

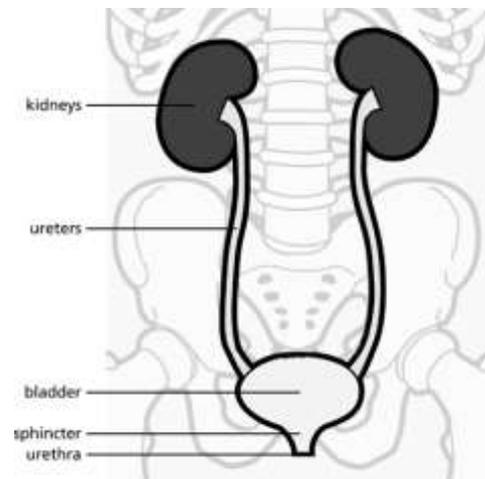


Kelly procedure (soft tissue reconstruction of the bladder neck): information for families

This information sheet from Great Ormond Street Hospital (GOSH) explains the Kelly procedure used to construct and strengthen the sphincter at the bladder neck following the initial closure of bladder exstrophy and what to expect when your child is admitted to GOSH for the operation.

The urinary system consists of the kidneys, the bladder and ureters. The kidneys filter the blood to remove waste products and form urine. The urine flows from the kidneys down through the ureters to the bladder. The ureters tunnel through the wall of the bladder at an angle to form a flap that acts as a valve. There is also a ring of muscle (sphincter) at the junction of the bladder and the urethra that stops urine leaking out in between wees.

When weeing, the muscles of the bladder wall squeeze the urine out of the bladder, at the same time as the muscles in the sphincter need to relax to let the urine flow down the urethra. The valves between the ureters and bladder prevent urine flowing backwards into the ureters so that all the urine in the bladder is passed in one go, as the urine cannot travel anywhere else. As the urine leaves the bladder at a high pressure through the urethra, the valves stop this high pressure being passed on to the kidneys.



What is a Kelly procedure and why does my child need one?

After the initial closure of the bladder exstrophy, there is no sphincter at the junction of the bladder and urethra. The Kelly procedure (also called a soft tissue reconstruction of the bladder neck) uses existing muscle and soft tissue to create a ring of muscle that acts like a sphincter. This holds urine in the bladder allowing it to stretch and gain more capacity and also helps form a strong stream of urine when weeing.

The surgeon can create a tummy button (omphaloplasty) during the same operation if preferred.

In boys, the Kelly procedure may also involve a reconstruction of the urethra and penis or it may be done in a separate operation at a later stage.

During the same operation, the ureters may be re-positioned within the bladder if they are not joining the bladder in the correct place. This can cause a condition called vesico-ureteric reflux (VUR) where the valves can fail, allowing urine to flow backwards from the bladder to the kidney. Depending on the severity of the VUR, sometimes the urine can flow backwards as far as the kidneys. This can damage the kidney and eventually lead to kidney failure. The ureteric re-implantation operation involves disconnecting the ureters and re-attaching them in the correct place. For more information about this operation, please see our separate information sheet.

Are there any alternatives to the Kelly procedure?

The Kelly procedure is a highly specialised operation and currently, GOSH is the only hospital in the world to offer it. Other hospitals may offer different methods of bladder neck reconstruction.

When the doctors suggested a Kelly procedure for your child, they may have explained alternative methods of keeping dry, such as a bladder augmentation (enlargement). However, some procedures are not suitable for every child.

The ultimate aim of the Kelly procedure is to allow your child to remain dry for most of the time while weeing normally through the urethra. Following a Kelly procedure, other methods of bladder training such as biofeedback may be needed to help your child learn to control their bladder emptying, which can take several years to achieve.

Pre-admission assessment

The pre-admission assessment for the Kelly procedure usually takes place four to five days

before the operation. Preparing for a planned operation, test or procedure before coming in to hospital avoids delays and reduces the risk of cancellation. The results of any tests and investigations are available in plenty of time and can also be re-checked if they are not within the normal range.

Your child will have a set of baseline observations as well as some blood samples taken to check that they are well enough for the operation. If your child has any medical problems, such as constipation or allergies, please tell the doctors. Please also bring a list of any medicines your child is currently taking, along with their dose schedule.

The nurse will explain the operation again and discuss options for anaesthesia and pain relief. They will answer any questions about the operation itself, the plan of care for your child's stay and recovery at home afterwards.

If your child is apprehensive about any aspect of the hospital stay, please contact us as soon as the Kelly procedure is suggested. Our play specialists and psychologists can help prepare your child, as can other members of the team, but this can take some time.

