The Crohn's and Colitis Storybook: Perspectives on Living with IBD
by the Patient Advisory Council of ImproveCareNow, edited by Christian Hanson

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Introduction

If you’re reading this, chances are that you, or someone you love, has Crohn’s or Colitis. IBD is a difficult disease that comes with a lot of baggage: frequent colonoscopies, expensive treatments, and painful symptoms.

IBD doesn’t just affect the physical body though, it affects the mind too. Living with the symptoms of Crohn’s and Colitis can cause frustration and fear. Remaining silent about these struggles can cause social isolation and feelings of loneliness. For young adults living with IBD, these social effects can become particularly acute.

With something as difficult as a chronic illness, no one should feel like they are alone. I hope that through this book every child with Crohn’s or Colitis may be inspired to speak out about their illness and to build a network of love and support in their own community.

Everyone’s path with IBD is different, but that doesn’t mean we need to walk alone.

—Christian Hanson
IBD Advocate and College Graduate
Education

When I was a kid, my dad would read to me before bed. Together we went through many of the great childhood classics like *Harry Potter* and *The Chronicles of Narnia*. This love of reading, which began in my earliest years, slowly grew into a broader love of learning.

Learning, like reading, is all about being exposed to new ideas, seeing the world through other perspectives, and seeking answers to questions. It’s possible to learn through books, movies, conversations, school experiments, and teacher instruction.

But sometimes there can be obstacles to learning. When I was 10, and again when I was 16, my flare ups with Crohn’s disease made learning difficult. I was tired all the time, had to miss school, and wasn’t spending time with my friends.

Anyone who grows up with IBD has faced similar struggles. In the following excerpts you will hear about my friends with IBD who have had to miss school because of their symptoms, have been unable to complete homework due to doctors’ appointments, and
who have felt frustrated at their disease for slowing them down when they want to “go go go.”

Through these difficulties, we’ve had to stand up for ourselves. In high school, I told my teachers about my symptoms, and they were lenient with me for missed classes. Others have talked to principals or school nurses to receive support.

Flares of IBD have also taught us how valuable education can be. Education is the ability to grow, challenge yourself, and make your dreams come true. It’s possible to learn inside and outside the classroom, with friends and by yourself.

There have been times when I stopped reading. On some days it is just too difficult to focus on a book when your health seems to be falling apart around you. But there is always the desire to learn, and chances are that on the days I feel good you will find me in a classroom, listening to an educational podcast, or on the couch in my room, a good book in my lap.
Why is education important to you?

**CATALINA**

Education is incredibly important to me because I’m an absolute nerd. I love learning, and dedicating time to my education is an investment in my mind and my future. Making sure I’m well rounded and well educated is a step toward fulfilling my goals and aspirations.

**EM**

Education is a tool I am using in order to fulfill my goals. Without an education I would never be able to work as a teacher to help others learn and grow.

**MISSY**

Education is important because it allows me to develop myself and grow.

**SHAWN**

Education is important to me because I really want to better myself as a person. I refuse to let my condition hold me back or prevent me from doing anything and everything I want to do in my life.
NICKI

Education is so important to me! I think that I value my education even more now because I have had to self-advocate for myself in school. I have learned to appreciate my days in school when I feel good. I also just love learning!

JULIA

Education is important because it opens up so many more doors, especially to advocate about my illness. I really love sharing my story, and by going to school to become an Occupational Therapist, in the future I will be able to help patients of my own.

DRAKE

Education is important to me because the more educated I am, the more of an impact I can have on the IBD community. I aspire to be a doctor and practice at an ICN center to help contribute as much as possible to the IBD community.
How has IBD affected your education?

**JULIA**

I had to take a year and a half off of school because of my IBD. I have always been a dedicated student, so to know that I was put behind because of my disease, which was completely out of my control, really drained my enthusiasm. I hope I can regain my excitement for school as I get back into the swing of things.

**NATALIE**

I have had a hard time taking many classes. Somedays I feel like my body has the energy to attend class or do homework, but not both. Because of hospitalizations I am going to graduate at least two years later than normal. It’s hard not to compare myself to others, but I try to be proud of myself.

