

Simple cystectomy with formation of an ileal conduit Removing the bladder and making a new way for pee to leave the body

This leaflet gives you simple, easy-to-read details about your operation. Expert doctors in the UK have written it. Please also remember the advice your own doctor or nurse has already given you.

Key points

- Doctors may need to take out the bladder if it causes serious problems.
- This is done if you have bad symptoms that do not get better with other treatments.
- The operation is called "a simple cystectomy and ileal conduit".
- When you have no bladder, pee will leave your body through a small opening in your tummy. This is called a stoma.
- Your pee comes out into a soft bag. The bag stays on your skin all the time.
- You will be shown how to empty the bag and look after your stoma.
- This is a big operation. There is a chance that things might not go as planned. Some people have problems afterwards.
- Taking out the bladder can stop the feeling that you need to pee all the time. But it might not stop pain in the bladder area if you have it.
- Some people may have a new bladder made from part of their bowel.
- It lets them hold pee inside and go to the toilet normally. These people do not need a
 pee bag.
- This is different from the operation used for bladder cancer.

Why do you need this treatment?

This leaflet explains what happens when a doctor removes your bladder.

Your bladder is the part of your body that stores pee until you go to the toilet. Sometimes, the bladder needs to be taken out. This happens if it is not working well and is causing problems. This procedure is called a simple cystectomy.

To help you pee after your bladder is removed, the doctor makes a new tube using a small part of the bowel. This new path is called an ileal conduit. It carries pee from the kidneys to a small bag fitted on the outside of your tummy. The bag collects the pee. It needs to be emptied when it is full.

Doctors use this operation for people who have very bad bladder problems that cannot be helped in any other way. Some people have pain in their bladder and always feel like they need to pee. This operation may help with the feeling of needing to pee, but it does not always stop the pain.

What does this operation involve?

The doctor will take out your bladder by making a cut in the lower part of your tummy. Sometimes, the doctor uses special tools through small holes instead of a big cut. We call this keyhole surgery.

Most people will need a new way for pee to leave the body. The doctor makes a small opening on the tummy called a stoma. We call this an ileal conduit or urostomy. Pee flows out through this opening into a soft bag stuck to the skin.

Some people may have a new bladder made from part of their bowel. This new bladder holds pee inside the body. You will need to empty it a few times each day using a soft tube called a catheter. You put the tube into your waterpipe or into a small hole in your side made by the doctor. If you have a new bladder, you do not need to wear a bag to collect your pee.

In some men, the doctor may also take out the prostate gland.

What are your other options?

There are many ways to help with bladder problems like leaking pee or bladder pain without having an operation. Doctors will only talk about removing the bladder if nothing else works or if other choices are not right for you. This operation is the last option and once it is done, it cannot be undone.

Some other ways that may help are:

- Pads to soak up the leaks. This is a good choice if the leaking does not bother you.
- Soft tubes called catheters. These go into your bladder. They drain pee from the body.
- Medicine and support to help with pain.
- Treatments that focus on bladder pain.
- A different operation called **hydrostatic distension of the bladder**. The doctor uses part of the bowel to make the bladder bigger. You can find out more about this operation here.

What happens on the day of the operation?

- Your doctor will talk to you about your medical record. They will also make sure that you understand and agree to the treatment. You will hear this called "giving your consent".
- You will meet the anaesthetist. They will talk to you about what type of anaesthetic you will have.
- You may have a general anaesthetic. This is where the operation is done whilst you are asleep. Or you may have a spinal anaesthetic. This is when the doctor makes you numb from the waist down.
- The anaesthetist will talk to you about pain relief.
- The nurse may give you special stockings and an injection to stop blood clots. Some people
 might need to use these stockings at home, after the operation. Your medical team will tell
 you if you need to do that.

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- Antibiotics are often given before surgery to avoid infection.
- The nurses will check to make sure you don't have any allergies.
- You will meet a special nurse called a **Stoma Nurse Specialist**.
- This nurse will help you choose the best place on your tummy for the stoma. A stoma is a small opening where pee will come out into a bag.
- The nurse will draw a mark on your skin with a pen to show the right spot.
- The doctor needs to see this mark during the operation. Do not wash it off.

What happens during the operation?

- The doctor makes a cut in the lower part of your tummy.
- They will take out your bladder through this cut.
- Sometimes, the doctor makes very small cuts. They use special tiny tools through the small cuts to remove your bladder. This is called keyhole surgery. A robot may also be used.
- In some men, the doctor may also take out the prostate gland.
- The tubes that carry pee from the kidneys to the bladder are called ureters.
- The doctor will join your ureters to a small piece of bowel. This comes out through your tummy to make a stoma.
- Pee will flow out through this stoma into a soft bag. This is called a urostomy.
- Some people may have a new bladder made from part of their bowel. This new bladder holds pee inside the body.
- If you have a urostomy, small plastic tubes will come out of the stoma. These are called stents. They help the body heal and stop pee from leaking.
- After making the stoma, the doctor will join the two ends of the bowel back together.
- The cut in your tummy will be closed with stitches or clips.
- A drainage bag will be attached to your stoma to collect pee.

What to expect after the operation

- You will usually stay in hospital for about 2 weeks.
- The drains in your body will be taken out once they stop collecting fluid. The small tubes in your stoma are called stents. They are usually taken out 2 weeks after the operation.
- The stitches or clips in your wound will be taken out after 2 weeks.
- Let your docotor know right away if:
 - you get a high temperature
 - you start being sick
 - your tummy hurts in a way you did not expect
- The hospital will give you advice to help you recover at home.
- You will get a summary of your hospital stay. Your GP will get a copy too.
- Any tablets you need, such as antibiotics, will be given to you before you leave hospital.
- You may feel very tired for a few weeks. This is normal and should slowly get better.

