

Body Image Toolkit

A resource created by members of Patient Advisory Council of ImproveCareNow. The purpose of this toolkit is to share personal experiences of body image issues from teens and young adults living with IBD. This toolkit includes stories from PAC members, in which they talk about the ways in which IBD, treatments/medication, surgeries, and comments from others have impacted how they perceive their own body.

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About the PAC

The Patient Advisory Council (PAC), is a community of young (14+) patients with Inflammatory Bowel Disease (IBD) who come together to give and receive support, ask questions, share information, and network with each other. For more information, and to join the PAC, please visit: improvecarenow.org/patients

Toolkit Disclaimer

This document was created by members of the ImproveCareNow Community. **Do not rely on the information in this document to diagnose or treat any health condition.** This information does not constitute medical advice and is not intended to be a substitute for professional medical advice, diagnosis, or treatment. Disclaimers posted at improvecarenow.org/icn_tools_disclaimer apply to this document.



Meet Toolkit Creator - Missy



Missy Neihart

- ❖ I am 24 years old.
- ❖ I am a paramedic.
- ❖ I have had ulcerative colitis since I was 11 years old, but was diagnosed with Crohn's disease at 21.
- ❖ I am currently in remission since my J-pouch surgery in 2017
- ❖ I love running, reading science journals, advocating for IBD patients, and spending time with family & friends.
- ❖ I believe that advocating for patients truly makes a difference in the lives of all IBD patients.



Meet Toolkit Creator - Rosa



Rosa Kelekian

- I am 24 years old.
- I am a Patient Advocate, applying to graduate programs in Social Work and Public Health.
- I was diagnosed with Ulcerative Colitis when I was 11.
- I am passionate about advocacy work, gardening, reading, and spending time with the people (and dogs!) I love.
- I believe that we all have unique knowledge and experiences to share that can make other IBD patients' lives easier!

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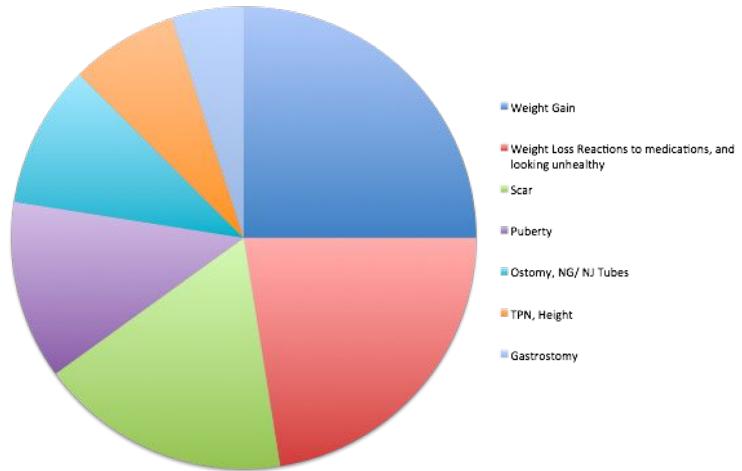


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Common Body Image Experiences for IBD Patients

PAC Members have experienced:

- Weight Gain
- Weight Loss
- Reactions To Medications
- Looking Unhealthy
- Puberty
- Ostomies
- NG/ NJ Tubes
- TPN
- Changes in Height
- Gastrostomies



Medications & Treatments

PAC experiences: the impact of IBD medications & treatments on body image



Experiences with body image and TPN

I got a TPN line put in freshman year and I had to walk around like that all year including perform in my musical where they had to give me a long sleeve shirt. that was pretty embarrassing and made me feel uncomfortable and secluded from the rest of the kids.

Contributor 3

Prednisone and moon face was difficult to handle in high schools. The weight gain that I couldn't control lowered my self esteem.

Contributor 11

Experiences with body image and medication reactions

Prednisone is probably the one that caused me the biggest body image issues. I had the typical chipmunk cheeks, weight gain and acne breakouts. Not only did I feel like my body was "flawed" but my mental health was severely affected as well.

