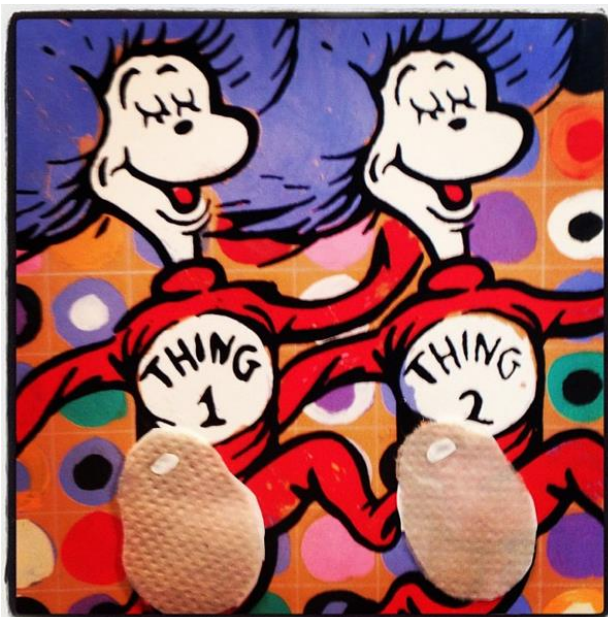
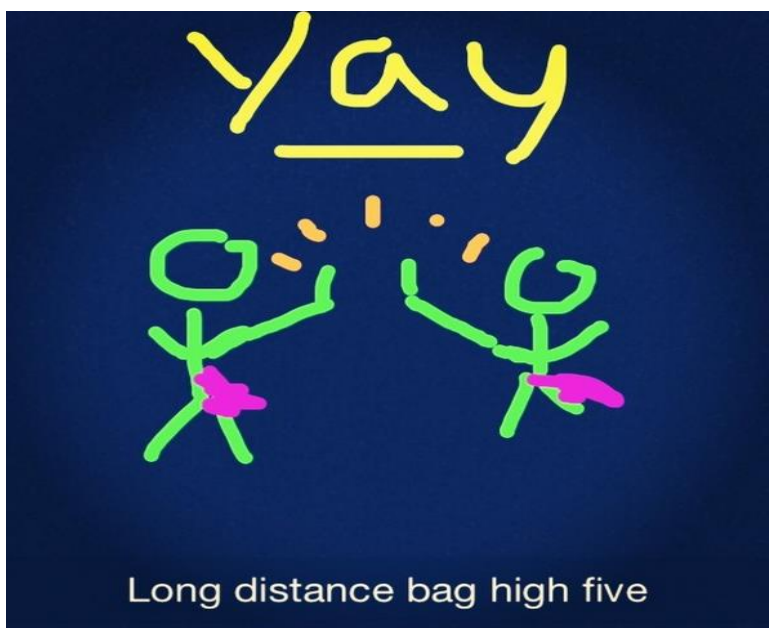


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the ostomy toolkit



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the ostomy toolkit: a guide to gutsy living

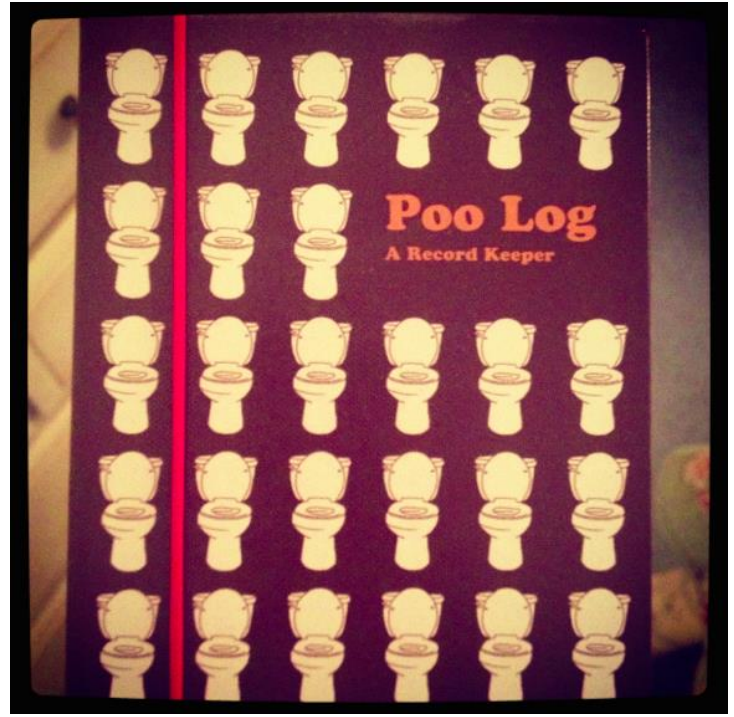
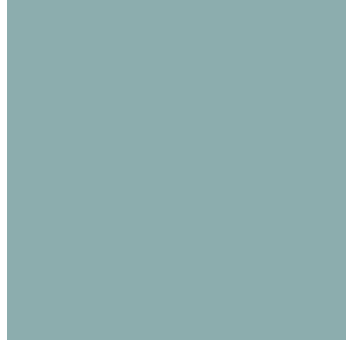
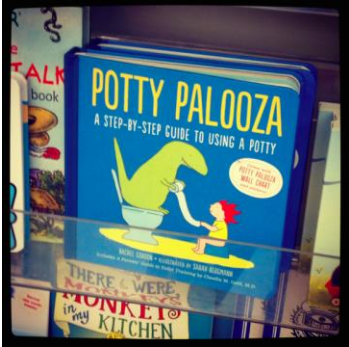
written and prepared by the Patient Advisory Council for the
ImproveCareNow Network

