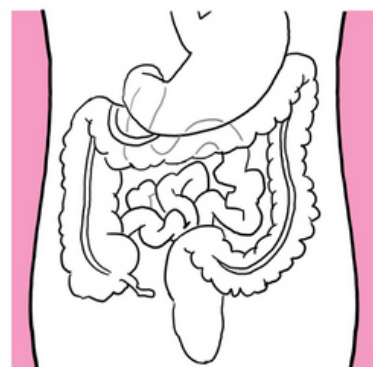


# Understanding Anorectal Malformations (ARM's)

## A guide for carers

### What is Anorectal Malformation?

Anorectal is the word that describes the bit of the bowel nearest the bottom: the anus and the rectum. The anus is the opening in the bottom, through which poos are pushed out. The rectum is the bit of bowel before the anus.



The cause of anorectal malformations (ARMs) is not known. There is nothing that families could have done to either cause the problem or prevent it from happening. Anorectal malformations affect 1:3300 to 1:5000 live births.

Anorectal malformation describes a variety of differences in the way the lower bowel and anus have developed. The most common problem is 'imperforate anus'. This is where there is no normal anal opening. Imperforate anus may occur in several forms:

- The rectum may end in a blind pouch that does not connect with the anus.
- The rectum may connect to the urinary or reproductive system, which means poo leaks out of the wrong place.
- There may be narrowing (stenosis) of the anus or there may be no anus.

### What happens when a child is born with an Anorectal Malformation?

When a child is born with an anorectal abnormality, they will have problems opening their bowels (getting their poos out). This may be because the anus is too narrow, or because the rectum does not attach to the anus in the right way.

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If the rectum is not connected to the anus the child will not be able to pass any poo. If the rectum is linked to the urinary system the poo will come out of the wrong place. It may also cause urinary tract infections (UTI).

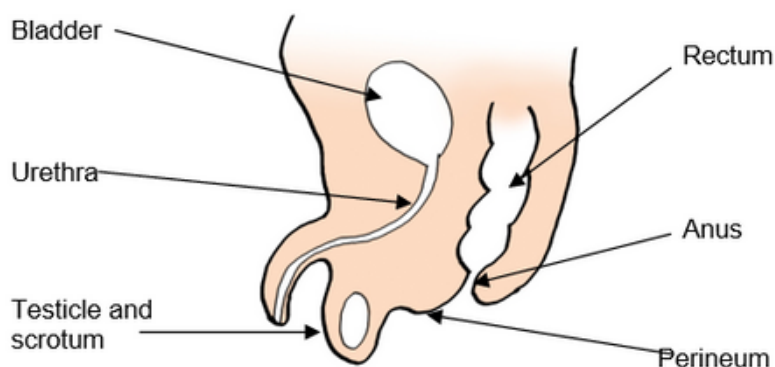
## Are there any other problems?

About half of children who have an anorectal malformation will have other problems as well, such as VACTERL association. This is an acronym for:

- **V**ertebral/spinal abnormalities
- **A**nal malformation
- **C**ardiac (heart) defects
- **T**racheal (airway) problems
- **E**sophageal (food pipe) problems
- **R**enal issues (malformations of the kidney and urinary tract)
- **L**imb defects – especially of the forearm

Children with Down's Syndrome are more likely to have an anorectal malformation, as are children with Hirschsprung's Disease (where the nerve cells to the bowel do not develop properly, so the bowel does not work as it should) and children who have a narrowing of the intestine (duodenal atresia)

## Pictures showing types of Anorectal Malformations - boys



Normal anatomy

# Understanding Anorectal Malformations (ARM's)

Pictures showing types of Anorectal Malformations - boys (cont.)



