TURNING SICKNESS INTO STRENGTH

How to Take Charge of Your Health for a Happier Life

By: Emily Levy
Lyme Warrior. Professional Patient. Award Winning Startup Founder.
My name is Emily Levy, and I am the CEO and co-founder of Mighty Well. I have chronic neurological Lyme disease and coinfections (specifically Babesia, Bartonella, and Ehrlichia), Postural Orthostatic Tachycardia Syndrome (POTS), and Secondary Chronic Inflammatory Demyelinating Polyneuropathy (CIDP). I was undiagnosed with Lyme disease for 7 years, and it wasn’t until after my freshman year at college when I finally found out what was making me so sick.

When I had my first Peripherally Inserted Central Catheter (PICC) line put in for long term IV treatment, I was told by my home care nurse to protect it by wearing a cutoff sock on my arm. I was shocked! “I'm sorry... what? A sock? On my arm? In public? Like... on dates? A SOCK?!”

And I wondered: **How was this ever going to fit into my lifestyle?**

**Mighty Well Was Born**

My personal mission in life directly tied in with the mission of Mighty Well: to help patients and their caregivers turn sickness into strength. Together with the Mighty Well team, I am leading the global charge that changes the perception of patients from victims to fighters.
About this Book

When I founded Mighty Well, people started asking me how I've learned to deal with my health setbacks while at the same time building a successful startup, excelling in college, and having a love life.

It was really hard for a long time. The truth is, I still have days where I struggle, but even on the worst days, I remind myself to live Mighty Well. That's why I want to share all the tips and tricks I've learned with you—from life hacks I've developed to helpful resources that can help you manage your condition.

I've been where you are today. Hopefully, by sharing what I've learned, it will be much easier for you.

“The key is focusing on what you can do and not on the things you can’t do.”

- Emily Levy
CEO and Co-Founder of Mighty Well
CHAPTER 1: 
Coping with Your New Condition

You will experience a mix of emotions as you try to cope with your new condition. You will experience shock, guilt, and anger. Later, as I was trying to better understand my condition, I realized how my situation is similar with people who have experienced a great loss. Psychiatrists believe that there are seven stages of grief and I believe this is a great place to start towards living Mighty Well.
Shock and Denial

To protect yourself from being overwhelmed and experiencing the unbelievable pain with the big loss in your life (your health!), you undergo shock and denial. This stage may last for weeks or even months for some people.

When I was diagnosed, I remember leaving my appointment in tears. I wasn’t sure if I was crying because I finally had an answer after all of these years, or was it because I knew that I had a long road ahead of me towards recovery.

When I got back to school, I was in denial that my life would change quite drastically. I still tried to do too many things: babysit, sit on the executive board of my school’s Hillel, go out on Thursday nights with my Kappa Kappa Gamma sisters. When I quickly realized that my body couldn’t keep up, I quipped that “I could still do it all.” My body told me otherwise. I slept through my classes and failed to keep up with my previous commitments.

Pain and Guilt

Eventually, the shock wears off. You slowly acknowledge what truly happened and the pain starts to kick in. While your first instinct is to avoid the pain, it’s very important not to run away from it. Instead, you must experience it fully.

In my case, the person who felt the most guilt was my mom. She had been trying to find answers for me for years, taking me to all of the best doctors and specialists, yet still not finding the answer.

With Lyme disease, the longer that you are undiagnosed, the harder it is to treat because of the devastation that it can have on your organs, nervous system, and brain.

My mom felt guilty that she didn’t figure out what was wrong with me sooner, especially because so many people in my community have been faced with tick borne illness, and my younger brother had already been in treatment before me.
Then came my own guilt. I felt guilty that my mom felt all the guilt! It was a vicious cycle that quickly lead to anger.

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**Anger and Bargaining**

There are times that the pain turns into anger. You may lash out. You may blame others for the loss. You may keep asking yourself: 
"Why me?"

