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

Your child has been diagnosed with an anorectal malformation and will have a primary repair (a single reconstructive surgery). 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.

Dilating before surgery

- You will be taught how to do rectal dilations by your child's doctor.
- Daily dilations will make sure your child's anus is big enough for poop to come out.
- Poop should be liquid.
- Be sure to use plenty of lubricant.

Surgery: Anorectoplasty (Creating a new anus and pulling the intestines through it)

- Expect your child's anus to look different.
- You will have to restart rectal dilations when your child's doctor tells you to, usually 2-3 weeks after surgery.
 - $\circ~$ It is common for your child to be uncomfortable with the dilations at first and each time you go up on the dilator size. Dilations will get easier over time.
 - You will need to keep doing rectal dilations until your doctor tells you to stop.
- It is common for your child to have a sore and raw bottom for a while.
 - 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 differently than baby poop or poop in general.
 - Expect some large poops and many diaper changes with just small poops.
 - You may want to use a plastic tote to bathe your child so there is less water to drain and refill when they poop during a bath.
- 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 make adjustments 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.
 - If your child is constipated, they still may have watery poops. This is because the watery poop will leak around the hard poop.

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Frequently Asked Questions

- How can I keep my 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 barrier 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.
- How long will I have to do some sort of maintenance/care for my child?
 - Your child will likely need care, whether big or small, for the rest of their life.
- How long will my child stay in the hospital after surgery?
 - If there are no problems, your child will stay in the hospital for less than a week.

General Advice

- 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 you let the nurses know if you
 - $\circ~$ changed your child's diaper and how much it weighed.
 - o fed your child and how much.