What happens before you go home?

Your medical team will tell you how the operation went. You should:

• ask questions. You should know what has been done

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- ask the surgeon if everything went as planned
- let the staff know if you have any pain or discomfort
- · ask what you can and cannot do at home
- make sure you know what happens next
- get advice about how to look after yourself at home
- be told what to look out for when you get home
- ask when you can start doing the things you normally do
- be told who to contact if you have problems

Possible after-effects of the procedure

Most people recover well, but there are some things that can happen. Everyone is different. Your doctor will talk with you about what these risks might mean for you.

Almost everyone:

- In men, the part of the body that carries sperm is removed during the operation. This means they will not be able to make a baby.
- Some men find it hard to get an erection. This means the penis may not become firm. This can happen if the nerves are damaged during the operation. Sometimes, the nerves can be saved, but not always.
- If you have a new bladder made from your bowel, you will need to use a soft tube called a catheter. This is used to drain your pee. You will need to do this a few times each day. You will be shown how to do this. Over time, this becomes easier to manage.

Common problems. These happen to more than 1 out of every 10 people:

- Pee infections that keep coming back.
- Having stringy or sticky stuff in your pee. This is called mucus.
- Still feeling pain in the bladder area, even after the bladder is taken out.
- You may bleed a lot during surgery. If this happens, you may need to be given some blood.
- If you have a new bladder made from your bowel, you may leak pee at first. This often gets better. Some people still leak, especially at night.
- Your bowel may stop working for a few days. This can make you feel sick, bloated or cause you to be sick.
- You may need a drip to give your body water.
- You may need to put a soft tube in your nose. This goes down the back of your throat into your tummy. It will help your tummy feel better until your bowel starts working again.

Occasional problems. These happen to about 1 out of every 50 people:

- The level of salt or acid in your blood may change. This can make you feel unwell and may need treatment.
- The skin around your stoma may become tight, lumpy or weak. This can cause swelling or make it hard for pee to come out. You may need another operation to fix it.
- You may get pee infections that keep coming back for a long time. These may need medicine or other care.

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- The place where the doctor made the cut may swell or bulge. This is called a hernia. It may need another operation to repair it.
- The tubes that carry pee from your kidneys may become narrow or blocked. This can stop pee from flowing properly. You may need more surgery.
- Problems after the anaesthetic. This might be a stroke, chest infection or heart attack. This might need treatment in the Intensive Care Unit. Some of these problems may cause death.
- If you have a new bladder made from your bowel, hard lumps may form inside it. We call these bladder stones. These may need treatment.
- Sometimes, the doctor starts with keyhole surgery but finds it too hard to continue. In that case, the doctor may need to make a bigger cut to finish the operation.
- If you have a new bladder made from your bowel, your body may take in too much acid from it. This can change the balance of chemicals in your blood and make you feel unwell. To help with this, you may need to take special tablets called bicarbonate tablets.

Rare problems. These only happen to about 1 out of every 250 people:

- You may need another operation if:
 - o there is bleeding or leaking from the bowel
 - o there is bleeding or leaking from pee tubes
 - o the bowel becomes blocked
- Scarring or narrowing around the stoma. This may need treatment or another operation.
- You may get loose poo called diarrhoea. This sometimes happens when part of your bowel
 is taken away. If the diarrhoea does not stop, you could lose vitamins. You will need to take
 food supplements.
- Scarring in the bowel or in the tubes that carry pee from the kidneys. This may need more surgery.
- Damage to the bottom part of your bowel during the operation. If this happens, the doctor may need to make a new opening on your tummy for poo to come out. This is called a colostomy. It is usually temporary.
- If you have a new bladder made from your bowel, it may tear or burst. This can cause pee to leak inside the body. If this happens, you may need another operation.
- Your kidneys may not work as well over time.
- In rare cases, problems from the operation can lead to death.

Risk of getting an infection in hospital

About 6 out of 100 people get an infection whilst they are in hospital. This includes MRSA or C. difficile infections. The risk is higher if you:

- have a tube in place for a long time
- have had your bladder removed
- stay in hospital for a long time
- have been in hospital many times

General information about your operation

Before your operation

Tell your team if you have implants. These are things like:

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- o a pacemaker
- o a joint replacement
- Tell your doctor if you take blood-thinning tablets.
- If you have ever had MRSA, you should tell your doctor.
- You should tell your doctor if you may be at risk of variant-CJD. This might be if you have had:
 - a corneal transplant
 - o a neurosurgical dural transplant
 - o human growth hormone treatment
- You can ask your doctor about their own results and experience with this operation.

Smoking and surgery

Smoking makes surgery riskier. Stopping before your operation helps. For help to stop smoking, call the NHS Smoke-Free Helpline: 0300 123 1044.

Driving after surgery

You must make sure that you are well enough before driving again. Talk to your doctor about this. If you cannot drive for more than 3 months, <u>tell the DVLA</u>. You should also check with your insurance company before driving again.

Important

We have worked hard to make this leaflet clear and correct. But it cannot replace advice from your own doctor or nurse. Always ask them if you are worried or unsure.

What should you do with this leaflet?

You can keep this leaflet. If you have more questions, ask your doctor or nurse. They can explain more.

Online access

You can see this leaflet on the internet. Scan the special picture (QR code).



https://rb.gy/hxau1p

Feedback

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We'd love to know what you think! You can share your thoughts by emailing us at admin@baus.org.uk

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Questions and notes

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