**CATALINA**

IBD has greatly affected my education. It’s often difficult to balance my homework and taking care of my disease. I often have to go to the bathroom in the middle of class, or miss class entirely given my symptoms. I also have to sleep more than most of my friends, so I don’t have as much time to do homework or study after class.
MISSY

During my freshman year of college I was forced to drop out of my classes because I was too sick. I ended up in a flare that would persist for two years and eventually result in the removal of my colon. I am graduating a year late because of this.

EM

IBD has affected my education in many ways throughout the years. In high school, I was constantly coming in late, or not at all, due to my symptoms. In college, IBD has made it hard for me to stay on track with my assignments, and recently I was forced to take a semester off to focus on my health.

SHAWN

Because my Ulcerative Colitis was so active at the end of high school, I had to delay going to college. When I managed to transition into college, I had to start slow with online courses.

NICKI

IBD has affected my education in a multitude of ways! I have had to miss many days of school because of it. Because of the missed school, I often have to work with teachers and professors to make up the missing work.
How are you a self-advocate in school?

BECKY

Dealing with IBD in school can be tough. The best way to advocate for yourself is to talk to your teachers. Tell them about IBD and how they can help you (unlimited bathroom passes, etc.) Also, become friends with the nurse and the office workers who deal with absences. It’s good to know them as you might be seeing them a lot!

DRAKE

Be confident in telling others about having IBD. Telling someone that you have IBD, and being able to tell them about the disease, makes it so much easier to describe the accommodations you need. Also, before entering a new school, contact the person in charge of disabilities services. This allows you to have a sense of comfort knowing that someone is there to advocate for you.

MISSY

I am always prepared with a summary of my condition so I can help inform others about my condition. I also keep the disability office up to date with what is going on with my disease and if I am going to need help. I also make sure I talk to teachers right away so they know what is going on and how they can help.
I self-advocate in many aspects of my schooling. In high school, I was constantly communicating with my teachers about the status of my disease. In college, I immediately went to the disability office in order to ensure I would have the proper accommodations to help me succeed.

In college, I have learned to work with disability services to get extra time on tests, excused absences, and priority scheduling for classes. I have also learned to be more outspoken and pushy with professors about my IBD when they seem reluctant to offer me my necessary accommodations.

In high school, I didn’t want to share my condition with others. I was worried people would judge me, and I feared others my age just wouldn’t understand. During my senior year of high school, my symptoms became much more severe. I explained to my teachers that I have a condition and I cannot wait when I need to use the bathroom. I was embarrassed to say IBD or Ulcerative Colitis, so I played it off as more of a bladder problem.

I self-advocate in school by talking about my disease, and by asking for accommodations that make my days easier.
Self-Care

I’ve never met someone who doesn’t like to laugh. Laughing and smiling are known to relieve stress and increase feelings of happiness and joy. Whether it’s from a funny television show or a friend’s joke, I think we can all agree that laughing is just plain fun!

How you feel mentally is closely connected with how you feel physically. Just as laughing might make you feel more energetic, feeling stressed can lead to exhaustion. This connection is even more important for those of us with IBD, where too much stress can actually trigger a flare. This is why self-care is so important.

Self-care is all about helping your mind feel relaxed, even if your body is not. The following section shares stories about how to take care of your mental health, including through mindfulness, exercise, and socializing. A favorite activity of mine is to listen to great music like U2, Fleetwood Mac, or Halsey.

Sometimes taking care of your mental health is less about boosting your mood, and more about talking through your worries or frus-
trations with a trusted friend or family member. Many of my closest friends have benefitted from the great support of a therapist or psychologist (if you don’t know one, that’s ok, just ask your parent or your doctor).

When I was in high school, no one really talked about self-care. I felt awkward telling my friends or family that my mood was always so low. But once I finally shared what I was going through, it was like a dam had burst! Not only did I feel better, I found a lot of friends who felt the same way, they were just scared to talk about it too.

