

This booklet has been designed to help those involved with the care of children with anorectal malformations to understand what these are, the treatment involved and the importance of good long term bowel management.

This booklet is part of a series for children with bowel problems. Titles of other booklets currently available in this series:

- 'Talk about going to the toilet'
- 'Talk about constipation'
- 'Understanding constipation in infants and toddlers'
- 'Understanding toilet refusal – the child who will only poo in a nappy'
- 'Understanding Bowel training'
- 'Understanding Hirschsprung's Disease'

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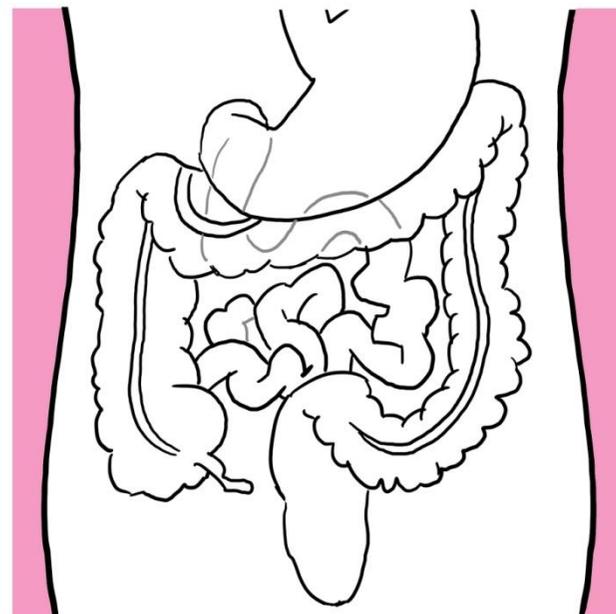
Illustrations: Les Eaves

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## Understanding Anorectal Malformations (ARM's)

A guide for carers



## What is an Anorectal Malformation (ARM)?

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

The cause of ARMs is not known and families need to be reassured that there is nothing they could have done to either cause or prevent the problem from occurring. Anorectal malformations affect 1:3300 to 1:5000 live births.

We know the incidence is increased in children with Down's Syndrome.

The abnormality can vary. The most common problem is 'imperforate anus'. This is the absence of a 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 at 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, because the structure of the anus and rectum is not connected in the right way, the child will have problems getting their poos out. This may be because the anus is too narrow, or the rectum does not attach to the anus in the right way.

There will also be children who cannot get their poo's out at all, because the rectum is not connected to the anus.

Sometimes poos will come out in the wrong place – for example, if the rectum links up with the urinary system. This can cause urinary tract infections.

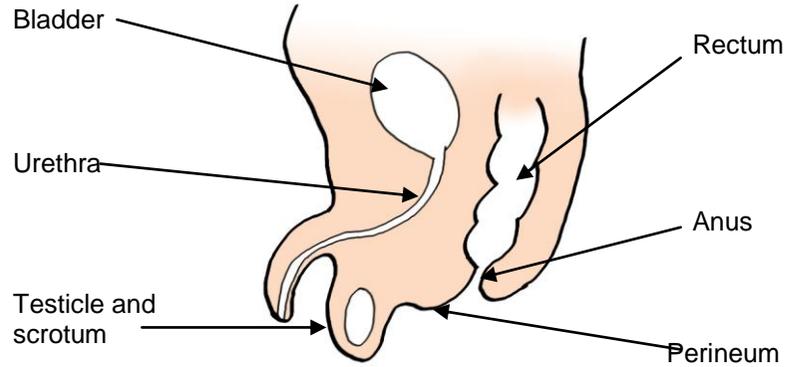
## Are there any other problems?