For Lyme patients, there is also what is called “Lyme Rage.” This term is often associated with unexplained irritability and fits of rage and are quite common to Lyme patients. While there are many theories as to what exactly causes these fits of rage (like the Lyme bacteria itself), the bottom line is that it can pretty much ruin your mood and in worst cases your relationships with other people. I am sure you can envision what that looked like in my case!

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**Depression, Reflection, Loneliness**

While this stage is still very painful and uncomfortable, you’re showing progress. This is the time where you will reflect on the loss you’ve experienced. Reflection is a good thing, as it allows you to examine where you are now and where you might want to go next.

I lost quite a few friends during the time I was diagnosed and undergoing treatment. Luckily, I tried my best to focus and reflect on what I had instead of what I lost. I am thankful that I have a boyfriend (and now fiancé!) and a best friend who not only understood my condition, but also shared my vision for the company we founded together. Yes, it was very lonely to lose some friends, but the important thing was with the people who mattered most to me and all of the new amazing people who came into my life because of getting sick.

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**The Upward Turn**

As you continue to live your life and adjust to the loss, you will feel more calm. Depression and loneliness slowly diminishes. It’s as if the dark clouds are starting to clear, giving way to a bit of sunshine.

I started seeing an upward turn when I founded Mighty Well. I started to see the light at the end of the tunnel—or at least the light towards reclaiming my life. It was that upward turn of acceptance that got me thinking that:

I am more than just my diagnosis. I am many things, and my condition is a piece of the puzzle that makes me who I am.
Reconstruction and Working Through

In this stage, you feel like yourself more and more. Your mind starts to clear, and you’re more functional. Plus, you’re more practical and you start to find ways to solve problems associated with the loss.

This stage was quite unexpected for me, as I went beyond myself. I didn’t only find ways to make my life easy with my new condition. I had the desire to solve problems for other people. I realized that I’m not the only one who’s experiencing this kind of pain.

Acceptance and Hope

It’s been a long journey to this stage, but it’s finally here. You’ve completely accepted your reality. However, acceptance doesn’t translate to happiness. But the good news is that you start to become hopeful again. You can plan for the future and get excited about a few things.

I started to accept that maybe I can’t do everything that other 24 year olds are doing: going out to bars on a Friday night, signing up for the latest Spartan Race, or taking that Zumba class.

Instead of looking at all of the things that I can’t do, I started thinking of all of the things that I CAN do:

- I can go to dinner and a movie with friends.
- I can go for a drive to the beach to watch the waves roll in.
- I can meet up with friends for coffee.

I can. I will. And I do!
Understanding the Seven Stages of Grief and applying it to my own experience not only gave me hope, it also gave me some kind of structure—something solid to hold on to.

Have you recently been diagnosed? I hope that it will give you some sense of structure as well. If you’ve been diagnosed for a long time now, where do you think you are in the seven stages? Regardless of which stage you are, know that it will get better.

Remember that there is also no strict progression from one stage to another. You might experience the first three stages all at once and each stage may last days, weeks, or months. The most important thing to remember is to focus on your own pace.
4 TIPS To Cope with Your New Condition

Coping with your new condition is made up of a maze of emotions. It can be messy. You’ll feel lost most of the time. Let me share a few tips, based on my past experience, that hopefully can make it easier and much better for you.

Create realistic expectations.

Accepting that it’s not temporary was huge for me. When I first relapsed, I was like: "Oh in four months I’ll be better." Once I accepted that it may take time, it was a lot easier to handle everything thrown at me.

I’m still hopeful and optimistic that I’ll get to where I’d like to be eventually, but not setting everything to a timeline is so much easier. Those unrealistic timelines leave us feeling like we failed in some way, when that is NOT the case!

Love yourself truly.

It was a long journey to learn how to be kind to myself. I had to understand that I have inherent value, and that my value was not solely tied to productivity and earning money. That’s when I had to change my inner dialogue completely.