for pediatric ostomates, from pediatric ostomates



IMPROVECARENOW





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the ostomy toolkit

gutsy living with a little gutsy help

Version 2, 7/15/2015

+ a big gutsy thank you to all of our contributors

bios

Kristen Buckingham

Hello, my name is Kristen Evelyn Buckingham, I'm soon to be eighteen years old, I'm currently a senior in high school, and I have severe Crohn's disease. Because of my experience I'm inspired to help others as much as I can; I volunteer at Children's Mercy Kansas City, Mo. (my current hospital as well), I got involved with PAC, and got accepted into a medical program at my high school. Having Crohn's disease has opened my eyes to what I truly want to be in life, and that is a pediatric gastroenterologist. Now the fun stuff! Growing up I always knew my mother had gastroenterology issues, as she was diagnosed in her late 20's with colitis. Around the age of 12, I noticed blood in the toilet as I wiped. I told my parents about this and of course they already had some knowledge due to my mother's condition. My parents were honestly in some denial about what was going on with me at first. They didn't want to take me out of school knowing I would miss too much. Overall I don't think my parents wanted to believe it. A year passed and my condition got worse: more blood, irritable bowel, nervousness, stomach pain, lower abdominal pain, and anemia. My parents finally took action, and we consulted my family physician. He knew about my mom's condition and my family history of IBD. He immediately ordered a colonoscopy for the following week. He told my parents it was Crohn's disease, and I was 14 at that time. We kept the same meds until my new doctor decided to take a big action, and she ordered an MRI. As a result, I was diagnosed with Crohn's (again) at 16. I started Remicade during my first hospital admission in December but it didn't work, so that summer (about 3 weeks shy of my 17th birthday) I got admitted again and I was told I needed my colon removed. I now have a colostomy bag, and I've had it for a year now. We are looking at a reattachment surgery sometime this summer, but will continue treatment infusions for the rest of my life.

Jennie David

My name is Jennie, I am 23 years old, and I have had Crohn's Disease for 12 years and a permanent ileostomy for 5 years. I graduated from Boston University with double honors in Psychology, and am earning my PhD in Clinical Psychology at Drexel University. Ever since I was 14, I have wanted to be a pediatric psychologist for children with chronic illnesses to specialize in medical decision-making and transition to adult care. The summer I had my ostomy surgery was the summer I turned 19, and all I wanted for my birthday was to have my surgery; many nurses and doctors would give me a quizzical look at my admittedly odd request, but they couldn't fully appreciate the genuine freedom from symptoms the surgery would provide for me. While having an ostomy is a very personal thing, I am incredibly proud of my decision to have ostomy surgery. Since my surgery I have hiked Machu Picchu, completed a sprint triathlon, and ran a half-marathon. I am the former Co-Chair of the Patient Advisory Council for ImproveCareNow. Beyond my Crohn's and ostomy, my favorite television show is 'Grey's Anatomy,' I love the color purple, I do lots and lots of baking (especially cupcakes!), and I love to write. After I was diagnosed with Crohn's, I wrote that I wanted to "rise above my disease and excel," and every day I try my very best to live by those words.



Ethan Fitter

Hello my name is Ethan Fitter, and I am 17 years old. I am just graduated from Madeira High School in Cincinnati, Ohio. I got my Crohn's diagnosis during the summer after seventh grade, and I was, during my initial flare, hospitalized for 23 days. Since then, I have had a colectomy and an ileostomy (not for my birthday) at various times in high school. With all that going on, I was still able to actively participate in tennis and marching band and play chess. I like to read just about anything and in the fall I will attend Northern Kentucky University to play trumpet. When I first got my ileostomy, I was really scared and didn't even look at it until a few days after the surgery. I eventually came to terms with it and decided that I wouldn't let it dictate who I was, so I'm doing everything I want to do. Life with a bag is harder than one without it, but it doesn't change what you can do or who you are.