Rectum ends with no opening  
- anus absent

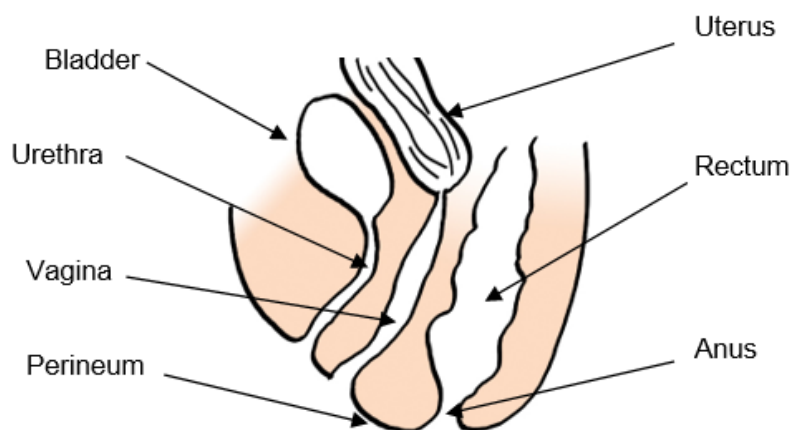
'Low' defect



Recto - vesical  
fistula. Some stool  
(poo) may leak out  
through the urethra

'High' defect

Pictures showing types of Anorectal Malformations - girls



Normal anatomy

# Understanding Anorectal Malformations (ARM's)

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Pictures showing types of Anorectal Malformations – girls (cont.)



Rectum ends with no opening  
– anus absent

'Low' defect



Recto-vaginal  
fistula. Some  
stool (poo) may  
leak out through  
the vagina

'High' defect

## How is Anorectal Malformation treated?

The babies with anorectal malformations will have investigations to find out more about the problem. These may include abdominal x-rays, abdominal and spinal ultrasounds and Magnetic Resonance Imaging (MRI). The investigations will look at the baby's spine (backbone), sacrum (tailbone) and the anorectal area (bottom), as well as the urinary and genital systems.

An ECG will usually be done to make sure that there are no heart problems.

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Surgery is usually needed to correct the malformation. The type of surgery will depend on the type of malformation. Sometimes, if the abnormality is severe, a colostomy may be needed to allow normal bowel movements to occur and allow the baby to gain weight and grow before further operations are done.

A colostomy is where the bowel is brought to the surface of the abdomen (tummy) and an opening is formed. The poo is collected in a special bag, placed over the opening.

If the baby needs a colostomy, lots of support will be provided from the children's stoma nurses or community nurses. They will show you how to look after a colostomy and tell you how to order the supplies you need. Your health visitor should also be able to provide more general support.

Some children have an associated problem with their bladder, so checks should be done to ensure the bladder is working normally.

Your child's doctors and/or nurses will explain all of your child's investigations and care to you and will give you the opportunity to ask questions.

## What about toilet training?

Most children who are born with an anorectal malformation will achieve full continence (become clean and dry), although they may need extra help with this. If the malformation was extensive, your child might find it difficult to get complete control. They may need to have further surgery or regular bowel washouts to become continent of faeces (poo).

Constipation can be a problem for all children who have been born with anorectal malformations. This needs to be treated as soon as it happens. Children with constipation usually needs laxatives (medicines that help with pooing), and also a good fluid intake and diet. Sitting in a good position on the potty or toilet (bottom well supported, feet flat on a firm surface and knees higher than hips) may also help.

It is recommended that all children who have an anorectal malformation start a bowel management programme as soon as possible after the surgical correction has been completed. It is likely that all children born with anorectal malformations will need to take more care of their bowels than other children.

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It is important a structured bowel management programme is introduced which should be well established before potty training commences

All children should also start to work on the skills they will need for eventual toilet training as early as possible. More information on this is available in the Bladder & Bowel UK children's information library (toilet training section).

The paediatrician, children's specialist bladder and bowel nurses, community nurse, health visitor or school nurse will be able to support children with anorectal malformations and their families, if there are problems with incontinence, toilet training and/or constipation.

There are different options available to help children who are struggling with soiling (bowel leakage) and/or constipation. Some children can stay clean with laxatives and good toileting programmes. Others may need suppositories. These are little bullet-shaped tablets that are inserted into the rectum to help with emptying. Some children may need rectal washouts, which are also called transanal irrigation.

Your child's healthcare professional will discuss with you and your child what is likely to be the best option for your child.



An image of a rectal washout kit. There are different rectal washout or transanal irrigation kits available. This is one example.

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## Further sources of information and support

### Max's Trust

A charity that works to raise awareness of anorectal malformation and provide support to the UK anorectal malformation community: both adults and children Website: <https://maxtrust.org/>

### Vacterl Association Support Group

A UK based support group for families of children born with vacterl syndrome - [www.vacterl-association.org.uk](http://www.vacterl-association.org.uk)

Find more information about child bladder and bowel health in our information library at [www.bbuk.org.uk](http://www.bbuk.org.uk). You can also contact the [Bladder & Bowel UK confidential helpline](tel:01612144591) (0161 214 4591).

For further advice on bladder and bowel problems speak to your GP or other healthcare professional.

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