Contributor 1

Prednisone had the biggest impact for me. I was extremely self conscious in high school from the moon face, weight I gained in my back/stomach, the acne/skin issues and how skinny it made my arms and legs...I felt awful when anyone would comment on it (and one guy even asked me when my face would be normal again). I'm super self conscious of this and some days wouldn't want to leave the house because of how my face looked.

Contributor 12

Summary: Body Image, Treatment, and Medications



- Ask as many questions as possible about the impact drug therapies may have on your body and psychosocial health.
- Always express concerns about possible side effects that may affect your body image and psychosocial health, and maintain open communication with your health care providers.
- If you are ever uncomfortable with the impact of a drug therapy, talk to your provider about it!
- Reach out to other IBD patients who may be on similar therapies, to learn about ways to cope.

Surgery

PAC experiences: impact of surgical procedures & side effects on body image



Experiences with body image and ostomies

My ostomy is inconveniently placed so I often have to adjust it in public which is very embarrassing.

Contributor 3

Sometimes I feel insecure about my ostomy because it's not something that a lot of people have and it made me feel self-conscious about my body. I was worried what people would think of me and I was worried about not being able to have a relationship because I had something "abnormal" on my body.

Contributor 5

Experiences with body image and ostomies

I had unplanned surgery to remove my entire colon and get an ostomy right before I was supposed to take my IB exams senior year of high school. At that point I was so run down and desperate not to be sick anymore I didn't second guess surgery. My parents were more resistant because they were afraid of how it would affect my future relationships and ability to be social or spontaneous- all valid concerns, but I just didn't have the energy to care at that point. I started freshman year of college 3 months later and for the most part had an easy time adjusting to life with the ostomy. I was feeling so much better I could actually do more things socially than I had been able to do prior to surgery. Whenever I told a friend about it I tried to be very casual so they didn't feel that they needed to pity me or be awkward about it...In terms of intimacy, I would say having the ostomy has made me more careful of who I choose to spend time with.. I always try to be very matter-of-fact, but also very light on the details of what it actually is or how it works unless they explicitly ask.

Experiences with body image and gastrostomies

I used to be very insecure about my G-Tube because it was something I wasn't used to. I was worried about what people would think of me and when I would look at myself, sometimes I wished it was gone and that my illness would disappear.

Contributor 5

I did nightly NG feedings for two years and then switched to Gtube button when my nasal passages swelled up and closed from the constant in and out of the tube. I could hide it pretty well under loose clothes, but sometimes it would get really weepy at the site and stain the front of my clothes in the middle of the school day. I'd have to carry my books or my bag in front of my stomach to keep people from commenting on it.

Contributor 10

Experiences with body image and scars

I have a TPN scar and a scar from a laparoscopic ostomy surgery. I am proud of my scars because I think they are battle scars.

Contributor 3

I had three scars from a resectioning surgery, and when I first took off the surgical tape I panicked for a bit because my belly button didn't really exist any more. I had some issues with that for a while until the scars relaxed out a bit, and now I have a naval again and you can hardly tell I have scars - they look more like razor nicks now.

Contributor 4

Experiences with body image and scars

I've never been insecure about my scars. They've always made me feel more confident because it shows how strong I am.

Contributor 5

My scars have always been the least of my image problems. I wouldn't mind showing them at the beach or in a crop top if I was happier with my weight overall.

Contributor 10

I always worry about people seeing my scars. At times I worry that people will find them unattractive or think I'm weird or gross because of them.

Contributor 6

Summary: Body Image & Surgery



- Ask as many questions as possible about the surgical procedure.
- Understand what will change inside and outside of your body as a result of the surgical procedure.
- Work with a psychologist or social worker to transition to a new lifestyle if your surgery includes major body changes.
- Always express concerns about possible side effects that may affect your body image, psychosocial health and lifestyle, and maintain open communication with your health care providers.
- Reach out to other IBD patients who may have had similar procedures to learn about ways to cope.

