



# Complex Child E-Magazine

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## Life with an Ostomy: A Mother's Perspective

by Jodee Reid

My daughter Matisse has never pooped; she never even passed meconium after birth. Along with bilious vomiting and an unwillingness to feed, her lack of pooping alerted us to the fact that our baby was sick. We would not know how sick for several months, since in the meantime she was misdiagnosed with a condition called Hirshsprungs disease, but it was believed that parts of Matisse's large bowel did not work.



Matisse

As devastating as this was for us, her parents, we were somewhat reassured to hear there was hope for our baby, namely a surgery that would bring her “working” intestine out through a stoma or opening onto her abdomen. Called a colostomy, she would poop into a bag until such a time when the procedure could be reversed, allowing time for her large bowel to fully develop in its own time.

## Colostomy Surgery

Matisse was just six days old when she had her colostomy surgery. Having never been through surgery myself, I was incredibly scared for my newborn. There were also fears about what she would look like afterwards. I had been shown pictures of what to expect: one or two stomas that looked like cherries sitting on my daughters lower abdomen. I would have to learn to keep these cherries looking healthy and clean. I would need to learn to change a stoma bag and protect the surrounding skin from degradation. My biggest concern then was not about the impact of having a child with an ostomy, but keeping her alive and getting her home where she belonged.



Stoma

I will never forget seeing the stoma for the first time. There was a little bit of horror that my perfect girl now had part of her intestine sitting on her belly, which was quickly followed by a determination to overcome my own issues of self image and get on with the job at hand, learning to look after the stoma. Every opportunity I got I did her ostomy care and it soon became second nature.

Unfortunately, soon thereafter we realized that Matisse did not have Hirshsprungs disease since her colostomy did not solve her inability to poop. Instead, she had chronic idiopathic intestinal pseudo-obstruction, a condition in which some or all of the intestines have weak, absent, or uncoordinated contractions, meaning the passage of food through the gut is obstructed.

At six weeks of age, Matisse's colostomy was reversed and an ileostomy was formed, using a part of her intestine that worked slightly better. An ileostomy is similar to a colostomy, only it uses the end of the small intestine, the ileum, instead of the colon. Although the basics in changing a bag are the same, the care is a little different, since the stool from the ileum is not formed and is more liquid than stool from the colon.

Initially surgeons told us that Matisse's ostomy would be reversed one day. Now, almost ten years later, we know that even following the intestinal transplant that she is listed for, she will likely always have an ostomy. Her anal sphincter, which will not be

transplanted, does not function, so even with a functioning transplanted intestine she will never be able to pass stool normally.



Ileostomy with Bag in Place on an Adult

### **Practical Advice for Ostomies**

Matisse found out she would always have an ostomy at six years of age, and she was fully aware that other kids do not have an ostomy. She was really upset; however, she realizes that this is her life. Although she has learned to live with her stoma, she knows that others can be cruel, and there are times when she is not comfortable with how others react to her ostomy bag.

I'm sure we will deal with many self esteem issues over the coming years, but here is how we have coped so far:

- ❑ Always be prepared! We have ostomy kits in both cars, at school, in the prepacked hospital bag, in my husband's day backpack that he takes on trips, in my handbag, and at grandma's house. If you don't have one, guaranteed you will have a leak! We also carry a container with a lid so we can empty her bag even if there is not a restroom available. Again, it is almost a guarantee that you will have a full bag when there is nowhere to empty.

- ❑ If Matisse is not ashamed of her ostomy, then neither are we. If she does not want to hide her bag, then that is fine, and if she does, we find a way for it to be unseen.
- ❑ As a little girl, all Matisse's dolls and stuffed toys had ostomies. This gave her some sense of control over her own situation, as she was able to change the bag and pretend to empty it. There was little fuss, then, when it came to having her bag changed or emptied, and less temptation to tamper with her own bag.



Ostomy Bag Cover from Gus Gear

- ❑ For babies and infants, onesies were the best clothing we could find to keep the ostomy intact and away from little fingers. Now we use ostomy bag covers to conceal the ostomy contents from view when using clear bags or when Matisse wants it covered. You can also purchase wraps at [www.gusgear.net](http://www.gusgear.net).
- ❑ Try lots of bags and wafers until you find the perfect fit/solution for your child's needs. Most companies offer samples, and if you can, chat with an ostomy nurse from time to time to see what is new that may serve your purposes better.
- ❑ Your ostomy nurse can also offer solutions for smell that may be escaping through the bag. Some people also use a water bottle to rinse out the bag after emptying to reduce odor.
- ❑ For the ileostomy, we use a urostomy bag that has a tap at the end. At night we can attach a Foley bag to the open tap that allows for the overflow of overnight stool.
- ❑ We use a two-piece bag and only change the wafer if it is peeling off to help prevent skin breakdown when removing adhesive. We only use water to remove the wafer, but in the past have used special wipes to remove the adhesive.



Ostomy Bag

- ❑ If the wafer (or base of the bag) is not sticking well, heat them a little to make them more pliable. You can do this with a hair dryer, which is also good for drying the skin after cleaning around the stoma to help the bag stick. Obviously, caution is needed to ensure the wafer and hair dryer setting are not too hot for your child's skin.
- ❑ I talk to Matisse's class at the beginning of every school year. I tell them about her medical stuff and take her medical doll (it has all the same devices as she does), and explain in an age appropriate manner. The intent is that the class can get their curiosity out all at once and then hopefully treat her normally thereafter. I also send a letter home to parents explaining in more detail so they can discuss with their child if the child has more questions.
- ❑ Matisse is allowed to empty her ostomy bag in the nurse's office at school, as it is pretty smelly. This eliminates teasing.
- ❑ Matisse does swim. We check her ostomy bag prior to going into the water to make sure there are no leaks. She does not tend to submerge too deeply in the water or do anything crazy like diving because she also has a central line. I do try to cover the ostomy with a swim top and/or bag cover just to prevent others from getting upset that she is swimming. I see the ostomy bag as no different from a swim diaper for a baby. You are taking every precaution to prevent an accident, but cannot 100% guarantee it.
- ❑ For us, Matisse's ostomy is the easy part of her care. She can empty it herself and change the bag and wafer if need be.

I hope these tips and information make things a little easier for others dealing with ostomies.

*Photos courtesy of Remedios44, DCwom, and GusGear.*