Self-care can take a lot of different forms. It can be as simple as drinking a smoothie to boost your energy, or as important as asking your doctor if you could talk to a professional about how to deal with some of the harder parts of life, like IBD. In both cases, the act of self-care is nothing to be afraid of.

Standing up for yourself doesn’t just help you, it paves the way for others. I hope that in the future we will all feel a little more comfortable talking about our struggles, because that is a world with more support, happiness, and laughter.
How do you take care of your mental health?

I keep high self-confidence inwardly and outwardly. I practice mindfulness and visit a therapist every Saturday.

The best way for me to take care of my mental health is to exercise. Running allows me to clear my mind and makes me feel in control of my disease. Another way to take care of my mental health is through talking to others about IBD. Talking to others makes me feel like I am not alone in this fight.

I put my health first, no matter what. I have tried “doing it all” with working, school, and having a social life, but sometimes that became too much stress. I have learned to balance my life responsibilities, and that is the key to health.

I make sure to tell friends or family when I feel that my mental health is declining. I visit a therapist on a weekly basis, which I find very helpful.
MISSY

I am open about my disease and how I am feeling, whether mentally or physically. I talk to people, including my mental health professional. That allows me to feel more relaxed.

CHRISTIAN

I do the things I enjoy most: listening to great music, seeing friends, and reading good books. These activities energize me and put me in a great state of mind.

CATALINA

I’ve seen therapists in the past, which has been incredibly helpful. Additionally, when I’m feeling overwhelmed or upset, I take time to read or watch a movie and distract myself from what’s going on. Taking time to hang out with my friends is also helpful and makes me feel less alone.
What are some ways you boost your energy?

**MISSY**

Although this sounds counterintuitive, I go running. Although running is hard with fatigue, afterwards I feel a boost of energy. If that is too hard, and I am really feeling bad, I will drink smoothies, snuggle up in bed, or take baths. I also boost my energy by making sure I eat food that is healthy and good for my body.

**DRAKE**

If I can force myself to exercise, even just a little bit, I feel so much better. Not only do I get physically energized from being active, I also think to myself “IBD ain’t gonna hold me back!” After conquering a good workout I feel like I can take on the world. It makes me feel like I have control over my disease.

**CATALINA**

I drink espresso! I also drive around in my car at night and listen to 80s rock.

**EM**

To boost my energy, I like to go for a walk in the park by my house. I also like watching movies and listening to music.
NATALIE

When my fatigue is bad, I rest. Even if I can’t fall asleep for a nap, I lie on my bed with a heating pad and watch Netflix. When I’m at school, I try to drink a bunch of water and grab a snack that won’t upset my stomach.

JULIA

I try and surround myself with light-hearted people who always manage to make me laugh and put a smile on my face.

NICKI

The biggest way in which I boost my energy is through exercise! I know that some people may absolutely abhor exercising, but exercising, especially running, boosts my mood so much! I feel much more relaxed after I run, and running allows me to wash away my worries for a portion of my day. I also enjoy watching funny movies with friends!
How does IBD affect your mental health?

**JULIA**

I believe that I have always had some mental health issues, but once I was diagnosed they became even more evident. IBD forced me to try and find help, and I am glad I did.

**NICKI**

I used to have depression due to steroid side effects and I still suffer from anxiety. However, I have learned to cope with my mental health over time. If you have mental health issues just remember that YOU ARE NOT ALONE!

**CATALINA**

IBD greatly affects my mental health. Having IBD, especially as a young adult, is incredibly difficult. Sometimes it can seem overwhelming and it really impacts the way I’m feeling emotionally.

**MISSY**

IBD can affect my mental health through feelings of anxiety and depression. When I am feeling sick, my mental health is out of whack. And when my mental health is out of whack, I feel bad.
I have found that if I’m not okay mentally, my physical symptoms will reflect that. IBD can be very isolating and, without talking to other patients, it can often feel as if no one understands. Constant hospital visits, medications, and diets can all be very trying.

My IBD causes me to feel many symptoms of anxiety and depression. Not only does the fact that I have a disease make me feel anxious, but I am also constantly worried about the other aspects of my life that are affected, such as my schooling and body image.
Why is self-care important?