About 50% of children with 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 (malformations of the kidney and urinary tract)
- **L**imb defects – especially of the forearm

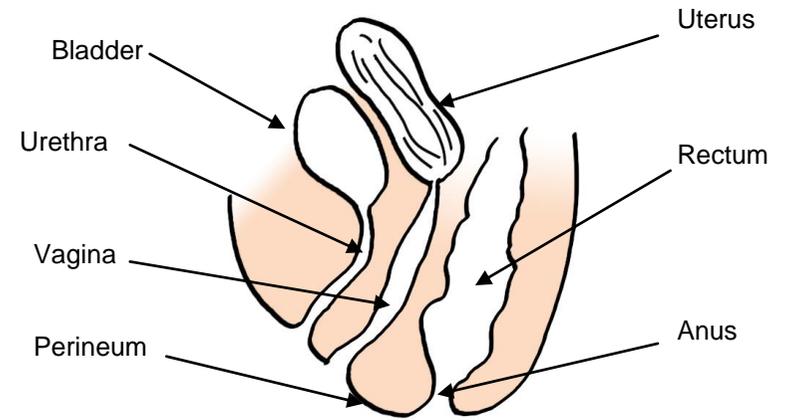
Down's Syndrome, Hirschsprung's Disease and narrowing of the intestine (duodenal atresia) may also be seen in children who have anorectal malformations.

**Pictures showing types of anorectal malformations - boys**

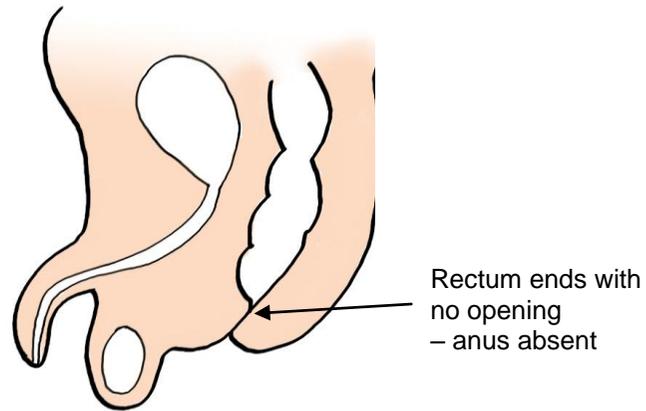


**Normal anatomy**

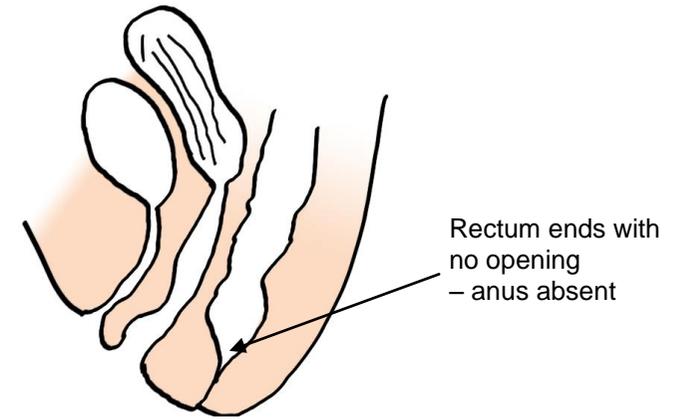
**Pictures showing types of anorectal malformations - girls**