Shift your mindset.

Changes in your life—whether big or small—always starts with how you perceive things.

When you have an illness, it’s so easy to focus all your attention on the negative aspects. However, I’ve learned how to focus more on my wellness rather than my illness. Instead of asking what should I do about my illness, I ask: How do I support my wellness? You can see how this small mindset shift creates a huge difference. It’s very empowering!

Sharing is caring.

Don’t be afraid to open up to your inner circle. I know this can be hard and not everyone will be understanding. Start slow and say how you are feeling both emotionally and physically. If you can, show them a YouTube video or documentary examples of other people who are going through the same thing. That way they don’t think it’s just all in your head. If they are your true friends, then they will be there for you through thick and thin.

If you aren’t ready to go to your inner circle yet, start opening up on social media. Try making a health related private Instagram account or join groups on Facebook that are disease- or condition-specific. I think you’ll find that there are more people out there like you than you thought!

Pro Tip: Join our private Friends in the Fight Facebook page for uplifting insights and experience from our community.
Pre-pack your food. Be specific.

When you have the energy, do healthy meal prep and put in the fridge or freezer. Some days you won’t feel well enough to cook for yourself and eating out gets expensive. Try to find a meal plan that is specific to your medical condition.

For me, I have focused on being as plant based as possible and cutting out gluten, alcohol, and switching to stevia based products whenever possible. I am trying to reduce the inflammation in my body and heal my gut from years on medication.

Do what works for your body and don’t be afraid to try new foods! Every Sunday night, I spend about two hours cooking for myself and try to make 3-4 different meal types, so I don’t get bored of the same thing. I put my meals into individually sealed containers, and try to aim for 6-8 meals to get me through the week.

Now, that you have taken care of your emotional well being. It’s time to get practical! Yes, your life is a little bit more challenging than it once was. But with smart planning and applying a few life hacks in your everyday life, you’ll feel less overwhelmed and you can focus on what matters most.
My go-to right now is one-pot meals filled with quinoa, garbanzo beans, and lots of green leafy veggies. This fills me up, and I know I am getting the protein I need.

If you can’t cook right now, ask a friend or loved one to help make a few meals for you or sign up for a meal deliveries.

**Be packed and prepared.**

While the food is cooking, I spend an hour on Sunday prepping my medication for the week. I organize it into days of the week so that I can grab and go first thing in the morning. It is one less thing to fuss over.

When my new medication gets delivered, I also do the same. I make daily packs of all of the medical supplies that I will need, so it is one less thing to think about during my crazy week of meetings, photo shoots, doctors appointments, and trying to sneak in naps.

I have a made up mini travel bag packed for when I leave the house. It’s filled with my medical supplies and anything I might need while I’m on the go. This allows me to carry my pill container, most of my herbal tinctures, a snack, tea, extra medical supplies, inhaler and other things like stevia and Alka Seltzer Gold all in one place!

Try to find one that can also hold a freezer pack insert if in case you have a medication that needs to be kept cold. The way I organized my medical supplies and my things actually inspired our team to create our upcoming products: the Mighty Med Organizer and Mighty Pack. The Mighty Med Organizer makes it easy for patients to carry diabetic supplies. The hard exterior shell protects and disguises the goods inside.

The Mighty Pack, on the other hand, has insulated compartments to keep food or medication cold, converts from backpack to tote, fits over a wheelchair, easy to clean separate compartments to keep tech, medical supplies, and personal objects separate.

Preparing your things around your daily, weekly, and monthly routines makes a huge difference. It might take some time before you can find the right combination, so just keep on experimenting.

**Get organized with your files.**

Make a binder with important tests and reports. Then every time you see a new doctor, specialist, or if you wind up in the hospital, you can easily give them your medical records to help save money and time.