If you don’t take care of yourself, you are not going to be able to take care of other aspects of your life, such as your schoolwork or your relationships. Self-care can help you to feel better about having IBD and lessen the physical symptoms of IBD.

Self-care allows you to feel more relaxed and confident in yourself and your IBD. Practicing self-care is important in maintaining my health and well being.

Although physicians do their job on my medical side, I as a patient have to do my part too. I have to take medications as prescribed and take mental and physical breaks as needed, otherwise all efforts are in vain.

Monitoring not only your disease, but also your mental health, can mean the difference between relapse and remission. Given the difficulty of managing IBD, it’s important to take time for yourself.
Self-care improves my self esteem, my stress levels, and my overall wellbeing. An added bonus is that lower stress levels help me avoid flares.

I believe my mental health is connected to my physical health and vice-versa. My goal is to keep both as healthy as possible.

Self-care allows you to be your best self and accomplish your dreams. Everyone needs time to slow down and restore their energy. Self-care is important, and can be fun too!
Relationships

Who was the first friend you told about your IBD? For me, it was my youth group leader when I was a junior in high school. I was diagnosed when I was ten, which means that I had lived almost six years without telling a single person about my Crohn’s!

Of course, my parents and sister knew. But I felt awkward talking to them too. It felt weird for me to mention my symptoms, or how I was feeling. It even felt weird talking to my doctors and nurses, so I kept my responses to their questions as short as possible.

When you grow up with something that makes you different, it is easy to feel isolated. It’s easy to feel like no one understands you. After a while, it’s even possible to forget what it is like to connect with friends on a deep level. It’s like standing on the edge of a pool everyone is playing in, but you have forgotten how to swim!

For me, everything changed after I told my youth group leader about my Crohn’s. That night I slept as if a weight had been lifted off
of my shoulders. That same feeling happened when I told one friend, and then another, and then another.

Out of all the people I talked to for this book, every single one was happy that they had shared their experience with a trusted friend. Of course, friends might ask awkward questions, or be confused, or not know what to say. Friends who haven’t lived with a chronic illness won’t understand how much it changes your life, or they might take their own health for granted. But true friends will also make an effort to understand and provide support, and having that weight of silence lifted off of you is a great feeling.

This section ends with a list of role models, with and without IBD. These role models can be famous athletes, artists, friends, or family. Often they are people who have faced hardship and succeeded despite challenges. And the funny thing is, even these role models need support, because life is a team sport! Don’t be afraid to find inspiration in your role models, build your circle of support, and be a role model for others.
How do you describe your IBD to friends?

An autoimmune disease where the body mistakenly attacks tissue causing inflammation in my GI tract and causing symptoms which can be different for every patient.

If I don’t have a lot of time to talk, I just say that it’s a disease where my immune system attacks my intestines. If I have longer, I’ll go into greater depth, and maybe use some visuals. I’ve used everything from chalkboards to clay models and live demonstrations.

My elevator speech about IBD usually goes something like this: IBD is an autoimmune disease affecting my intestinal tract. This means my immune system sees my intestinal track as an invader and constantly attacks it much like when you have a viral or bacterial infection. There is no cure for it currently, and it can effect every inch of the intestinal track. Some of the side effects are frequent bathroom trips, internal bleeding in the G.I. tract, and weight loss. I try to joke about having IBD to make it seem like it is a somewhat normal thing. I don’t want people to know that at times I am in pain or am suffering due to the complications of the disease.
EM

I usually mention that I have Crohn’s disease to them and then answer as many questions as they have. I really like making jokes about it because it helps me to feel more normal and it also makes the disease more approachable to my friends.

JULIA

I’d say the way I describe my IBD to each of my friends is slightly different depending on the personality and prior knowledge of my friends.

CATALINA

I tell my friends that IBD is an autoimmune disease that affects the digestive tract. With some of them I go more into the specifics, but usually that is enough.

NICKI

I initially describe IBD to my friends as a chronic disease that affects my digestive system. I know that description is not detailed, but it gets the point across. After getting to know someone better, I explain it to them in more detail, including how it affects my everyday life.
Is it easy to talk to your parents/guardians about IBD?

