

## Royal Manchester Children's Hospital

## Information for Patients

# Epispadias

This leaflet is for parents or carers whose baby or child has recently been diagnosed with Epispadias. We understand that you may be confused and worried about what will happen. This information leaflet aims to support you by covering some commonly asked questions.

## What is Epispadias?

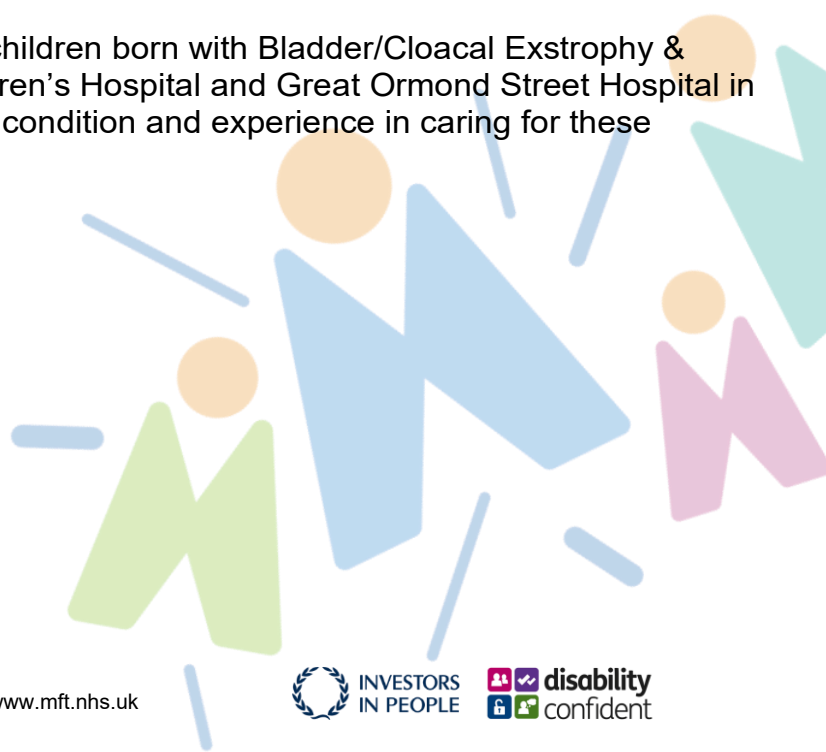
Epispadias is a birth defect that affects the way the urethra (the tube that carries urine from your bladder to the outside of your body) develops. It is part of a wider spectrum of birth defects known as the Bladder Exstrophy and Epispadias complex. It affects approximately 1 in 120,000 males, and 1 in 500,000 females. Epispadias is at the minor end of the complex with cloacal exstrophy being the most severe form.

Epispadias is a surgically correctable birth defect, but each child is unique and therefore their journey with Epispadias and the care they receive is specific to individual needs.

## Why do I have to come to Manchester or London?

There are two specialist centres in the UK for children born with Bladder/Cloacal Exstrophy & Epispadias, which are Royal Manchester Children's Hospital and Great Ormond Street Hospital in London. We have a vast understanding of the condition and experience in caring for these children. Our specialist team is made up of:

- Consultant Paediatric Urologists
- Consultant Paediatric Anaesthetists
- Clinical Nurse Specialists
- Consultant Orthopaedic Surgeons
- Clinical Psychologists
- Play Specialists



## What is Epispadias, Bladder Exstrophy and Cloacal Exstrophy?

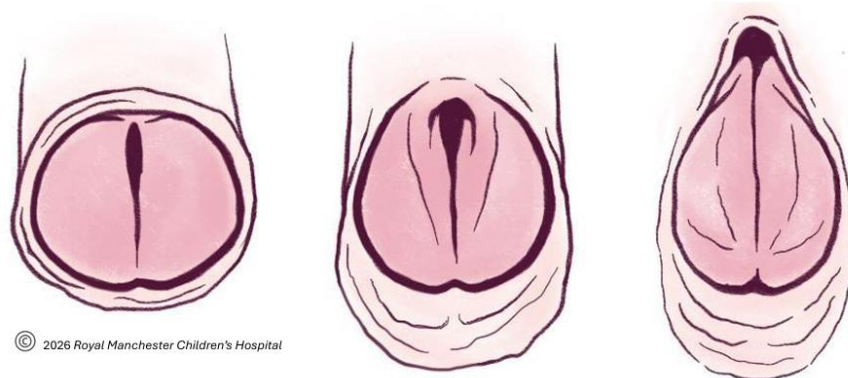
These conditions are part of a spectrum of birth defects, with Epispadias being at the minor end of the spectrum, and Cloacal Exstrophy being the most severe form.

