with depression, and your doctor will be able to refer you to the proper resources.

In the meantime, be on the lookout for these symptoms, several of which would occur every day over an extended period of time:

- A depressed mood
- A marked diminished interest or pleasure in taking part in any activities
- Insomnia or hypersomnia
- Psycho-motor agitation or retardation
- Fatigue or loss of energy
- Feelings of worthlessness or excessive or inappropriate guilt
- Diminished ability to think or concentrate or indecisiveness
- Significant weight loss or weight gain when not dieting
- Recurrent thoughts of death or suicide[9]

Since some of these symptoms, such as fatigue and weight fluctuations, may be caused by the illness itself, depression can be difficult to discern.[10]

Another tricky point is that depression may advance as your condition does. "Depression is one of the most common—and potentially dangerous—complications of every chronic condition because it often worsens with the condition," Shirey writes.[11] The key is to be aware; check in with yourself and, most importantly, get help if you need it.

Destiny is not a matter of chance, it is a matter of choice; it is not a thing to be waited for, it is a thing to be achieved.

—William Jennings Bryan

Seeking Aid for Depression

Loved ones, support networks, professional counselors, and, for some, medication are ways to get through the depression. After his diagnosis with dementia, Matthew Dubiner knew his depression was harming him and his relationships. He turned to his family and an Alzheimer's support network for help.

> Each of us rides the waves of happiness and depression, and I had plummeted to the depths at the trough of despair. I was losing me! At the same time, my anger and denial were drowning everyone who cared about me. These negatives carried over into every aspect of my family's daily lives. ... This was two years ago. Today, though a great deal of anger remains lodged within me, I am filled with a tremendous sense of gratitude for my wife, my children, and for the Long Island Alzheimer's Foundation. These horrific feelings have undergone a small yet meaningful metamorphosis. By being involved and active in understanding my situation, I have begun to channel my energies in a manner that is positive rather than one which saw only destruction as its end product.

Like Dubiner, when I was close to bottoming out, I found much-needed support through an organized group. In my case, it was Al-Anon, a support program designed for friends and loved ones of alcoholics. This lively and compassionate organization not only helped me understand my family dynamics, it also

helped me navigate my journey with a chronic illness. Everyone's solution will be unique. Find the one that works for you.

Acceptance: The Key to Getting on with Living

Acceptance of a chronic illness takes time. It is important to identify and experience the different emotional stages that come along with diagnoses before reaching acceptance. There are no short cuts.

Also helpful is realizing there is no shame in having a chronic illness—that it isn't anyone's fault. I've come to understand that life isn't fair, and if I try to keep score and compare myself to others, I will surely lose.

The bottom line is we can accept that we have a chronic illness and make the best life we possibly can, or we can shrivel up with our anger. I choose life.

WHAT'S NEXT?

Okay, I'm Ready to Move Forward—But How?

Still, even after you've faced the feelings surrounding your diagnosis, and you are ready to "choose life," it is often hard to know where to begin. How do you care for your children, go to work, sustain your relationships—all the things you used to do? Such matters, things you may have "turned off" as you coped with the initial emotions of diagnosis, can suddenly press in at you from all angles.

My advice: Tackle one issue at a time. Foremost is your *health*. Get informed about your illness. Take control of your medical care. Listen to your feelings, listen to your body. When you tune in to yourself, you build up a backlog of strength that you'll be able to tap when you are ready to tackle the rest of life's issues.

Adjusting to chronic illness takes time, but you will soon begin to see how to regain a full life. In the following pages, I will describe how I have navigated my

way through the hills and valleys of illness. With this guide—and plenty of effort, awareness, and spirit—I'm confident you will make your way, too.