Day before admission

The day before the operation, we will call you to confirm fasting times. It is important that your child does not eat or drink anything (fasts) for a few hours before the anaesthetic. Fasting reduces the risk of stomach contents entering the lungs during and after the procedure, which can cause severe and long term damage.

We strongly encourage you to give your child food and drink right up to the times given, waking them during the night if necessary, to minimise the time for which they have to fast. However after the times given, they should have nothing at all to eat or drink. You should follow these instructions exactly. Otherwise, your child's admission may be delayed or even cancelled.

Your child should also have a bath or shower and a hair wash the night before surgery. Being clean before an operation can reduce the risk of developing an infection afterwards. For more details, please see our *Pre-operative hygiene* information sheet.

What happens before the operation?

Your child's surgeon will visit you to explain about the operation in more detail, discuss any worries you might have and ask you to give your permission for the operation by signing a consent form. An anaesthetist will also visit you to explain about the anaesthetic and pain relief after the operation. A nurse will accompany you and your child to the operating theatre, where you can stay until your child is under general anaesthetic. We will then bring you back to your child's post-operative ward. Your child will be away from the ward for up to eight hours.

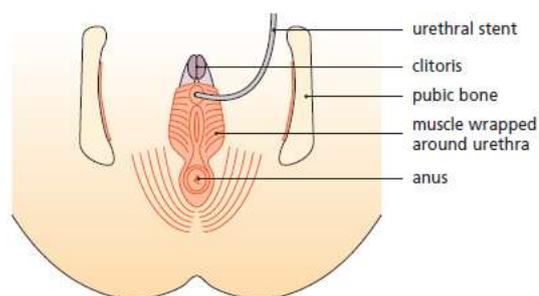
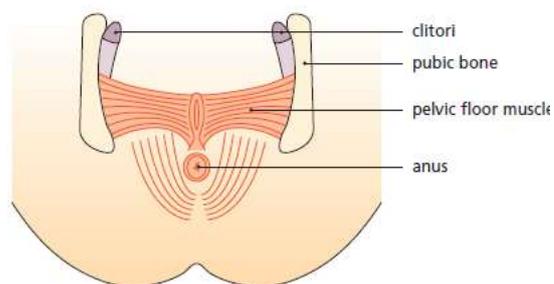
You can leave the hospital for something to eat or to get some fresh air – please check that we have your mobile phone number.

What does the operation involve?

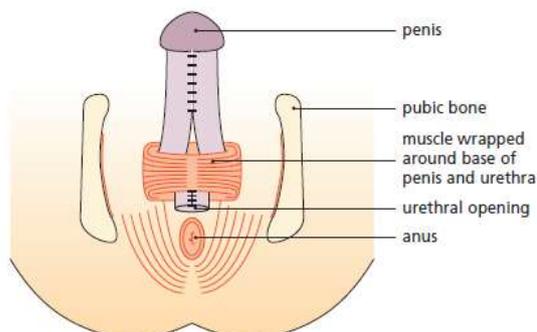
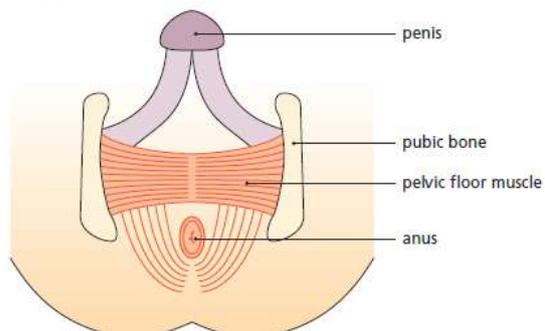
While your child is under general anaesthetic, the surgeon will make a vertical incision (cut) in their lower abdomen, wherever possible using the original scar from the bladder exstrophy repair.

They will disconnect the muscle and soft tissue from the pelvic bones to wrap around the bladder neck. The incision will be closed with dissolvable stitches.

Girls



Boys



In boys, the penis is separated into two halves, so the surgeon will disconnect each half from the pelvic bone and join it together. The muscle and soft tissue will then be wrapped around the base of the penis. Boys will have a foam dressing over their penis to protect it while it heals.

Are there any risks?

All treatments carry an element of risk, but this must be balanced against the quality of life without treatment.

All surgery carries a risk of bleeding during or after the operation. There is also a risk of infection but your child will be given a dose of antibiotics while in the operating theatre to reduce this risk. There is a risk that the tissues involved in the operation could be damaged, such as the tissue at the tip of the penis in boys, which may need further surgery.

Every anaesthetic carries a risk of complications, but this is very small. After an anaesthetic, your child may feel sick and vomit. They may have a headache, sore throat or feel dizzy. These side effects are usually short-lived and not severe.