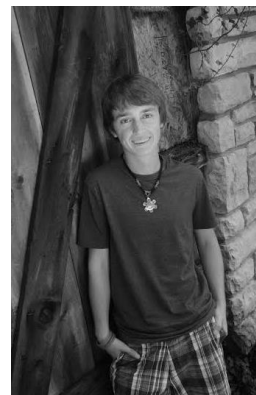
Sharon Fitter

It's June when I write this, a favorite month for many teachers, including me. I am writing this while on the annual beginning of my summer vacation. It's hard to believe how much my life has changed since my trip four years ago when my youngest child called me into the hotel bathroom to show me a drop of blood on the toilet seat. This wasn't the first one he had seen, and it wouldn't be the last. Ethan was a typical kid who had just finished 7th grade. This all started out of nowhere. We finished our trip with a few more bathroom stops than usual. Things got worse when we got home. Within a week, we had made 2 trips to the pediatrician and had two emergency room visits, the 2nd resulting in a 23 day stay at Cincinnati Children's Hospital. They promised he wouldn't leave this time until they figured out what was wrong. Ethan was diagnosed with IBD and eventually Crohn's Disease. The fast pace continued. Remicade was needed to stop the bleeding during his almost constant bowel movements. A speech pathologist helped him learn how to swallow the many pills he would need to take each day. His large intestine survived the megacolon of his initial flare, but it had to be removed 18 months later after medication and an ostomy couldn't calm it down. The colectomy was Ethan's ticket to feeling well again. For the past 2 ½ years, he has had almost no flares, has missed very little school, and has participated fully in high school marching band, chess, and tennis. Re-connection is a possibility, but not in the near future. As a special education teacher, I have never had a student with Crohn's on my caseload. I have, however, worked with students with other medical issues and/or similar needs. Ethan has a 504 plan, and we have revisited it a few times. For any student with special needs or medical concerns, it is important to create a plan that makes sense for the student and to keep an open line of communication between home and school.



Alex Jofriet

My name is Alex Jofriet. I am 19 years old and I attend the University of Cincinnati, where I'm majoring in Cellular Molecular Biology and minoring in Communication. I was diagnosed with Crohn's Disease at age 9 and have dealt with the ups and downs of a chronic disease ever since. Crohn's is the reason I visit Cincinnati Children's Hospital and Medical Center often but not the reason why I keep coming back. I keep coming back so that my experiences can serve as an example for others and I have certainly had my share of experiences. One of those memorable experiences would be spending three weeks in the hospital the summer before freshmen year while waiting for and recovering from surgery. During those three weeks, I was let out on a pass almost every day to go to band camp. I will never forget the fact that the staff worked very hard to get me that pass and to schedule my treatments in such a way that I was able to maintain a little bit of my normal routine. Enough about passes, though the real focus is on the reason for the surgery. It started in Europe with a big ball of puss. While in Belgium and Holland, I had an abscess growing in my small intestine. When I got back the abscess had grown so large it was almost completely blocking the passage of food through my ileum (small intestine that many Crohn's patients have difficulty with). When I got back the doctors discovered this fact and it led to a three-week hospitalization. That same three weeks I had a resection surgery with an ileostomy placement. I had to have an ileostomy placed because I had too much inflammation in my small intestine for the surgeon to safely hook me back together after surgery. Sound familiar? I was told before an ostomy was an option, but wished with all hope that I did not have one when I woke up. When I realized I had an ostomy, I was scared and frightened because I really did not want to have the bag. I was scared what my friends would think and what I could wear. At that time I was someone who talked about my disease a lot, but the bag was something I struggled to tell people about. The magic of having a bag though is that unless you tell someone they will never know. I had my bag for a year and a half. While a year and a half is not a lifetime, like people with permanent ostomies live with, it was still a relatively long time for a temporary ostomy. The greatest thing about having an ostomy was watching how the longer I had my bag the more I came to like it. Eventually, when I was ready to have my reversal surgery I was wishing I did not have to get rid of it. I am just happy to have had an experience with an ostomy because I no longer fear the bag. I currently co-chair the Patient Advisory Council for ImproveCareNow.



