Anorectal malformations

This leaflet explains about anorectal malformations. If you have any further questions or concerns, please speak to a doctor or nurse caring for your baby.

What is anorectal malformation and why does my baby have it?

Anorectal malformation (ARM) is where the anus (opening in your bottom where poo is passed) and rectum (lower end of the digestive system immediately above the anus) have not developed properly. There are several different types of ARM.

- Small bottom hole (anus) in the wrong place
- Absence of bottom hole
    a. An abnormal connection, or fistula, joining the intestine and urinary system
    b. An abnormal connection joining the intestine and vagina
    c. In girls the intestine can join the urinary system and vagina in a single opening (known as a cloaca)

The malformation occurs when the baby is developing within the womb. There is no known cause.

It can be associated with other problems of the digestive system, urinary tract and spine and can be seen with VACTERL association (in which there are Vertebral, Anal, Cardiac, Tracheal, Esophageal, Renal and Limb abnormalities). Your baby will have further investigations such as X-rays, echocardiography, MRI and ultrasound scans to exclude these.

What are the signs and symptoms?

It is usually diagnosed after delivery by physical examination (baby check). A missing bottom hole maybe be noted on examination or poo maybe seen coming out of the wrong hole for example: urethra (hole where urine is passed) or vagina.

Does my child need any tests to confirm the diagnosis?

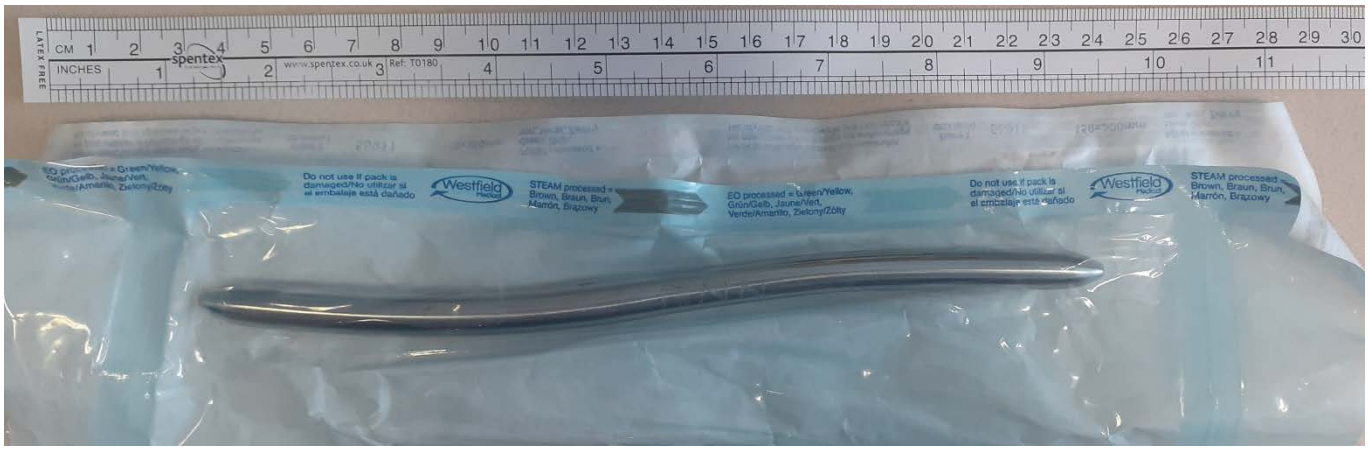
Your baby will be examined by a doctor on the neonatal unit. Abdominal X-ray will be done and ultrasound scans are done for further assessment. On admission to the unit your baby will stop feeding and have a nasogastric tube (NGT). This tube is passed through the nose and into the stomach. This will enable the team to empty out stomach content, which will reduce discomfort and minimise vomiting that may be caused by the blockage in the bowel due to the absent / abnormal bottom hole. To ensure that your baby does not become dehydrated, a cannula (small tube) will be placed into a vein, to enable us to give intravenous fluids. The cannula will also be used to give your baby any medicines that they may need.

Once the surgeon has examined your baby and obtained the results from X-ray/scans they will decide what treatment your baby needs. They will explain the treatment needed for your baby.

What treatments are available?