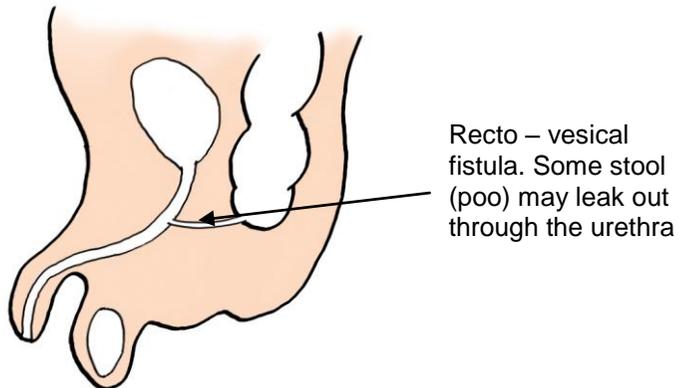
**'Low' defect**



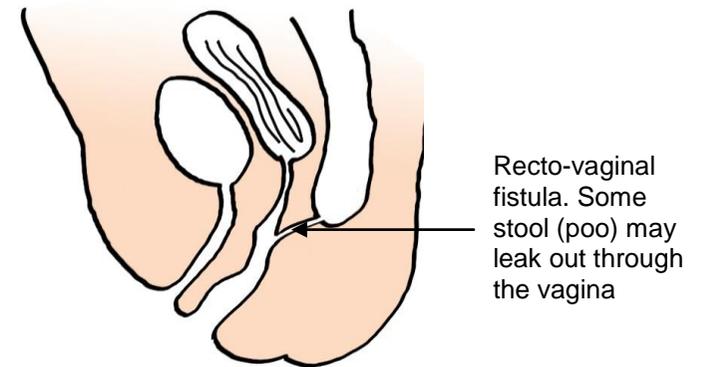
**'Low' defect**



**'High' defect**



**'High' defect**



## How is an anorectal malformation treated?

The baby will usually need surgery to correct the malformation. The type of surgery will depend on the malformation and the child will need investigations to find out the extent of the problem, before surgery takes place.

The investigations may include abdominal x-rays, abdominal and spinal ultrasounds and Magnetic Resonance Imaging (MRI). These investigations look at the spine, sacrum (tailbone) and the anorectal area, as well as the urinary and genital systems.

An ECG will also be performed to check that there are no heart problems.

Sometimes, if the abnormality is severe, the baby will need a colostomy to allow normal bowel movements to occur, and allow the baby to gain weight and grow before further operations are undertaken.

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, stuck over the opening.

A colostomy can be a scary thing to contemplate living with initially, but there is support available from stoma nurses or paediatric community nurses. They can show you how to look after a colostomy and will also tell you how you can get the supplies, which you will need.

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



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



## Further sources of information and support

### **Anorectal Malformation society (ARMs)**

Information and support for families caring for children with ARM's

Email: [reachingout2families@gmx.com](mailto:reachingout2families@gmx.com)

### **Bladder and Bowel UK (Formally PromoCon)**

Bladder and Bowel UK, part of the charity Disabled Living, provides qualified impartial advice and information regarding products and services for children and adults with bowel and/or bladder problems

HelplineTel: 0161 607 8219

Email: [bladderandboweluk@disabledliving.co.uk](mailto:bladderandboweluk@disabledliving.co.uk)

Website: [www.bladderandboweluk.co.uk](http://www.bladderandboweluk.co.uk)

### **Breakaway**

Breakaway are the UK's only residential weekend activity breaks designed for young people aged 4-18 with bowel and /or bladder diversions/dysfunctions, and their families.

<http://www.breakawayfoundation.org.uk/>

### **Champs**

CHAMPS is an appeal set up to raise awareness of children with Bowel and Bladder disorders, dysfunctions and diversions. They raise funds that will directly benefit children by supporting research, awareness campaigns and support groups

[www.champsappeal.co.uk](http://www.champsappeal.co.uk)

## Contact a Family

**Contact a Family** is a UK charity for families with disabled children. We offer information on specific conditions and rare disorders as well as advice regarding related issues such as benefits and finance  
e-mail: [info@cafamily.org.uk](mailto:info@cafamily.org.uk)

## Diversions

Diversions is a support network, based in the North West of England, for families with a child or young person living with a bladder or bowel diversion/dysfunction

Email: [diversions@live.co.uk](mailto:diversions@live.co.uk)

## Down's Syndrome Association

Provides information and support regarding all aspects of Down's Syndrome to all those who need it

Langdon Down Centre

2a Langdon Park

Teddington

Middlesex

TW11 9PS

Tel: 0333 1212 300.

Email: [info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk)



## 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)