**Classic Bladder Exstrophy** is an abnormality of the lower part of the tummy where the bladder, urethra (the tube that takes urine to the outside of the body), the pelvic bone and the genitals are affected. The bladder is seen on the outside of the baby's tummy. The urethra is open along the top and is not formed into a cylindrical tube as it should be, and the tummy button is in a lower position. The pelvic bones do not come together completely at the front (this is known as pubic diastasis). In boys, the penis is tilted backwards and is often shorted and wider than normal. In girls the clitoris is split.

**Epispadias** is a less extensive form of the condition. The bladder is not visible outside the tummy but the urethra (the tube that takes urine to the outside of the body), is open on the top side and is not formed into the cylindrical tube shape as it should be. In girls, the clitoris and labia are split. Epispadias is always present in both Bladder Exstrophy and Cloacal Exstrophy, however it is possible to see Epispadias on its own (without Bladder Exstrophy or Cloacal Exstrophy). In boys, there are different degrees of Epispadias with Glanular Epispadias being the mildest form (with the urethral opening near but not at the tip of the penis) and Penopubic Epispadias the most severe form (with the urethral opening nearer to the pubic bone/abdomen).

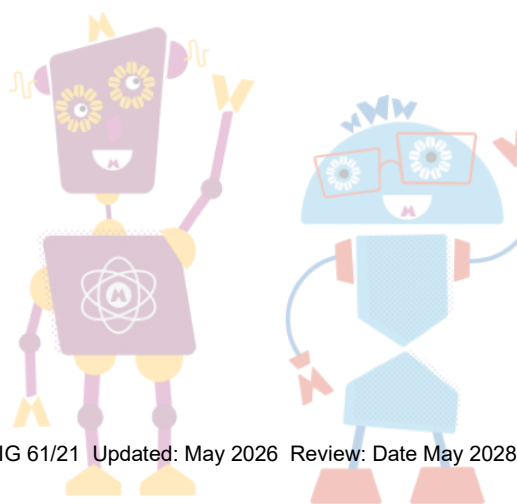
In **Cloacal Exstrophy**, the bowel and bladder are both seen on the outside of the baby's tummy.

Diagram showing female and male Epispadias



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## Why has this happened?

It is not known what causes Bladder Exstrophy & Epispadias defects. The problem occurs between the 4<sup>th</sup>-10<sup>th</sup> week of pregnancy when various organs, tissues and muscles begin to form. Bladder Exstrophy & Epispadias **does not** occur because of anything the mother or father did or did not do during pregnancy.

Our specialists are working in conjunction with geneticists and researchers across the UK to try to ascertain if there is a genetic link that makes it more likely for a baby to be born with Bladder Exstrophy & Epispadias, but so far results have been inconclusive. You and your baby may be asked to enrol in the study, and we may ask permission to take some blood samples for our data. If you are a suitable candidate for the study, this will be discussed with you by a member of the medical and genetics team when you come to clinic, and it is entirely your choice if you choose to enrol. Not enrolling in the study does not affect the level of care you and your child receive from our team.

## So what happens first?

Bladder Exstrophy & Epispadias are both surgically corrected in a series of operations over the first years of life. The overall aim of treatment is to protect the kidneys and correct the abnormalities, so that your child's urinary system and genitals work properly and look as normal as possible.

If your baby has been born with Epispadias, they will pass urine freely into a nappy from birth but, without an operation, they will struggle to control their urine and gain continence.

In boys, Epispadias is usually diagnosed at birth, as the abnormality is more obvious as it usually affects the external appearance of the penis. The surgery is delayed until the child is approximately 1-2 years old and will change the external appearance of the penis, bringing the urethral opening out at the tip of the penis, making the surrounding muscle and skin into a tube. Depending on the severity of the Epispadias, the penis can appear shorter and wider than average, even after surgery.

Female Epispadias is often diagnosed later, around 3 or 4 years of age, as it isn't always clear there is a problem until potty training proves to be unsuccessful, and a medical professional examines the child and notices they have Epispadias. In children who have a delayed diagnosis, their Epispadias repair is usually scheduled shortly after they are seen by our team in clinic. This operation changes the external appearance of the genitalia and the urethra is reconstructed to give the best chance of urinary continence in the future.

Once our team at Royal Manchester Children's Hospital have been informed of your baby/child and their diagnosis, we will arrange an out-patient appointment for you to attend our clinic to meet the team and we will talk to you about the operation and how surgery will be timed.

## What happens when an operation date is available?

You will receive a letter by post asking for you to bring your baby to the hospital for a pre-operative appointment, this is usually the week before the operation.

During this appointment the doctors will make sure that all the blood tests have been completed, scans have been done and you will be given the opportunity to meet the anaesthetist who will look after your

child throughout the operation.

In order for surgery to be performed your baby will receive a general anaesthetic. General anaesthesia is frequently used in new-borns and children. The anaesthetist will monitor your child continuously throughout the procedure.

The anaesthetist will talk to you about the general health of your child and any relevant medical history, particularly in relation to heart and lung disease. The anaesthetist will also need to know any significant family history related to anaesthetics. If there is any family history of heart or muscle disease, these may need further investigation. If your child has an allergy to any medication, you must bring this to the attention of the anaesthetist.

