

Anorectal Malformations

This leaflet offers more information about anorectal malformation. If you have any further questions or concerns, please speak to the staff member in charge of your baby's care.

What is an anorectal malformation?

Anorectal malformations are congenital defects where the anus (the opening at your bottom where poo is passed) and rectum (the lower end of the digestive tract immediately above the anus) have not properly formed preventing faeces (poo) from passing through the anus.

It is not clear why this happens. It is a rare problem, occurring in 1 in 3,000 babies and affects slightly more boys than girls.

There are different types of anorectal malformations:

- **Imperforate anus** - no anal (bottom) opening
- **Ectopic anus** - small opening in the wrong place
- **Anal stenosis** - narrow opening.

These malformations are usually classified as low anorectal anomaly or high anorectal anomaly.

A **low anorectal anomaly** is where the anus is closed over, in a slightly different position or narrower than usual.

A **high anorectal anomaly** is where the bowel has a closed end and does not connect with the anus or it connects with another part of the body through a passage called a fistula.

An anorectal malformation can sometimes be associated with other problems and the doctor will examine your baby closely to check for this. Your baby will need other tests such as x-rays and ultrasounds to see if other systems in the body (kidneys, spine, oesophagus) have developed problems (VATER syndrome).

If your baby has a high anorectal anomaly with a fistula, the faeces will be able to pass out of the body, usually through the vagina in girls or through the urethra in boys.

How is an anorectal anomaly diagnosed?

An anorectal malformation is usually diagnosed soon after birth on examination. Sometimes the anal malformation is not always obvious until your baby starts to feed and the abdomen (tummy) gets bigger, he/she starts to vomit and fails to pass meconium. (First stool.)

How is it treated?

If feeds have been started they will be stopped and a nasogastric tube (a tube that passes up the nose and down via the food pipe into the stomach) will be inserted. This will help to empty your baby's stomach, stop them vomiting and make them feel more comfortable. Your baby will be given fluids and antibiotics through a drip in their vein

The treatment then depends on the type of anorectal anomaly. All types of anorectal anomaly will need an operation:

If your baby has a **low anorectal anomaly** the operation is called an 'anoplasty'.

This is a relatively small operation and your baby should be able to start feeding and pass stool a few days after the operation. Initially it may be necessary to pass a dilator (small rod) each day to prevent the anus from becoming narrow. If your baby has had a new anus created, you may be asked to stretch (dilate) it using a small rod called a dilator.

Your surgeon or surgical nurse specialist will show you how to do this before you go home.

If your baby has a **high anorectal anomaly** they will need a series of operations.

The first operation is to make a loop stoma. This means bringing an end of the bowel out onto the surface of your baby's tummy so that they can pass stool into a specially fitted bag.

The second operation is done several months later when your baby has gained weight and is stronger. This is called a 'pull-through' to join the bowel to a newly created anus.

The third operation is to close the stoma. This happens when your baby's bowel and anus are working well a few months after the second operation. The three operations are usually completed by the time your baby is six to nine months old.

Before the operation your baby will have investigations to give the surgical team more detail of your baby's bowel anatomy.

Your child needs to be able to pass faeces to prevent it building up in the bowel, which could lead to discomfort and infection. Therefore, unfortunately there are no alternatives to these operations.

What happens after the operation?

Your baby will come back to the neonatal unit on a ventilator to help them breathe and the nurses will give pain-relieving medicines so that they are comfortable. For the first few days, your baby will need a 'drip' for intravenous fluids until they are able to feed. This will also allow the bowel to rest and start to heal. After a few days your baby can start with small amounts of milk and the amount will be increased as he or she tolerates it. If you wish to breast feed, the nursing staff will teach you how to express and store your milk to feed your baby when they are ready.

If your baby has had a stoma and mucous fistula created, the stoma nurse specialist and our neonatal nurses will teach you how to look after them both. We will make sure you feel confident about caring for the stoma before you go home.

You will be able to go home once your baby is feeding well and starting to gain weight.

Going home

After the anoplasty or the pull-through operation, your baby may have a very sore bottom. It is not a good idea to sit your baby upright or do anything that puts pressure on the healing area for several weeks after the operation. After your baby has passed faeces, cleaning your baby's bottom with olive oil will also ease any discomfort. Whenever possible, leave your baby's bottom exposed to the air, as this will help it heal too.

You will need to come back to hospital for an outpatient appointment about six weeks after each operation. We will write to you with the operation date.

You should contact your family doctor if:

- your baby has serious abdominal pain and/or diarrhoea
- your baby has serious constipation
- your baby does not have full bowel control by the age of three.

What are the long-term effects?

The outlook for children with anorectal anomaly depends on the type of abnormality.

Many children may need extra bowel training at a later stage as they are unable to develop normal bowel control. With modern techniques it is usually possible for the children to be clean and this will be explained to you if it is needed.

Your baby will need check-ups with the surgeon. These happen regularly until your child is a teenager.

If St George's Hospital is not your local hospital

Once your baby has had surgery and made a good recovery, i.e. when their specialist medical and nursing requirements are fewer, the baby will be transferred back to the care of your local hospital. This transfer is a sign of progress and will not occur until the baby is ready. It will allow you to be closer to home and become familiar with your local healthcare professionals.

Useful sources of information

BLISS

Bliss is a support group which is able to offer support and advice to families with babies with a range of conditions.

68 South Lambeth Road
London SW8 1RL

BLISS Helpline: 0870 7700 337

Email: Information@bliss.org.uk

Website: www.bliss.org.uk

Use your smartphone to scan the QR code (you may need to download a QR code scanning).



For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.stgeorges.nhs.uk

Additional services

Patient Advice and Liaison Service (PALS)

PALS can offer you on-the-spot advice and information when you have comments or concerns about our services or the care you have received. You can visit the PALS office between 9.30am and 4.30pm, Monday to Friday in the main corridor between Grosvenor and Lanesborough Wing (near the lift foyer).

Tel: 020 8725 2453 **Email:** pals@stgeorges.nhs.uk

NHS Choices

NHS Choices provides online information and guidance on all aspects of health and healthcare, to help you make decisions about your health.

Web: www.nhs.uk

NHS 111

You can call 111 when you need medical help fast but it's not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year. Calls are free from landlines and mobile phones.

Tel: 111



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