NATALIE

It is easy to talk to my dad because he has it. My mom has trouble understanding sometimes, but she tries hard to research everything and remain informed. Sometimes I don’t talk to my parents because I don’t want to bother them and I know they will be upset.

JULIA

I can talk to both my parents about my IBD. They are both extremely involved in my health, recovery, and medications. My mom is the one I go to first when there are issues or I need to talk. She is much more sympathetic and also she understands better. I still don’t think my dad really understands the chronic part. He doesn’t understand why after my surgeries I still have pain and fatigue. He’s a very black and white person, and that’s ok, but that does make it a lot harder to talk to him about certain things.

DRAKE

It is very hard to talk to my parents about IBD because I don’t want them to worry about me. They have already been through so much with my hospitalizations, that I don’t want them to go through anything else.
MISSY

My parents are always there for me and want what is best for me, but ever since moving to college it has been harder to discuss things like changes in medications, or why I went to the ER, because my mom feels like she can’t do anything and continues to question if I’m taking care of myself. She trusts me, and just wants the best for me, so it’s hard for her to be so far away. Sometimes I don’t tell her when I’m sick so she doesn’t worry.

SHAWN

It is sometimes easy to talk to my family about my IBD, but sometimes I’m embarrassed. IBD is not an easy topic to discuss.

EM

It’s pretty easy for me to talk to my parents about my IBD. They are so open and receptive with whatever I tell them. Even if I have to share a bathroom story with them they are not grossed out at all!

NICKI

At first, it wasn’t easy to talk with my parents about IBD because I knew that they wouldn’t understand me and would just try to lecture me about my health. I am now very comfortable talking about IBD with them, though, because I have matured and learned that they want to help me in whatever ways possible. They always have seen me as “Nicki,” not just a sick person.
Who are your role models (with or without IBD)?

**SHAWN**

My role model with IBD would have to be IBD advocate Sara Ringer. She is so strong and educated. She not only does an excellent job of advocating for patients but she also takes the steps needed to make political change too!

**NATALIE**

My dad, because he has Crohn’s and I’ve always looked up to him, even before I was diagnosed

**MISSY**

My role models are all the IBD patients who are incredibly resilient and accomplished despite all of the things they have been through.

**JULIA**

My inspirations are the people who don’t let IBD, or any chronic illness, define who they are. Sometimes I feel like this disease is all I really am, so it’s amazing to see people who accomplish incredible things and become influential for something other than their disease.
A young patient from my center is definitely my IBD inspiration. Before she was even 10 years old she faced Crohn’s disease like it was a game of hopscotch. She’s been through multiple surgeries and treatments and never complains or cries about pain. She is tougher than most Marines and I aspire to be like her everyday. She is also the kindest and most loving person, which you can see through her relationships with her parents and the way she talks about having IBD.

My biggest role models are my two older brothers. They have done so much for me and have supported me in my IBD journey since the beginning. Neither of them have IBD, so they don’t completely understand what I am going through, but they are still extremely empathetic. They have both gone through their own struggles and have inspired me by believing in me!
How have your friends responded when you first told them about your IBD?

**CATALINA**

My friends were really receptive when I told them I had IBD. It’s the kind of thing that most people don’t know how to respond to, so if I seem to have a positive outlook on it, they’ll feel much more comfortable with my disease and what it means for my life.

**EM**

Most of them responded with lots of questions and sympathy. Now they have learned as much as they can about IBD and are always looking for ways to help make my life easier!

**JULIA**

All my friends were super supportive! When I became really ill and ended up in the hospital my friends visited me and it was really comforting to have them there.

**MISSY**

When I first told my friends about IBD they were very confused, but still supportive. Most of them just wanted to learn more. There have been times though when people made fun of me or judged me for having this disease, and that was hard for me to deal with.
They rarely say anything more. No one really asks me about it, although I wish they would. Most of the time, I have to tell them how I’m doing because they don’t often ask. One of my friends googled Crohn’s Disease on Wikipedia, and that meant a lot to me, but that’s the most caring they seem to be.