Bianca Siedlaczek

My name is Bianca. I am 16 years old and I am going to be a junior in high school. When I was diagnosed with Crohn's in 2008 at CS Mott's Children's Hospital when I was nine years old. For the longest time many of my medications were not working for me, so my doctor suggested surgery and said it would get me healthy again. Therefore, I decided to have the surgery to get an ostomy bag. Although I had surgery to get an ostomy bag, I did not have to get my colon taken out. I am very thankful I decided to have surgery because I have been able to grow, as my growth has been stunted since I was first diagnosed, and to get into remission! Being someone who is constantly around the hospital, I love pet therapy, so my dog and I are in the process of joining "Therapaws of Michigan." With that being said, I am very passionate about raising awareness for IBD. To help raise awareness I have an IBD Instagram (@ibd_awareness). My Instagram is mostly humorous, inspirational quotes, and so on. I am also a co-chair of ImproveCareNow's Patient Advisory Council. Other than my Crohn's Disease, I would love to travel the world with my best friends. My favorite TV show is 'Grey's Anatomy' (I love any type of medical drama series!). I also love inspirational quotes, with my favorite quote being, "We gain strength, and courage, and confidence by each experience in which we really stop to look fear in the face... we must do that which we think we cannot," by Eleanor Roosevelt. I love this quote because I believe we really do gain strength, courage, and confidence from overcoming our fears.



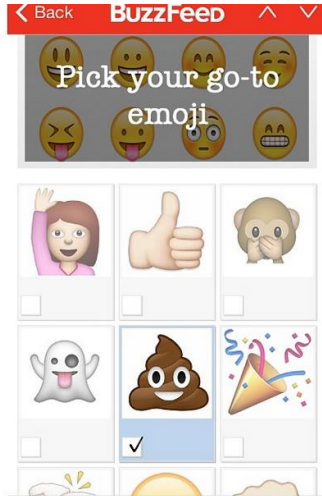
Cinda Lemont

I've had a permanent ileostomy since 2000. After 15 years of severe Crohn's disease, my ostomy gave me my life back. Before my ostomy, I couldn't do anything, but now there's nothing I can't do! I think one reason I adjusted so well to life with an ostomy is that I was so sick for so long. I've mentored adult ostomates and parents of pediatric ostomates, and that seems to be a major factor. If you're sick for a long time, you just want to have a normal life, but when it's an emergency surgery, you'll have a different perspective. There was a moment in my post-ostomy life that I am very proud of: my younger son was diagnosed with Crohn's Disease at age 11, and he came to me a few days later and said, "Mommy, I know I might have an ostomy someday, but it's OK, because I know you do everything you want with an ostomy." As bad as I felt about his diagnosis, I was proud of myself for having set a good example. That motivated me even more to continue helping adults and children who have IBD and ostomies.





tips & tricks from ostomates



Q: How do I tell my friends about my ostomy?

A: “Since I just started high school last year many of my friends don’t know that I have Crohn’s Disease or that I have an ostomy, but I have told a lot of my really close friends. For me, it was easy to tell my friends. I would just tell my friends that I would be having surgery pretty soon and they would then ask, “Why?” so then I would tell them. The friends that I did tell, I was very glad that I had because a few of them got me get well gifts and it was really nice to know that they cared. A few of my friends even called me the day after my surgery, which was really awesome to hear that they truly cared even though they didn’t fully understand what my disease was all about. My advice for telling your friends about your ostomy is to be completely honest with your friends. Don’t be afraid to tell your friends anything. Your friends will care even if you think they won’t. Although if you don’t feel comfortable talking to your friends about your ostomy, don’t stress over it. When the time is right, you’ll know. Don’t worry about telling your friends, they will care for you!” – Bianca

A: “Above all else, having an ostomy is a very personal and you have the ability to decide who to tell and how you explain it all. Personally, I was always very open about my ostomy and can remember holding up my shirt to show friends a week or two after my surgery. I talk very positively about my ostomy, and have honestly never had a negative reaction. I typically explain my disease, the need for surgery, and that now I don’t have a large intestine and wear a cloth bag on my belly at all times. I love to educate people and raise awareness, and encourage other ostomates to only tell others when they are ready and prepared.” - Jennie



tips for telling friends from Kristen

- You can inform your friends before the surgery that you'll have a ostomy
- Learn more about your ostomy for your own knowledge (this will make it easier to describe it to your friends)
- You can even show them your ostomy bag (if that's something you're comfortable with)
- When shopping for clothes, take your friends with you and they can help you pick out clothes you like that won't show your bag through your shirt (you can still wear normal clothes!)
- If your friends have any more questions, find a medical video online (make sure to find one that reflects your own attitudes about an ostomy) or find a blog with pictures
- **The key to telling people and friends is to make sure you're comfortable with it yourself and being comfortable in your own body – remember, everyone goes to the bathroom one way or another!**





Q: How does having an ostomy impact going to school or college?



