Newborn Services

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 (ARM)?

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.
In addition, the urinary tract (urethra (wee tube), bladder and kidneys) is affected most of the time.

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

There are different types of anorectal malformations. Types are classified according to the place where the bowel ends and whether there is an abnormal connection between the bowel and the nearby structures (vaginal opening in girl and urinary tract in boys). The abnormal connection is called a **fistula.**

- **ARM types in boys**
  - **Rectoperineal fistula:** In this type the anus will be in a position closer to the scrotum and is usually tighter than normal.
  - **Imperforate anus with Rectourethral fistula:** (commonest type) in this type the rectum ends in a narrow tube (fistula) that joins the urethra rather than ending at the bottom.
  - **Imperforate anus with Rectovesical fistula:** In this type the rectum ends in a narrow tube (fistula) that connects with the urinary bladder (the organ where urine is stored).
  - **Imperforate anus with no fistula:** In this rare type the rectum doesn't end at the bottom and doesn't connect to the urinary tract.
- **ARM types in Girls:**
  - **Rectoperineal fistula:** In this type the anus will be in a position close to the female external genitalia and is usually tighter than normal.
  - **Rectovestibular fistula:** (commonest type) In this type the rectum ends in a position very close to the vagina.
  - **Imperforate anus with no fistula:** The rectum doesn't end at the bottom and doesn't connect to anything.
  - **Cloaca:** A very rare and complex type where rectum, vagina and urinary tract all join together into a common channel and end in a single hole.

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, and oesophagus) have developed problems (VACTERL association).

V - Vertebra (spine)

A - Anus

C - Cardiac (heart)

TE - Tracheo-Esophageal (windpipe and food pipe)

R - Renal (kidneys)

L - Limb (arm or leg)

How is an anorectal anomaly diagnosed?

An anorectal malformation is usually diagnosed soon after birth on examination.

How is it treated?

Few types of ARM can be treated surgically in a single stage. However, most babies with an ARM will need **three operations**.

First operation (Stoma formation):
It is a life-saving operation that should happen in the first days of life to allow the baby to pass stool. In this operation, the bowel is brought to the surface of your baby's stomach. The artificial opening is called a 'stoma'. A bag is stuck to the skin to protect it and collect stool. Most parents quickly learn how to look after their baby's stoma.

Second operation (Anorectoplasty):
It is a delicate operation to reconstruct the tubes in the correct position and give the baby a new anus in the normal position. It is usually done at around three months of age. Following the operation, the new anus in most of the cases will need to be dilated (stretched) to prevent narrowing while healing.

Third operation (Closure of stoma):
The operation involves assessing the reconstructed anus and if everything is fine the stoma will be closed so that the baby will be able to pass stool out of his/her bottom. It happens when the reconstruction has healed and the anus has been stretched to a normal size. This usually takes at least three months from the date of the second operation.

What happens after the operation in neonatal unit?

Your baby may 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.

Due the involvement of the *urinary system* in most of the ARM types, the Paediatric Urology team will be involved in the management of your baby. In addition to the long term follow up, there may be need for active involvement while your baby is in the neonatal unit before discharge.

Following stoma formation, the stoma nurse specialist and our neonatal nurses will teach you how to look after it. 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

You will need to come back to hospital for multiple outpatient appointments in about two to six weeks to meet with the General Paediatric Surgeon, Paediatric Urology team, Surgical Specialist Nurse and the Neonatal doctors.

You should seek urgent medical advice if:

- your baby's stoma stopped functioning (i.e. stopped discharging stool)
- your baby is vomiting excessively and/or having diarrhoea.

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 to 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.

Bliss
Fourth Floor
Maya House
134-138 Borough High Street
London
SE1 1LB

Tel. 020 7378 1122

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 wings (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

AccessAble

You can download accessibility guides for all of our services by searching 'St George's Hospital' on the AccessAble website (www.accessable.co.uk). The guides are designed to ensure everyone – including those with accessibility needs – can access our hospital and community sites with confidence.

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