My friends really didn’t have a good understanding of IBD. Sometimes they would say things that are offensive to someone who actually suffers from the condition. Over time my friends saw me go through pills, injections and infusions, and began to understand how serious my condition is. Honestly, there’s no way you can “describe” the pain and trouble of IBD.

Most people are mainly supportive, or give just “automatic responses” because they never know what to say—they don’t understand it. Some try to relate and say they have a relative with it, and you just have to smile and nod even if what they’re saying is ignorant.

I have NEVER had a negative response from telling somebody I have Crohn’s disease. Most, if not all, of my friends have wanted to know more about the disease. By being an advocate, and blunt about having Crohn’s disease, I have been able to become more confident in managing my disease.
Perspective

For the past two years I have volunteered at a hospital in Rhode Island. Each month, college-aged mentors, including myself, gather with teens who have chronic illnesses. We eat dinner together, play games, and talk in small group discussions.

In one of those small group discussions, the question came up: would you get rid of your chronic illness, if you also had to give up all the lessons you had learned from it? My first instinct was to say yes, I would give up Crohn’s. IBD is hard to live with. It’s painful, frustrating, expensive, and never-ending. It impacts every aspect of your life.

When our teens answered this question, though, I was shocked. One after one, they said “no.” They all agreed that the lessons they learned from their illness, their perspective, was worth it. As one teen said, “I would be a completely different person if I hadn’t had my chronic illness. I would lose a lot of compassion, and the friendships I made along the way.”
And she’s right: living with a chronic illness is a struggle, but with struggle comes wisdom. My friends with chronic illnesses do carry a valuable perspective on life. Many are quick to empathize with the suffering of others, they have strong values, and are among the most reliable of friends.

Of course, it is possible to gain this wisdom without living with a chronic illness and, on the other hand, IBD doesn’t always lead to more inner peace or understanding. There are times when IBD gives the gift of wisdom, but other times when it takes far too much energy, happiness, and health to ever make it feel worth it.

A few weeks later, I am still not sure whether I would give up Crohn’s and all the lessons it has taught me. But what I do know is that, through all the pain and suffering, those who live with IBD do gain a unique perspective, one that should not be taken for granted.
How has living with IBD made you a better person?

I think you learn many valid life lessons in a short amount of time with a chronic illness. It makes you “wise beyond your years.” I’ve become more empathetic, compassionate, open minded, patient, and understanding.

I think I’ve learned what is really important in life and how to pick and choose your battles. IBD has made me a much more empathetic person towards people who struggle with all kinds of things. I have also become much more outspoken about my IBD and opinions in general. This may sound super cliché, but I would not be who I am today without having IBD.

IBD has been instrumental in teaching me about perseverance and resilience. Everyone goes through something tough at some point in their lives, and learning from your struggles is instrumental in making sure you internalize your struggles in a positive way. IBD has taught me to manage an infinite number of responsibilities. The skills that IBD has taught me have been very helpful in every other part of my life.
MISSY

Living with IBD has made me a more confident person in every area of my life. Through some of my hardest times with IBD, I have learned how to be a great leader and stronger individual. I have also become a great public speaker from all of my experience talking about my disease and advocating.

SHAWN

Life with IBD has made me a better person. It’s shown me how strong I am, and taught me to appreciate the little things in life.

EM

Living with IBD has made me a more compassionate person. It has also helped me realize that I can overcome many trials and still come out a stronger person.

JULIA

I believe that there is a long list of reasons why this disease has made me a better person. I am more grateful, compassionate, and far less judgmental, just to name a few.
Which area of your life does IBD affect the most?

**JULIA**

IBD affects my whole life. It is constantly on my mind because I am pretty much always in pain. I am extremely hopeful that over time it will get better and start to affect less and less areas of my life.

**EM**

My IBD affects my day-to-day life the most. Although I am used to it, I have to deal with daily pain, monthly doctors appointments, missing school or work without much notice, and high levels of fatigue. It can be hard to have to constantly explain to people why I am this way.