A: “I went to college very far from home and began my sophomore year about a month after my ostomy surgery. At the time I had a private bathroom in my dorm room, which was very helpful, but having an ostomy and using public washrooms is also very doable. I used the Disability Services on my campus so that I had letters for my professors in case I needed to use the bathroom during an exam to empty my bag, and I liked having the reassurance of the letter in the off chance I needed the accommodation. I always had my emergency kit in my backpack so that I had extra supplies in case of a leak. Notably, I had several college professors who weren’t completely sure what an ostomy was, and I used it as an opportunity to explain what an ostomy was, and in certain situations, I’ve even lifted up my shirt a little bit to show them my ostomy!” – Jennie

Q: Does having an ostomy make it harder to travel?



A: “Have ostomy, will travel! Ironically, I have traveled more with my ostomy than I did before my surgery. When I travel, I make sure to have plenty of spare supplies (especially if I’m going to an international destination) and ensure I keep them on my person (i.e., in my carry-on and not in my checked luggage if I’m flying). Most importantly, having an ostomy qualifies as being able to use the medical lines at airports and such and I have taken advantage of that plenty of times. I have a card that says I have an ostomy, but you could also get a note from your doctor so that airport security will allow you to use the special line without hassle.” - Jennie



Q: What do I need to know about ostomy supplies?

A: “Two of my absolute favorite ostomy skin care products have to be ‘Cavilon No Sting Barrier Wipes’ and ‘Stomahesive Powder.’ Both products help to protect against and heal irritated skin. I have used these products ever since I had my surgery and I have not yet experienced any problems around my stoma. I use these supplies right before I put a new bag on. I first use a barrier wipe around the stoma and where the bag will be. Next, I lightly dust the skin with the powder. Lastly, I reapply a new barrier wipe. This process works very well for me, it allows for extra protection against irritated skin. I also like having two-piece bags because it is easier for me. I use a mini bag during the day and a larger bag at night. I prefer the mini bags because it is easier to hide under clothes. Also since I am quite small the larger bags would scratch up my thigh when I used to wear a larger one-piece bag all the time. A two-piece bag is actually very easy. Taking the bags on and off the wafer (the piece that connects the bag to the skin) is pretty easy. When putting



a bag on the wafer the bag “clicks” in just like a Tupperware container. For me having a two-piece bag is very easy and very manageable.” – Bianca

A: “I experimented with a variety of ostomy supplies, and finally found the perfect combination of supplies for me. I use a two-piece system: I love the moldable flange because I don’t have to bother cutting my stoma size, I can just stretch it and it will conform to my stoma size naturally, and then I use “day” and “night” bags. My “day bags” are pediatric size bags that are very small and very low-profile under clothing, while my “night bags” are larger and are optimal at night to hold more output so I don’t have accidents or have to wake up in the night to empty the bag. I will wear a flange (also called a “wafer”) for about 4 to 5 days, and will change my bag every day (I shower in the evenings and will shower with my day bag on, and then put my night bag on after the shower and then my pajamas!). The bags I use have cloth over them, so you cannot see any of the waste as it comes into the bag. I clean the skin under my bag with stoma wipes (they look like baby wipes) and then I use a barrier wipe around my skin to help protect it, and it also helps the flange adhere better and last longer. I always say good ostomy supplies are the difference between clean underwear that fits you versus way-too-small itchy underwear – it’s important to be comfortable in your supplies!” – Jennie



A: “I didn’t want to deal with more than one piece. My favorite product is Coloplast Brava strips. I put them around the edges of the bag, and it helps prevent leaking. Curved scissors are nice to cut holes to the correct size.” – Ethan



ostomy lingo 101

- **colectomy:** a colectomy is a surgical procedure where the entire large intestine (also known as a colon) is removed
- **proctocolectomy:** a proctocolectomy is a surgical procedure where the entire large intestine (also known as a colon) and the rectum are removed
- **resting ostomy:** a resting ostomy is when an ostomy is surgically created without the full removal of the colon (e.g., a resection and temporary ostomy)
- **stoma:** the piece of the intestine that is brought to the abdominal wall and sewn down, this is the next exit for waste
- **ileostomy:** an ileostomy is when the stoma is from the ileum (the small intestine)
- **colostomy:** a colostomy is when the stoma is from the colon (the large intestine)
- **flange:** a flange is the bandage-like appliance that goes around the stoma and sticks to the skin; it is like a turtleneck for the stoma (also called a “wafer”)
- **bag:** a bag is where the waste collects after it comes out of the stoma
- **drainable pouch:** a drainable pouch is when a bag has a spout where the waste can be emptied into the toilet
- **closed pouch:** a closed pouch is when a bag does not have a spout and the only way to get rid of the waste is to put on a new bag (closed pouches can be good for exercising or quick showers when you will throw the bag out shortly)
- **one piece system:** a one piece system is when the flange and bag are attached (i.e., one piece)
- **two piece system:** a two piece system is when the flange and bag are separate appliances; in this scenario, the bag snaps onto the flange (like snapping on the lid to a plastic container)
- **“take down” surgery:** a surgery that depends on individual disease, where the ostomy is ‘reversed’ by reconnecting the stoma to the intestine.*

*To learn more, please read about Alex’s experiences on page 13.