If the bottom hole is small, the surgical team may treat with anal dilatation. This involves passing an anal dilator, once or twice a day, into your baby's bottom, in order to stretch the opening. This may be uncomfortable for your baby, but should not be painful. You will be shown how to do this and you will be given a plan to follow at home.

Example of dilator



Alternatively the surgeon may decide at this stage to perform an operation to make the hole bigger (anoplasty).

If there is no bottom hole, your baby will need corrective reconstruction. This may require several surgeries, not all at the same time.

The first part of surgery is to form a stoma (colostomy), which will be located on the abdomen (tummy). It is formed from a part of the intestine known as colon or large bowel. The stoma will enable your baby to get rid of the poo, which will be collected in a bag attached to the stoma. Your baby will be discharged home and reviewed in clinic by the surgeon at about three months of age.

The second surgery, to create a new bottom opening (ano-rectoplasty), will be done at about 4-6 months of age.

The final surgery to close the stoma will be done a few months after. During that time you will be taught how to help keep the newly formed anus open using dilators.

Please ask for a copy of our leaflet, **Your baby's operation.**

After surgery

Following initial surgery your baby will come back to the neonatal unit to recover from the surgery. They will initially be ventilated (that is, a tube is passed from in the mouth to the lungs and connected to a breathing machine). This allows the baby to recover from the general anaesthetic and surgery, enabling us to keep the baby comfortable. Baby will remain on intravenous fluids until the surgical team decide the baby can start milk feeds.

If your baby has a stoma, you will be shown how to care for the stoma and change the bag. Please ask for a copy of our leaflet, **Your child and their stoma.**

Your baby may need further investigations, which will be discussed with you. A paediatric urologist (doctor specialising in care of the bladder), may also be involved in the care of your baby. You will be informed if a referral has been made.

Once baby is taking all the milk from the breast or bottle, gaining weight, and you are happy caring for your baby, your baby will be discharged home. Oral antibiotics may be given to your baby, due to abnormal positioning of the bowel and high of risk urinary infections.

In some situations, St Thomas' may not be your local hospital. If this is the case, before discharge home we may transfer your baby's care to your local hospital. This will not happen until the surgeons and the neonatal team are happy with your baby's progress.

Long-term and follow-up

Long term problems will depend upon the type of abnormality. Problems which may arise in the future include bowel management and your child may need extra help in 'toilet training' as some children have difficulty being able to control when they have their bowels open. Following discharge home, your baby will have regular check-ups with the specialist medical or surgical team in the outpatient department, where these problems will be discussed, and you will be given support in dealing with them.

Useful sources of information

The Junior Ostomy Support Helpline (JOSH) **w: http://www.colostomyuk.org/josh/**
t: 24 hours a day: **0800 328 4257**

Contact us

If you have any questions of concerns about anything in this leaflet, or Anorectal Malformation (ARM) in general, please contact the Neonatal Unit, **t:** 020 71884045.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit **w:** www.evelinalondon.nhs.uk/leaflets

Evelina London Medicines Helpline
If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline. **t:** 020 7188 3003, Monday to Friday, 10am to 5pm
e: letstalkmedicines@gstt.nhs.uk

Your comments and concerns
For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.
t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk
t: 020 7188 3514 (complaints) **e:** complaints2@gstt.nhs.uk

Language and Accessible Support Services
If you need an interpreter or information about your care in a different language or format, please get in touch. **t:** 020 7188 8815 **e:** languagesupport@gstt.nhs.uk

NHS 111
Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.
t: 111 **w:** www.111.nhs.uk

NHS website
Online information and guidance on all aspects of health and healthcare, to help you take control of your health and wellbeing.
w: www.nhs.uk

Get involved and have your say: become a member of the Trust
Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, please get in touch.
t: 0800 731 0319 **e:** members@gstt.nhs.uk **w:** www.guysandstthomas.nhs.uk/membership

Was this leaflet useful?
We want to make sure the information you receive is helpful to you. If you have any comments about this leaflet, we would be happy to hear from you, fill in our simple online form, **w:** www.guysandstthomas.nhs.uk/leaflets, or **e:** patientinformationteam@gstt.nhs.uk

Leaflet number: 4843/VER1
Date published: October 2019
Review date: October 2022

A list of sources is available on request

NHS
Guy's and St Thomas'
NHS Foundation Trust