Body Changes

PAC Experiences: IBD related weight gain/loss and body image



Experiences with body image and weight gain/loss

Weight gain and loss is honestly a part of my everyday life even when I'm not sick or flaring up. I gain and lose weight extremely easily which some people might think is a good thing but in reality, it makes me feel inconsistent. I feel odd when people compliment me and say things like 'oh, you've lost weight!' or even 'oh, you've finally gained weight because you looked so skinny before!'

Contributor 1

I used to be really thin and underweight (80lbs at 15yo). For some reason, I still viewed myself as not being thin enough. I have gotten a few comments about 'go eat a sandwich' because of my weight, and that certainly didn't help. Oddly enough, though, my body image problems almost went away entirely once I gained the ~20lbs my doctors told me to gain. Even though I weigh more now, I feel better about myself.

Contributor 4

Experiences with body image and weight gain/loss

Weight gain/loss has made me feel both confident and insecure. Confident because when I gained weight, I looked somewhat healthy. But, I am still thin, so constantly looking small and underweight makes me feel weak sometimes.

Contributor 5

Prednisone has caused significant weight gain throughout my IBD journey. It honestly makes me more self conscious than my scars or ostomy ever has. When I gain weight I get very depressed.

Contributor 6

Experiences with body image and weight gain/loss

Weight gain has been a difficult aspect of my body image for me. Each time I was told I had gained more, I had a hard time viewing that as healthy weight, but rather as another negative part of having Crohn's disease. I had weight loss as well, though it was honestly less difficult to deal with psychologically than gaining. Society and my own ingrained images of a "perfect body" really messed with my body image and self esteem. I am constantly reminding myself that I have fought my own battles to be here. What I am is enough.

Contributor 7

Weight gain and loss - both happen in IBD. Sometimes people will ask me why I don't look malnourished implying that I must not be sick and that's not the case. Weight gain and loss make you look at yourself differently and negatively.

Contributor 4

Experiences with body image and weight gain/loss

When I was first diagnosed, I was really skinny; people would come up to me and shockingly say, "Oh my God, you're so skinny," as if I wasn't aware of that already. It was uncomfortable for me because I was actively trying to gain weight. Additionally there were conflicting emotions associated with my losing weight-- being skinny is viewed as a "good" thing in society, but I knew that it was unhealthy that I wasn't gaining weight. It was hard having to realize that I was unhealthily skinny when there's such an emphasis on being skinny. On the other side of the spectrum, I now have the opposite problem of gaining weight since starting treatment. I've been used to not gaining weight for so long that it's weird to see my body change and my weight increase. It's led to some issues with body image just because I'm not used to seeing myself gain weight.

Contributor 9

Experiences with body image and weight gain/loss

Weight gain was difficult to deal with because it was something I had no control of even though I remained physically fit.

Contributor 11

My weight fluctuates a lot, even when I'm not flaring. I've been anywhere from 70 lbs to 120 in the last 8 years, and it's definitely impacted my connection to my body. I hate looking emaciated and feeling weak, but I also had a hard time when I finally gained weight accepting how my body looked. It's frustrating because every time I feel like I reach the weight I want to be (or my body looks a way I am comfortable with), I have a flare and lose it again.

Contributor 12

Experiences with body image and weight gain/loss

I had been fighting to stay at 90lbs for years and at 18 years old still hadn't gone through puberty. Within 3 months of getting my surgery I started growing hair, boobs and finally got my period for the first time that summer. I put on a little weight and was really happy, despite getting an ostomy right before I went into my freshman year of college. However, as my body rebounded I began gaining what I saw as too much weight. I had never learned healthy eating or exercise habits because I had always been sick and eaten whatever I wanted to try and gain weight and now the stress of school was weighing heavy on me and causing me to binge eat - pretty soon I was once again extremely unhappy with my body. I would half-heartedly try fasting or vomiting, but I could never really commit to it. I would get excited to catch the flu because I knew I might drop a few pounds from dehydration and lack of smell helping me to eat less. I finally tried the Whole30 one summer and not only looked great but felt amazing. It's just incredibly hard to maintain that protocol in your everyday life, especially while in school.