Q: Do I have to wear different clothing with an ostomy?

A: “Once people learn I have an ostomy, many people tell me, “I would never have known!” A large part of that is the way I dress and the fact that you cannot see the ostomy through my clothes. Many people think that wearing loose clothes is better, but in my experience that only makes the bag bounce around and seem more visible as you walk around. I prefer to wear clothes that fit closer to the body and that have some stretch in them – jeggings (jean leggings) and leggings are my favorite because they’re super comfy (they feel like pajamas!) and they have some give to them so that as the bag fills up, my pants can compensate. I wear a lot of flowy and long tops, and the more patterns the better! Particularly for bathing suits, patterned suits are great so that it camouflages the bag as it fills, and boy-short bikinis are ideal so that the bottoms come over top the ostomy. For formal dresses, there are higher underwear that I can tuck my bag into or even some specialty ostomy-cumberbunds. For me, my ostomy has never gotten in the way of wearing what I want and I always feel secure and confident in my clothes.” – Jennie



To the right, Jennie is in a bathing suit and also showing a close-up of her ostomy.



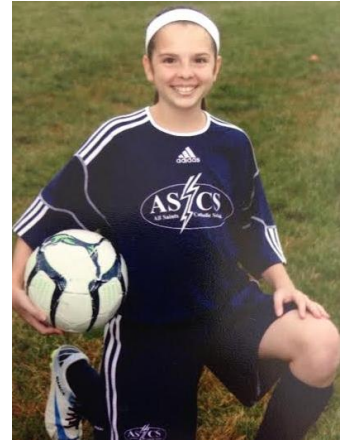
A: “Clothing for me is really easy. I only wear three types of clothes, t-shirts, athletic shorts, and athletic pants, and both the pants and the shorts have the same exact feeling and function. To incorporate my bag into my outfit is a two-step process. I first decided whether to tuck my bag into my pants or to let it hang out of my pants. My second and final step was to wear slightly too large shirts to keep everything well covered. Without a bag, I would be wearing Adult Mediums; since I have the bag, I wear Adult Large. If your outfit is more extravagant than mine, my only advice would be to wear things that are comfortable and cover up your ostomy bag.” – Ethan

Ethan is pictured wearing his normal clothes to the left.



Q: Can I play sports with my ostomy?

A: “Playing sports with an ostomy can be scary if you don't have any protection. I have played soccer ever since I was 4 years old, it's my favorite sport. I was so worried that after my surgery I wouldn't be able to play again. Luckily I did some research and found wraps or belts to buy for sports. These belts are just like a small amount of hard plastic like material that goes over your stoma and a soft belt that goes around your waist to keep the armor on. I bought one and when I played for the first time after surgery I was nervous. I was afraid that my stoma would still get hit from either the ball or someone else, but nothing happened and I played like I didn't even have an ostomy. I have been playing soccer for a long time now and I didn't let my ostomy get in the way. Don't be afraid to play sports with your ostomy, but make sure you have some sort of protection just in case you get hit with a bag. You don't have to give up playing a sport because of an ostomy.” – Bianca



To the right is a picture of Bianca in her soccer uniform.

A: “When I started playing tennis, it was during a time when I was wearing shorts and t-shirts and I let my bag hang out of my pants and wore large t-shirts. On the first day of practice I quickly realized that the constant movement would lift up my shirt and reveal my bag to the other teammates. While, if they knew I had it, this situation would be perfectly fine, but my preference was that if they didn't ask, I didn't care if they didn't know. I quickly decided that the current arrangements weren't going to work, so I tucked my bag into my shorts to get the bag out of that way and out of sight. After practice I continued to try out this new method and decided it didn't feel any difference than letting it hang out. What I learned from this was that during recreation, having the bag as comfortable as possible is most important, but during physical activities, I had to try different things to accommodate it to the sport. Once you find your happy spot, playing your favorite sports will feel just like playing without a bag.” – Ethan

Q: Does anyone use humor to deal with having an ostomy?