Keep a consolidated list of your symptoms and their severity, and add to it as time goes by. I update mine by the week or month, and color code it. Your doctors will love you, as they can easily and quickly see what’s important and what’s changing.

**Get inspired.**

Find an inspirational podcast or book to read during your tough times. My current go to is Girl Boss Radio on Spotify because it reminds me to be a strong and confident woman.

If you feel like you are missing out on school or find yourself wanting to take advantage of all your (not so) free time in bed, I also love Freakonomics Radio on Spotify because I feel like I am learning something and I don’t have to worry about getting migraines from staring at a Netflix screen.

Try to explore different podcasts or books that interests you to keep your mind stimulated at a level that you can handle!
Go easy on yourself.

When you need to scream, go for a drive and sing your favorite throwback at the top of your lungs. When I feel increasingly frustrated with my body, I drive to my favorite beach, which is about a 30-minute drive from my mom’s house. I sing at the top of my lungs and then calm down by watching the waves roll in. Usually sippin’ an iced latte made with coconut milk ;)

Find your routine and what calms you down. Maybe it’s a hike or a yoga class. There is something for everyone, but you have to be willing to find out what that is.

Build habits to make you happy.

Pick something to treat yourself with routinely. I get hair done at Drybar regularly because it’s a nice pick-me-up, and honestly, sometimes it takes too much energy out of me to wash and style my own hair. I feel like you need to treat yourself because it’s so hard being sick. Having even a small little thing to look forward to helps so much. What makes you excited? Try to incorporate it in your weekly routine, and see how it makes you feel.

Listen to your body.

If your body is telling you that you need a nap, take one. There is no shame in needing a break, and you will hopefully wake up feeling more refreshed and ready to tackle the world. Fortunately for me, I am down from needing a three-hour nap every day, to an hour-and-a-half nap once or twice a week. As your treatment progresses, remember that small victories matter!
CHAPTER 3: Dating with Chronic Illness

Aaah, dating. Dating is hard as it is. But it’s ten times harder when you have an illness. I have been fortunate enough to be with my boyfriend (and now fiancé!), Yousef, for five years, who just happens to be one of my Mighty Well co-founders. We started dating before we knew that I had Lyme and coinfections, and I am beyond thankful that he has stayed by my side—even when I smelled like garlic for six months thanks to an all natural Chinese herbal therapy I was doing!

There’s really no hard and fast rule as to when you should let him or her know. The best thing to do is to trust your instinct. I found out about my diagnosis the summer before starting my sophomore year. Yousef and I had taken a break for the summer, and on the first day back at Babson we went out for ice cream. I sat him down and told him about my recent diagnosis. I told him that he could either be with me while I went through treatment, or he could move on (and I would totally understand).

Thankfully, he decided that I was worth the hundreds of doctors appointments, days that I couldn’t do ‘normal’ college activities, get out of bed, freak accidents with my PICC line, and countless of laughs while watching Parks and Rec on the days I couldn’t get out of bed.

My wish for you is to find your Yousef. Don’t settle.

Lead with openness.

Be open from the beginning about your illness. If you are looking for a serious relationship, then this person will have to accept your health conditions. However, if it’s just the first few dates, it’s okay to not discuss your medical device if you’re not comfortable.

Disclose your diet.

If you have dietary restrictions, let the other person know early on because you don’t want to end up at a restaurant or bar where you can’t eat anything and then the other person feels bad that you can’t participate in the fun.
I remember one time Yousef brought me to a new ramen bar, and they didn’t have gluten free noodles. We only discovered this after waiting an hour for a seat! He felt so bad that there was nothing that I could eat.

Always plan ahead and check the menu! It will be worth finding a place that you all can enjoy! My go-tos are usually Mexican or Asian because I know they will have gluten free options that can be made according to my dietary needs.

**Don’t worry. It’s easy to fit in.**

If you can’t drink, there is no shame in that. So many times people have given me a hard time for not being able to drink alcohol when I have gone on dates and parties. It is frustrating in the moment, but then I realize that those people are so not worth my precious energy.