## Anaesthetic

General anaesthesia is induced using either anaesthetic gases through a face mask or by using anaesthetic medicines which are given through a small flexible tube called a cannula. The cannula is placed in a vein in your baby's arm. Once your baby is asleep, anaesthesia will be maintained using the anaesthetic gases.

In addition, it may be necessary to place a cannula (small tube) into a vein, so that your child can be given fluids, pain relief and antibiotics through the cannula both during the surgery and once they are back on the ward. Sometimes a blood transfusion is also required during the operation.

## Pain Relief

Once your child is asleep the Anaesthetist will ensure that your child is pain free. Pain relief during the procedure will be provided using medicines given either through the cannula (intravenously), a regional anaesthetic technique (such as an epidural or spinal block) or a combination of the two.

After the surgery, pain relief will continue to be given, but can usually be given via the mouth (orally). Sometimes your child will also be given antibiotics and medicines to keep the bladder relaxed whilst it heals which, again, can usually be administered orally. It is a good idea to ensure you have some Paracetamol and Ibuprofen at home should your child need pain relief when they are discharged.

## Immediate post-operative care

When the operation is finished, your child will be taken through to theatre recovery whilst they wake up from the anaesthetic, and you will usually be taken down by the nursing staff to be with them whilst they wake up and to escort them back to the ward when they are ready.

It may be necessary to give some fluid and medicines through the cannula (intravenously) at first, but patients can usually eat and drink quite soon after surgery so this may not be necessary for long. The anaesthetic can sometimes make you feel a bit sick, so if your child experiences this, please let the nursing staff know as there is medication they can give to help ease this side effect.

As the Epispadias repair involves reconstructing the urethra, a catheter (small tube) will be placed in the urethra for approximately 2-3 weeks after the surgery. This is to ensure everything heals after the operation and enables the bladder to continue to drain urine through the catheter following the surgery. The nursing staff will show you how to care for the catheter. For most patients, they can drain the catheter directly into a nappy, as children find this less restrictive than a catheter bag.

Children can usually be discharged the following day, and you will be referred to a community nursing team by the ward staff for ongoing support if required. The catheter can be removed by parents (full education is provided), community nurses or by the team at the Children's Hospital. The way we take the catheter out depends on the exact surgery that has been performed and what the consultant preference is.

## Psychological care at Royal Manchester Children's Hospital

At Royal Manchester Children's Hospital there is an experienced team of doctors, nurses, play specialists and clinical psychologists committed to ensuring your child gets the best possible care and treatment both physically and emotionally.

A clinical psychologist is someone who has studied behaviour and feelings. They use this knowledge to try to understand the problems that children and their families may be having and suggest different ways of trying to help.

## Psychological aspects of living with Bladder Exstrophy & Epispadias

Living with any kind of physical health problem can present challenges, even if only from time to time. Bladder Exstrophy & Epispadias are conditions that tend to present different challenges for children and their families at different ages and developmental stages. These hurdles can be overcome, and with support and encouragement, children can grow up to feel good about themselves and in charge of their lives.

## When might I see the clinical psychologist?

A clinical psychologist will try to meet you on the ward when your child is an in-patient as part of our routine package of support. You might also see the clinical psychologist in clinic when your child comes to an out-patient appointment to see the doctor. Your child's doctor or nurse may suggest you see the psychologist to help with a particular problem, or you can contact the psychologist directly if you would like some support. The clinical psychologist is a regular part of the hospital team who are there to help you and your child manage and cope with his/her condition.

## How can the clinical psychologist help?

Children who have physical health problems, and the families who care for them, often face problems from time to time. These can be distressing, and sometimes families need help with these problems. Clinical psychologists can help with difficulties children face about their health or treatment. They can also help with other emotional, behavioural and relationship problems. Clinical psychologists aim to help parents and children understand their problems and find ways of solving them.

Research is clear – with good support from family, teachers and friends, children with Exstrophy and related conditions do extremely well. But the process of learning to cope can be hastened by timely intervention by someone like a psychologist.


All of us need help from time to time and a psychologist can provide:

- A listening ear

- Understanding to help piece things together
- Support to achieve things that are proving difficult
- Ideas of how to face/handle problems

## Contact

If you would like to discuss any of the information in this leaflet further, please contact a member of the team.

 In case of problems or advice please call:

Secretary

Jenny Powell (Clinical Nurse Specialist)

Ruth Hurrell (Clinical Psychologist)

Theatre Scheduler

Ward 77 (urology ward)

Ward 76 (day case)

0161 701 1636 (for appointment queries)

0161 701 7707 (for clinical queries)

0161 701 4514 (for psychology queries)

0161 701 7614 (for surgery date queries)

0161 701 7700 (for urgent advice)

0161 701 7600 (for urgent advice)