A: “I use humor to cope with my ostomy and Crohn's disease, and there are plenty of great ostomy jokes! I have a t-shirt that reads, “No colon, still rolling!” and another that says, “I'm with colonless,” and a third that reads, “Young, Wild, and Rectumless.” It's also come in handy when explaining my ostomy to friends; a little humor goes a long way in explaining the nitty gritty of bowel surgery. It has also helped my friends communicate with me in regards to my ostomy – for example, a college roommate who was (as she put it) a “big bag fan” once said, “You know what, I was on the subway today and had to go to the bathroom, and I thought man, if I had a bag my life would be so much better!”” – Jennie



To the right are the 'colon cookies' Jennie makes every year on the anniversary of her ostomy surgery.



Q: Do I need an emergency kit?

A: “The ostomy nurse at Cincinnati Children’s Hospital helped Ethan get samples and 2 bags to use for emergency kits, one the size of a folder and the other more like a large pencil pouch. In the small kit, Ethan keeps an ostomy bag or two, scissors, tape, and a disposal bag. He can carry it with him anywhere. It’s usually in his book bag during school. He takes it to tennis matches and band competitions. When Ethan is at school or an all-day event, he takes a few more precautions. In addition to the small kit, he also takes a change of clothes (t-shirt, shorts, socks, and underwear), a large ziplock bag for dirty clothes, and a plastic grocery bag for discretion. He puts it all in a cinch sac, along with bottles of water. For school, he keeps a large kit in his book bag in his locker and one in the main office. That way he can go to whichever place is closer when he needs it, or he can ask someone to get his bag from the office if he is stuck somewhere and can’t get it himself. He used these kits mostly before he had an ostomy and had urgent trips to the restroom. He has not used them much since his colectomy.” – Sharon (Ethan’s Mom)

A: “While it’s unusual to need to change my bag urgently when I’m out of the house, it’s important for my comfort and peace of mind to have an emergency kit with me at all times. I use a small pouch (about the size of a pencil case) where I keep a couple extra bags, flanges, barrier wipes, and garbage bags – it’s also an easy place to keep any pills I need to bring with me when I’m on the go. I chose a pouch that had a design I really loved, and it’s very easy to throw into my backpack or even my purse so I can bring it with me wherever I go.” – Jennie

Jennie’s emergency kit can be seen to the right.



Q: What is a “take down” surgery? Will I have one?

A: “Depending on your individual disease, one of the options after an ostomy surgery can be a “take down” surgery. Please remember that this is not an option for everyone, and deciding not to have the surgery is perfectly okay. When your care team refers to a “take down” surgery, they are talking about the surgery by which you do not have an ostomy anymore; some doctors may also refer to this surgery as a “reversal.” The basics of this surgery include taking the stoma end of your ostomy and connecting it to the other end of the intestine that has either been healing inside your body or, in the case of a double stoma, outside your body. Once the surgery is complete, everything is “connected” again (i.e., as it was before your ostomy surgery) and you no longer have an ostomy. The “take down” surgery was easier for me after my ostomy surgery because I had a better idea of what it felt like to have surgery. The weirdest part about after the surgery is going to the bathroom again for the first time after being “connected.” Since you are no longer used to pooping “normally,” it makes for an interesting feeling during the first trip to the bathroom. It may be weird to poop that way again, but it usually is not a big issue and will feel normal again pretty quickly. The one thing I learned when I started going the bathroom without an ostomy after my “take down” was how much I had enjoyed not having the hassle of sitting in the bathroom for a long period of time when I had my bag; with that realization, I knew that if the doctors ever told me I would need a permanent ostomy that I would certainly be okay with that. After that “lightbulb moment,” I realized “take down” surgeries are not necessarily best for everyone and that is totally okay. When considering a “take down” surgery with your care team, make sure you and your family ask about the options you have and decide together what is best for you.” – Alex



ostomies & education plans: inside tips from Sharon, a teacher and a mom of a pediatric ostomate

Here are some tips I have learned from being on both sides of the table.

Teacher: I am an intervention specialist and have written IEPs, attended 504 meetings, and provided home tutoring and extended school year services over the past 15 years.

Parent: *I have been a team member to help create 504 plans for my son for the past 4 years. With Crohn's Disease and an ostomy, Ethan also has a medical plan.*

Notify your school, and meet with the teachers.

Teacher: We like to be aware when something may interfere with the learning process. It helps us understand changes we may see and helps us be on the lookout.

Parent: *It was nice to start a conversation in 10th grade while things were calm and let teachers know our healthy son. This was not an option in 8th and 9th grade when Ethan was already having various issues. We chose not to meet with the 11th grade teachers, and they were less sympathetic to late homework. We may meet again for 12th grade.*

Get information from your doctor or healthcare provider.

