Leicester Children's Hospital

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Caring for babies with an anorectal malformation

Children's Hospital

Information for Patients

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Babies can sometimes be born with a problem with the bottom opening (anus). The medical name for this is anorectal malformation (ARM).

This leaflet gives you information about the condition and what it means for you and your baby. Hopefully, this will be a starting point for you so you can ask us more questions.

It is quite natural that you have never heard of anything like this before. This is because it is a rare condition. However, the doctors and nurses looking after you and your baby are trained to look after children with ARM. They have done this many times before.

Nobody really knows what causes the condition, but this is not caused by something you did or did not do. It is important to remember that it is not your fault.

Unfortunately, this condition cannot be picked up on the scans that you had before your baby was born. It is usually noticed when your baby is checked soon after birth.

What is anorectal malformation and what does this mean for my baby?

Anorectal malformation (ARM) is a group of problems with the position or size of the bottom opening (anus), and the bowel just above (rectum). What follows is a rough plan of how we will help you and your baby. It is possible that your baby's treatment may be slightly different, depending on the type of problem they have. We will of course discuss each stage in detail with you.

For most babies born with this condition, the bottom opening is not in the normal place, or too small for baby to be able to poo properly. Sometimes there may be no opening. A baby with this condition will usually have surgery soon after birth to bring part of the bowel out onto the tummy wall. This will let the poo (stool) pass into a bag (colostomy or stoma).

Health information and support is available at www.nhs.uk
or call 111 for non-emergency medical advice

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To give feedback about this information sheet, contact InformationForPatients@uhl-tr.nhs.uk

This may sound scary, but a specialist stoma nurse for babies will teach you how to look after the colostomy. You will quickly become very good at it. You will be able to care for your baby in the usual way and do all the things new parents do.

Your baby will also have scans of the heart, kidneys and spine in case there are any other problems. Once again, we will discuss the results with you but please feel free to ask in case you have not heard from us.

Having surgery

The colostomy will let your baby feed and grow, until the next surgery can be safely done to create a new bottom opening. This operation is usually done within the first few months of life. Your surgeon has special training in treating babies born with this condition. They will meet you and discuss the operation with you in more detail.

- The operation is done through a cut in the crease between the buttocks.
- A new bottom opening of a good size is made in the correct place.
- The colostomy is kept in place so new poo cannot pass through the newly-made bottom. This helps the area to heal well. This can help give the best result for both the look and how well the bottom works. Sometimes a small amount of old poo or mucus can still pass from the bottom. If you are worried please take a photo to show to the team.
- Most babies are able to go home within a few days and recover very well.
- We will explain how to care for the wound. There is not a lot you will have to worry about other than to keep the area clean and dry.
- As the new bottom has a circular scar around it, it will tend to get a bit smaller as it heals. We will teach you how to pass a small tool (dilator) into the bottom to stop this from happening. The opening should not become too small for baby to poo through after the colostomy is closed.
- We will aim to close the colostomy a few weeks after the new bottom is created.
- Usually, you can expect all the operations to be done by the time baby is about 6 months old.
- Your surgeon and nurses will continue to work with you closely throughout to make sure that your baby has the best possible start.

Complications of surgery

Any type of surgery has risks involved. It is important you know about these and can ask any questions before agreeing to surgery for your baby.

- Bleeding: this may happen during or after surgery, and rarely may need a top-up of blood (transfusion) or another operation to stop the bleeding
- Infection: we give antibiotics during and shortly after surgery to reduce this risk, but a skin or wound infection may need a longer course of antibiotics, or rarely another surgery.

- Pain: some pain or discomfort is expected after surgery as a cut is made. We will give pain relief to your baby to make sure that they are comfortable. Please let the ward nurses know if you feel your baby is in pain after surgery so that we can help.
- Scar: there will be a scar on the tummy after the colostomy is closed. The scar from the new bottom will tend to be ‘hidden’ in the crease between the buttocks. Some people heal with thicker scars than others, but it is rare for further surgery to be needed for the scar.
- Colostomy problems: sometimes the stoma can sink in (retraction) or come out too much (prolapse) or narrow (stenose), which may need another operation if it is causing problems with looking after the colostomy.
- Narrowing at the newly-made bottom: we reduce the risk of this by teaching you to pass a dilator until the colostomy is closed. Rarely this may need another operation to widen the bottom if is too small and causing problems with passing poo.
- Newly-made bottom not in the correct place: we use a special tool during surgery to check where the muscles are that control opening and closing of the bottom (sphincters), and aim to place the new bottom in the middle of these. If the bottom is outside the sphincters, this could cause problems with control over passing poo.
- Damage to surrounding organs: in boys this can include the pipe (urethra) that carries pee (urine) from the bladder, or in girls, the vagina, depending on the type of ARM that your baby has.
- Leak or narrowing from closure of the stoma: when we close the stoma, we are joining 2 ends of the bowel back together to let your baby poo from the new bottom. If the join does not heal well, there could be a leak within the tummy. This will mean the stoma needs to be re-opened to stop further leaks. Rarely there could be a narrowing where the join is made, that makes it difficult for poo to pass through this area, which could need another operation.

Caring for your baby’s bottom

When your baby first starts to pass poo through the new bottom, they could poo very often. This could mean the skin around the new bottom is very likely to become sore and will need protection. The main reason for the soreness is that the skin is constantly wet due to contact with poo. Being wet softens the skin’s protective layer. This means it can be easily damaged.

There are a few important things that can be done to reduce the soreness of the skin:

1. It is important to protect the skin by use of barrier creams. There are many different kinds. Sometimes trial and error is needed to find the best one for your baby. The specialist nurses can help advise you with this.
2. The skin in the area is delicate so rubbing to clean is likely to make things worse. Try and clean by splashing or squirting warm water on the area and gently pat dry with a rolled up towel.
3. It is better to let some dried up poo stay on the skin than to try to remove it by rubbing.
4. Try to leave the nappy off for as long as possible.

Next steps

From the time the colostomy is closed until toilet training age, all you need to do is to make sure that your baby is not constipated. The part of the bowel just above the new bottom (the rectum) must be kept empty.

Keep a note of the foods that cause the poo to be hard and those that make the poo looser. This will be helpful later when your child is ready to potty-train.

Contact details

Specialist Paediatric Colorectal Nurses:	0116 258 5494
Specialist Paediatric Stoma Nurse:	0116 258 5184
Ward 10 (surgical ward):	0116 258 5438 or 0116 258 5362

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہِ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔

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