**NATALIE**

My emotional and mental life, because of anxiety, depression, and social isolation. Also because the side effects from my medications affect my ability to concentrate and study.

**MISSY**

IBD mostly affects my mental health and body image. IBD has changed my body a lot, that sometimes that is hard to adjust to.
IBD affects my energy. Towards the end of my infusion cycle I become very tired, and so it's important for me to always get lots of sleep and eat healthy foods.

IBD is always on the back of my mind, so I would have to say that it affects my whole life. I just want to be consciously aware of everything I am doing so I can live a healthy happy life!

I don’t think I could choose just one area of life that IBD that affects the most. At first it felt like IBD dominated every aspect of my life. Seven years later, I don’t feel like it controls me any longer, but it does still affect me mentally and physically.
What would you tell someone newly diagnosed?

Tell your parents that it is very important to have a physician you are comfortable with and trust. Overall, just hang in there! Life with IBD is hard, but it is still a life and you must live it to the best of your ability.

YOU ARE NOT ALONE. Pretty much everyone thinks that they are alone, but you have friends and family who will support you. Connecting with others is very important. Just find one person, with or without IBD, who can listen and talk with you! Also, in the long run, you’ll learn more about yourself than you ever thought you would and be more empathetic towards others because of Crohn’s or Colitis.

IT’S GOING TO BE OKAY! It may feel incredibly overwhelming at first, but I PROMISE you that life will go on, that you will feel better, and that this is just something new to incorporate into your day-to-day. There are tons of people out there with IBD, and the community is incredibly welcoming!
Don’t be afraid to push your limits. I felt like a lot of people put me in this box and told me there was no way out. If I wouldn’t have pushed myself, I might have never known life outside of that box. My first doctor told me I would never run competitively again, yet here I am in my fourth year in a collegiate program. I’m not saying go against your doctors’ wishes or to go lift 500 pounds after surgery. But I am saying that you will never become stronger, or feel more confident in managing your disease, if you let it limit yourself. Push yourself to live as normal a life as possible, because it is possible. This isn’t the end of the world. Having IBD is something that is very manageable and people can live a very normal life with IBD. It might not be easy all the time, but adversity only makes you stronger.

I would tell them that yes, there will be some ups and downs, but there are so many amazing people and organizations that will have your back. In the end you will become a far stronger person than you were before it all.

Talking about your disease and finding a group that helps you open up is very important. Find the biggest support system that can help you through the good and bad times with IBD.
What are you thankful for?

**MISSY**
I am thankful for the friends that have my back, the doctors that work so hard for me to be healthy and doing what I want to do, and my parents that are the most supportive and loving individuals I have ever met.

**EM**
Although I wish he didn’t have it, I am very thankful that my brother also has Crohn’s disease because with him I can vent, make jokes, and talk through symptoms.

**DRAKE**
I am thankful to be in remission and to be able to attend college while being a student-athlete with little to no complications. At times I feel like I am not grateful enough for my health. But I am also thankful for the IBD community who inspires me to always keep going.

**SHAWN**
I’m so thankful my doctor removed my colon!
JULIA

I am thankful for my family, my friends, and the opportunity to still be a part of this wonderful world of ours, because there really was a point where I thought I was going to lose all that.

NICKI

I am so incredibly thankful for my amazing family and friends. They have no idea how much they have done for me. I am also so thankful for my dog because she always knows how I am feeling and snuggles with me.

CATALINA

I am incredibly thankful to currently be in remission, as well as for all of the opportunities that have been afforded to me over the course of my life. I’m thankful to have a supportive family, for my ability to go to college, as well as for my friends and the love and care they have for me.
# Meet Our Contributors!

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The Crohn’s and Colitis Storybook was written in collaboration with the Patient Advisory Council (PAC) of ImproveCareNow. The PAC is a group of young adults with Crohn’s or Colitis who advocate for the improved treatment of children and young adults with IBD. ImproveCareNow is a network of people working together and dedicated to quality improvement and patient-powered research.

To learn more or get involved, please email pac@improvecarenow.org or visit www.improvecarenow.org