Teacher: I appreciate having a reference so I can look up information at a later date. It gives me better understanding of what the student may be going through.

Parent: *Information justifies requests I am making. Ethan's teacher's seemed interested in learning more. It also led them to ask some good questions.*

Meet as a team to write a plan that makes sense for the student.

Teacher: We know what goes on in the classroom and the expectations for students. It also helps to hear input from the student, either from the parents or by having the student at the meeting.

Parent: *I see how Ethan is acting at home, and he tells me things that he wouldn't tell a teacher. Parents have the right to request a meeting at any time. If the plan isn't working, meet again to talk about how to change it. We had asked for Ethan to have a seat near the door. He asked for us to take it out since it made him feel uncomfortable and in some cases prevented him from sitting near friends. After surgery, he couldn't lift his books, so a rolling backpack was added to his plan.*

Keep open communication.

Teacher: We know the information that needs to be taught and what skills students must learn to be prepared for the next stage. Teachers have different view about what to exempt when everything can't get done.

Parent: *I know how Ethan is feeling and what he can do when he gets home from school. I write e-mails to teachers to let them know when something was going on. Sometimes I ask for feedback to find out what they see at school, especially if Ethan seems fatigued or depressed at home. This gives teachers the opportunity to send a quick e-mail.*



ostomies & education plans continued

As students get older, they should advocate for themselves at school.

Teacher: A case manager will oversee plans in the public schools. By college or in the workforce, individuals need to ask for their own services or accommodations. In my district, teachers prefer for students to start taking care of issues on their own in 7th grade and be the main contact in high school.

Parent: Ethan was already in 8th grade when his first 504 was written, but he was not used to talking with teachers. He was an honor student who did fairly well in school. He was also very humble and did not want to be treated differently. It was hard for him to separate his cognitive ability from his energy level. He now understands that he is not “cheating” by using accommodations that he needs. I still send e-mails to teachers, especially at the beginning of the year, to let them know what to expect and that Ethan was not just making up excuses for not having homework or not being prepared for tests.

Be honest. Don't take advantage of having a plan.

Teacher: 504 plans are for leveling the playing field. IEPs are for helping students learn targeted skills. Neither one guarantees good grades.

Parent: For Ethan, it was hard to get back into doing full time school after missing several days of school and having work excluded or reduced in length.

Extra-curricular activities are part of school.

Teacher: Many teachers believe this; others think that academics need to come first.

Parent: A student should not need to give up everything else in their life in order to complete school work. Finding the right balance is important. For Ethan, activities sometimes motivate him to get work done (to stay eligible) or get out of bed in the morning.

Familiar teachers can be helpful at meetings.

Teacher: It helps to know what other teachers to contact about the student.

Parent: At Ethan's 10th grade meeting, the French teacher kept nodding her head in agreement and adding extra support to many things I was saying. I hadn't thought about how the other teachers would listen to their trusted colleague. Ethan was lucky to have some of the same teachers for more than one year. You have the right to request that a former teacher be present.

Don't forget the “extra” teachers.

Teacher: We need to know information about any student who will be in our classrooms.

Parent: Ethan had a close call in study hall on the first day of school one year. A lot of kids were in line to get passes to go to other places. He didn't know if the teacher knew about his restroom pass, so he waited and barely made it.



gastronauts: to gutsy infinity and beyond

“It can be hard to explain to friends, roughhousing cousins, and caring relatives about an ostomy. It’s awkward to show them the real thing. Pictures on the internet can be scary and overwhelming. Gastronauts were a perfect solution for our family. We learned about them at a booth at the annual IBD Family Education Day at the Manor House in Mason, Ohio.

Gastronauts are puppets that are ostomates. Also available are a doctor and nurse who can talk about procedures and medical issues. There are many puppets to choose from to reflect a variety of interests, personalities, or a sense of humor. Each Gastronaut comes with a personal story about why he or she has a stoma.

Puppets are kid friendly and not scary. They make it easier to talk about ostomies, what they look like, and why some people need them. Many of the children and parents on the Gastronauts website mention how happy the patients are to have a special friend with a stoma, just like them.

Perhaps the best news is that these puppets are free in most countries, including the US, for individuals under the age of 18 who have an ostomy.

To find out more about Gastronauts and how to get one, find out more by visiting: <http://www.thebowelmovement.info/the-gastronauts/>.” – Ethan & Sharon

Pictured are Ethan and his Gastronaut pal, Ron. Ron has an ostomy, just like Ethan.





the ostomy toolkit



prepared by the patient advisory council's advocacy
taskforce

email: pac@improvecarenow.org

website: https://improvecarenow.org/get_involved

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