The Kelly procedure is a major operation so your child is likely to feel uncomfortable for a few days afterwards. The nurses on the ward will monitor your child's pain and give them pain relief to keep them comfortable.

After the operation, there is a small chance that the urethra could narrow, making it harder to wee. This in turn could lead to urine being retained in the bladder which increases the risk of infection and ballooning of the ureters. This could lead to kidney damage in rare cases.

The Kelly procedure is not successful for every child – we keep detailed information about the outlook for children after surgery – please see the later section for details.

What happens afterwards?

Your child will come back to the ward to recover. For the first day or so, they will have an intravenous infusion (drip) giving fluids and medications until the bladder starts to recover.

Your child will need to have regular pain relief after the operation. Initially, pain relief will be given through an epidural. Depending on your child's age, they may have patient-controlled analgesia (PCA) through a pump so they can control their own pain relief.

They may also have ureteric stents in place, which are thin tubes inserted through the abdomen into your child's bladder and up each ureter. These drain away urine while the bladder recovers from surgery. A urethral stent will also have been inserted into the urethra to keep it open while the area heals.

Your child will also have a supra pubic catheter for a while after the operation to allow the bladder to heal. This catheter will be connected to a collection bag so urine can drain freely from the bladder. Younger children may use double nappies instead of a collection bag, so that the catheters drain into the outermost nappy.

It is quite common for children to have bladder spasms after this type of operation. This is quite normal. We will give your child medicine to reduce bladder spasms but if you are concerned, please tell us. Bladder spasms can show up as tummy pain or discomfort in the penis or bottom area. Constipation can make the spasms worse, so we will encourage your child to eat a balanced diet and drink plenty of fluids. Once they are up and out of bed, the constipation is likely to improve but we can give laxatives if needed.

After the first week, some of the tubes will be removed. The drip will be removed when your child starts eating and drinking again. The epidural is usually removed three to five days after the operation. Seven days after the operation, the nurses will remove the ureteric stents if they were inserted. This will be done on the ward – we will give your child pain relief beforehand although it may still be uncomfortable. Afterwards, your child will have an ultrasound of the area to check that everything is healing as it should. Boys will have

the foam dressing on the penis removed at this point too – this is done while they are under a short general anaesthetic.

You and your child will be able to go home once your child is recovering and has been reviewed by the doctors.

When you get home

Your child will still have the supra pubic catheter in place when you go home. We will show you how to flush it before you leave the hospital and give you our *Looking after your child's supra pubic catheter* information sheet as a reminder as well. We will also give you enough supplies to be able to look after the catheter until the post-operative review appointment. The catheter should stay in place until the post-operative review appointment in the Urodynamics Unit. We will give you the date for this appointment before you leave hospital.

The urethral stent will fall out on its own a few weeks after the operation. This should not be painful. You do not need to keep the urethral stent. If the urethral stent has not fallen out, it will be removed when you come for the post-operative review appointment.

- Keep an eye on your child's wound site for any redness or swelling. If you are concerned, visit your family doctor (GP) for a check-up.
- If your child is in pain, check their supra pubic catheter to see if it is twisted or bent over. Straighten it and then flush with 5mls of saline solution.
- Your child can have baths or showers when you get home. Change the catheter tapes when they get wet.

Post-operative review appointment

We will book this with you before you leave hospital after the operation. Around three to four weeks later, we will book you and your child into our Patient Hotel so you can make daily visits to the Urodynamics Unit for the next three days. The nurses there will clamp the supra pubic catheter so your child can start to pass urine normally again. This may be difficult to begin with but will improve in time. Once your child is passing urine comfortably, the supra pubic catheter will be removed.

Your child will need to come back to GOSH for regular follow up appointments, usually every three to six months, to have an ultrasound scan of their kidneys to check for any kidney damage as well as a bladder function assessment. As your child grows older, these appointments may only be needed on an annual basis. They will continue throughout childhood and adolescence, at which point, we will transfer their care to an adult hospital.

What is the outlook for children who have had the Kelly procedure?

We monitor the outcomes (results) for all children having the Kelly procedure so that we can continually improve the service we offer to children and families.

In our experience, over half of children are dry during the day time within three to five years of the operation, rising to 85 per cent after 10 years. Around a third of children are dry both day and night after three to five years, rising to nearly 60 per cent within 10 years. There are many ways we can help children to control their bladder function, please ask us for details.

If you have any worries or questions when you get home, please call the Urodynamics team on 020 7405 9200 ext 5916. Out of hours, please call Panther Ward on 020 7829 8814.