Experiences with body image and weight gain/loss

Puberty took a while to hit me which made me feel slow and out of the loop but once it did I felt better.

Contributor 3

I have had issues with stretch marks from quick weight gain and loss.

Contributor 8

This is a little awkward to write about, but I'm very flat chested. At least I know the reason why now, but I still haven't seen any changes since I've started treatment. I feel like I'm lagging behind other girls my age, and it's started to slightly lower my self-confidence.

Contributor 9

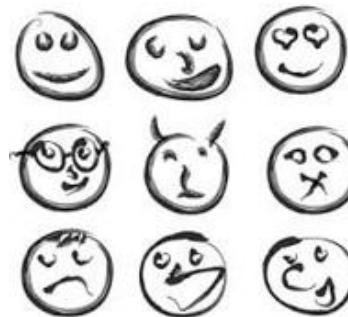
Summary of Body Image & Body Changes



- Bodies change a lot as we grow and mature. IBD can interfere with these changes, but the main goal is to be a healthy weight, not to look a certain way.
- Talk openly with friends, loved ones and your care team about your experiences related to body changes.
- Work with a psychologist or social worker, along with your care team, to address concerns and implement changes in your lifestyle to help with your concerns.
- Be aware of how your body changes and talk with other IBD patients to learn how they have coped.

Other Perspectives

PAC perspectives: feelings associated with IBD, body changes & body image



Experiences with body image and “looking unhealthy”

Some people comment that I am not looking well. I find that this makes my otherwise invisible illness visible and allows me to tell others how I am really feeling.

Contributor 2

Every time I see someone they say ‘wow, you look better’ which is offensive because I know I didn't look good and you don't need to rub it in.

Contributor 3

I actually get this a lot and it's difficult to find the words to respond because sometimes I will ‘feel great’ but may not ‘look great’ and vice versa. I'd say that I try to find ways to make myself ‘feel beautiful’ by running to de-stress or baking. Simply doing things I enjoy has always helped me!

Contributor 1

Experiences with body image and “looking unhealthy”

When I would look in the mirror before I was diagnosed, I did not like what I saw. From other people, however, the response was most often, "You don't look sick." And I found this almost as bad as "You look sick." I wanted someone to validate the struggle I was undergoing, because of how I felt I looked. I was sad about my body and how it was "malfunctioning".

Contributor 7

People telling me "You look sick" or "you look unhealthy" is not very good for my self esteem. It's also just rude. I am aware of the fact that I look sick, because I am chronically sick and likely will be for the rest of my life. I know people likely have good intentions, but it's unnecessary and makes me feel like I have to look/act a certain way for people to take my disease seriously.

Contributor 9

Advice for improving sensitivity about body image issues & IBD

I believe at this point, simply bringing up that body image and IBD is an issue is the main thing that providers and others can do for those suffering with body image issues. They can perhaps refer those individuals to psychologists who specialize in body image and are more qualified.

Contributor 1

Providers can perhaps mention it to their patients and devote time to it during appointments. Your health is THE most important thing in your life. If you're putting on weight because your body can finally feed itself that's only a positive, but you still have to realize that now it's on you to make good choices with what you eat and how you exercise. They should bring it up with their patients and explain to them it is only temporary, and how it's more important to make a patient feel better health wise. Don't comment on looks - if you need to talk about someone's weight, do it tactfully. Don't say "you're too skinny" (because we know), instead talk about ways to gain back weight. Similarly, if someone's gained weight/you can tell their body's changed, you don't have to comment on it - they know, and are probably super conscious of it.

Contributor 9

Summary of Other Perspectives



- Talk with friends, loved ones, and your care team about how their comments impact how you're feeling about the changes in your body.
- Work with a psychologist or social worker, along with your care team, to address concerns and implement changes in your lifestyle to help with your concerns.
- Remember that there are other IBD patients out there who understand what you're dealing with - you are not alone!!