

What to expect for the staged repair of your child's anorectal malformation

Your child has been diagnosed with an anorectal malformation and will have a staged repair (a series of surgeries performed over many months or years). Your family will learn a new world of medical words, procedures, and concepts. It can be a stressful time. With our help, you will learn how to take care of your child.

This information came from other parents who have been where you are. They wanted to give you support, tips, and tricks to be as successful as possible. If you have questions after reading this information, please ask your child's doctor or nurse.

1st surgery: Creating an ostomy/mucus fistula (the end of the intestine is brought through an opening in the skin)

- The Wound Ostomy Team will teach you how to change the ostomy bag. Try to practice changing the bag yourself as much as possible with the Wound Ostomy Team watching. The more you do it, the better and faster you will get.
- Once you are home, expect the first few ostomy bag changes to take a while. You may have to change the bag one right after another because either the wafer leaks right away, or your child poops on everything.
- It is helpful to get everything ready before starting the process of changing the ostomy bag. Make sure the hole in the wafer is cut to the right size before you remove the paper backing.
- Expect that your child may poop in the bathtub once you can start giving them baths. You will have to drain the bath water and start all over again. You may want to use a plastic tote to bathe your child so there is less water to drain and refill if they poop during a bath.
- Ostomy bags often last for only three days, but they may break or come undone before the 3 days. The bag should last at least one day. If you are changing more often, contact the Wound Ostomy Team for help.
- It is common to have redness and soreness on the skin, under the wafer, and right next to the stoma. Contact the Wound Ostomy Team if this does not improve.
- The stoma may bleed when bumped. The bleeding will stop, and it will not hurt your child. Speak with your child's doctor or nurse if the bleeding does not stop.

Frequently Asked Questions:

- When, and from whom, should I order ostomy supplies?
 - The hospital's care coordinator will help set up the account for ordering ostomy supplies before your child is discharged from the hospital.

- ⊖ Once you are home, you will be responsible for ordering additional supplies. Be sure to get your order started for the next month.
- What bags are recommended
 - The Wound Ostomy Team will help determine which bags you should use.
- What paste should I buy?
 - Paste should only be used on children over 30 days old.
 - The Wound Ostomy Team will help determine which paste you can use.
 - Some parents prefer not to use ostomy strip paste because they feel it is harder to put on the wafer.
 - Putting the paste in a syringe will make it easier to put on. The Wound Ostomy Team can give you a syringe.
- How do you control the redness of the skin under the wafer and the skin next to the stoma?
 - Use water and gauze or a washcloth to wipe off poop.
 - Make sure the skin is completely dry before putting the wafer back on.
 - Apply powder and use a cotton swab to spread the powder where you need it. Lightly blow off excess powder.
- How do you keep the wafer/bags to stay on for a full 3 days?
 - Wear gloves when cutting a hole in the wafer and changing the bags. This keeps the oils on your hands from getting on the wafer or on the skin where the wafer will be placed.
 - Make sure the skin is totally dry where the wafer will be placed.
 - Warming the wafer between your hands before applying it to the skin will help it stick.
 - Regularly empty the bag before it gets too full and weighed down.
 - If the bag or wafer keeps falling off quickly, they may be too small. You can reach out to the Wound Ostomy Team for help.
- What do you use to cover the mucus fistula?
 - Use gauze with Vaseline and cover with medical tape or Duoderm.
 - You may also cover the mucus fistula with a small round Band-Aid. Be sure to change it regularly and add Vaseline.

2nd Surgery: Anorectoplasty (creating a new anus and pulling the intestines through it)

- You will continue to do ostomy bag changes at home as usual.
- Mucus will come out of the new anus.
- Expect your child's anus to look different.
- Start rectal dilations when your doctor tells you to. You will be taught how to perform these dilations by your provider, usually 2-3 weeks after surgery.
 - Be sure to use plenty of lubricant.
 - It is common for your child to be uncomfortable with dilations in the beginning and each time you go up on dilator size.
 - Dilations will get easier over time.

3rd Surgery: Ostomy takedown (removing the ostomy and reattaching the intestines)

Diaper Changes:

- Your child will poop a lot in the beginning, and you could be changing diapers one right after another for a while. The poop may smell different than normal baby poop or poop in general.
- Expect some large poops and many diaper changes with just small poops.
- It is common for your child to have a sore and raw bottom for a while.
- Expect it to take a little work and time to figure out your child's "normal" poop habits. There will be many changes and you will have to adjust things at times.
- Ask your child's doctor about signs of constipation. Your child may need laxatives, enemas, or diet changes in the future to help have regular poops.
- Even if your child is constipated, they still may have watery poops. This is because the watery poop will leak around the hard poop.

Skin Care:

- It is important to do skin care to keep your child from getting a sore, red bottom.
 - Change your child's diaper right after they poop.
 - Always use a thick layer of barrier paste with each diaper change.
 - For severe rashes, you may need to form a thicker barrier. Put a layer of stoma powder on first, then no-sting spray, then zinc-based paste. This is known as the "crusting" method.
 - Do not wipe all the paste off with each diaper change. Simply dab off the poop and put on more paste and powder.
 - Make sure the skin is completely dry before putting on the powder and paste.

General Advice:

- Keep doing anal dilations until your doctor tells you to stop.
- Write down questions when you have them so you can remember to ask your provider.
- While in the hospital, do not hesitate to ask questions.
- Help take care of your child while they are in the hospital. Be sure to let the nurses know if you
 - changed your child's diaper and how much it weighed.
 - fed your child and how much.
 - changed the colostomy bag, when and how much poop was in it.
- For any of the surgeries, if there are no problems, your child will stay in the hospital for less than a week.
- Your child will likely need some sort of maintenance or care, such as bowel management, for the rest of their life.