Sometimes it is just not worth explaining to people what you have going on health wise. I try to order sparkling water in a wine glass with lime, or a club soda with cranberry to disguise it as a vodka soda with cranberry. Other times, I will bring a cool iced tea can that I find at Whole Foods and try to pass it off as a microbrew. My usual go to is Guayaki Yerba Mate because of the cool can and yummy taste + health benefits! Just be sure to pick an option with low sugar!

**Involve them every step of the way.**

When things start to get serious, have the person you're dating come to a doctor's appointment. I think only then they will really start to see the severity of your health condition. You can see how they react and then decide if they can handle your lifestyle.

**Believe in love and have fun.**

Lastly, have some fun! *Your diagnosis condition or device isn’t the only thing that defines you; it is just a small part of you.* Find something that you love to do together! Yousef and I love comedy shows, live music, eating out, traveling, and long drives to visit our families. Sometimes staying home to watch Netflix and takeout is simply the best! Find someone who will love you, accept you, and be there for you through thick and thin. I promise, they’re out there!

Fun Fact: Emily and Mighty Well Co-Founder, Yousef, are both business and life partners.
When I get this question, I strive for concise honesty. If I am feeling okay, I say so. I find that if I'm having a bad day, being honest always helps. That way if I take a quiet moment to rest or relax they understand and don't think it is related to something else.

CHAPTER 4:
Common Questions People Ask and How to Handle Them

Thanks to our Friends in the Fight Facebook Group for Posting Your Top Q’s and A’s!

Q: “How do you feel?”  
A: “I’m on the mend”  
I try to focus on all of the positive things going on in my life. I try not to bore them with all of the bad days. Most of the time, people don’t actually want to hear how you are doing. However, if they genuinely offer some help, let them know how they can support you. Maybe it’s helping you with your kids one day a week or bringing you a meal.

Q: “You look great; you must be feeling well.”  
A: “I’m taking good care of myself.”  
Sometimes people lead with this statement, which isn’t actually a question. I no longer feel the need to discuss the particulars with people who don’t get it. I use this reply to be polite and quickly move onto the next topic.

Q: “Are you better yet?”  
A: “I’m hanging in there.”  
If they sound actually interested, I might explain a little more but normally I just leave it alone. I rarely get the response I’m looking for so it’s not worth the energy most of the time.

Q: “How are you feeling?”  
A: “Today’s a rough day but I am hanging in there.”  
When I get this question, I strive for concise honesty. If I am feeling okay, I say so. I find that if I'm having a bad day, being honest always helps. That way if I take a quiet moment to rest or relax they understand and don’t think it is related to something else.

Thanks to our Friends in the Fight Facebook Group for Posting Your Top Q’s and A’s!

When your friends and family are aware of your condition, it’s inevitable to get questions that you just don’t know how to answer. Should you be honest? How much should you share? Which details should you keep to yourself?

These questions that I get all the time, and while the answers here are not perfect and they always change depending on my experiences, I hope that it will be a good starting guide for you.
Would You Like to Know More?

I hope that you find this book helpful (and inspirational too)! If you want to learn more about me and what we do in Mighty Well, I invite you to:

Read Our Blog
Inspiring stories of turning sickness into strength, health related tips, and tools to live Mighty Well!

Check Out the Shop
We invite you to visit our website at mightywell.com to browse our items that you can get for yourself and for your loved ones. They are all designed with you in mind!

Join our Friends in the Fight Facebook Group

It has been a long and hard journey for me ever since I got diagnosed. But I am grateful because I would not be the person I am now if it weren’t for the challenges I’ve experienced. I’m proud that I was able to turn sickness into strength. More importantly, you discover the good people in your life. You get to connect with amazing group of people fighting the same battles. Life for me now is about the fight. But it is the good fight. The fight for good health, good people, and good life.

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