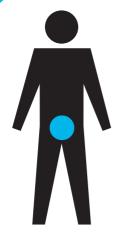


PROSTATE INFORMATION

SPOTLIGHT ON

Caring for your indwelling catheter at home





Introduction

There are several reasons why some individuals need an indwelling catheter (indwelling means it stays inside your body for a period of time) to drain urine from the bladder out of your body. Sometimes a catheter is needed for just a short time whilst for others, depending on the reason for having a catheter, it may be needed longer or permanently. The urologist, clinical nurse specialist (CNS) or nurses on the ward will explain why you have to have a catheter. You may be asked to sign a consent form before the catheter is put in place.

When you are ready to go home, your urologist or CNS will let you know how long you might need to have the catheter. The nurses on the ward or in the clinic will show you how to look after your catheter before you go home.

You may be given a **'Urinary Catheter Care Passport'** (see page 17 for more information). This is a booklet to help you and the whole medical team looking after you keep an accurate record of caring for your catheter and share/pass on important information to all those involved in your care. A district nurse may be organised to check on you when you get home, if it is felt that you may need assistance.

So, although you and your family may feel a bit anxious to hear that you are going home with a catheter and it may even sound a bit frightening at first, there are many people that you can contact for help and advice. If you have a catheter after radical prostatectomy you will be told who to contact should there be a problem with your catheter. If you have a catheter for another reason, it may be the community nurses you should contact. The district nurse (or community care team) may be involved in helping you care for your catheter when you are discharged from hospital.

In some areas there may be a continence care service/team or a continence advisory service. You can ask the CNS or your GP if there is such a service in your area.

It's important to remember that if you have a catheter because you have had a radical prostatectomy, then you (nor anyone else, including district nurses) should not try to remove it or change it. Instead, contact the CNS or ward staff in the hospital you attended for more help and advice.



Throughout the leaflet, information is given as a guide on how things might be done. However, as there may be more than one approach to caring for your catheter, if you are given specific information by your urologist, CNS or GP then it is important you follow their instructions and guidance.

What is a catheter?

A catheter is a long, thin, flexible, soft hollow tube that is used to drain urine out of your bladder into a drainage bag outside your body.

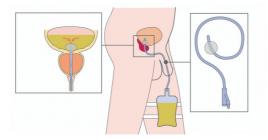


Image reproduced with kind permission of Orchid male cancer, www.orchid-cancer.org.uk

How is urine normally made and passed?

The kidneys constantly filter waste products from the blood to produce urine. Urine passes out of the kidneys, down two thin tubes called the ureters that empty into the bladder.

The bladder is a hollow organ that is made up of layers of muscle tissue. As it is made up of muscle tissue, the walls of the bladder can relax and stretch to store urine. When the bladder is empty it's about the size of a pear. It sits below and behind the pubic bone and above the prostate.

When the bladder is about half full, this triggers a need to pass urine. The bladder wall then squeezes to empty the bladder, when socially convenient, and urine then passes out of the bladder, down the urethra and out of the body.

If there is a difficulty with passing urine, then a catheter may be needed and is put into the bladder.





Why might I need a catheter at home?

Catheters may be used when:

- You can't pass urine into the toilet or urinal in the normal way. This can be for a number of reasons
- Sometimes during an operation to keep the bladder empty
- If your urologist, CNS or GP wants to rest your bladder and give it time to heal after an operation
- Sometimes after an operation such as a transurethral resection of the prostate (TURP) or radical prostatectomy to allow the area to heal.

What are the different parts of the catheter?

- Catheter tube placed into the bladder
- Leg bag to collect urine during the day
- Catheter valve if you don't need a catheter bag
- Night drainage bag which is larger to collect urine overnight
- Support for the catheter either a net bag or elastic straps
- Catheter bag stand may be used with a night bag.

How is a catheter put into the bladder?

Before a catheter is inserted, your urologist, CNS, nurse on the ward, or GP will talk through with you why you need a catheter and how long you may need to have it in place. Then it's just a case of letting the medical staff know that you agree to have the catheter. (You might hear this called catheterisation or being catheterised.)

There are two ways catheters can be put into your bladder:

- 1. The tube can be passed through your penis into your urethra (water pipe). This is called a urethral catheter.
- 2. Under local anaesthetic, or sometimes general anaesthetic, a small cut is made in the lower part of your tummy just above the pubic bone and the tube is passed through this. This is called a supra-pubic catheter and is fitted when a urethral catheter can't be used or if you are having a catheter for a long time.



No matter which kind of catheter you have (urethral or supra-pubic), caring for your catheter will be the same.

A catheter may be passed into your bladder under local anaesthetic by your health care professional or if you have had an operation it may be put in place during the procedure.

When the end of the catheter is inside your bladder a small balloon near the tip of the catheter is filled (or inflated) with sterile water. This keeps the catheter in place and stops it from slipping out.

Urine can be drained from your catheter either using a drainage bag or by using a catheter valve.

If you are using a drainage bag, instead of collecting in the bladder, urine drains straight down through the catheter into a drainage bag.

With a catheter valve (sometimes called a flip-flow valve) the urine will stay in the bladder until you open the valve, so you will probably have the sensation of having a full bladder as normal. Urine can be drained from the bladder into the toilet or a container via the catheter using the catheter valve. A catheter valve is not suitable for everyone with a catheter, so ask your CNS, urologist or nurse if it is suitable for you.

Because the small balloon is inflated inside your bladder, it needs to be deflated or let down before taking the catheter out, so you should **never** try to take or pull the catheter out yourself (unless you have been shown how to do this by the urologist, CNS or GP). In some instances, if medical staff think it necessary, you may be given antibiotics around the time the catheter is to be taken out.

At home, it is a good idea to check over the tube every day to make sure that it doesn't have any kinks in it, make sure the bag is emptied and held in a comfortable position.

There is a catheter retainer device that prevents pulling on the catheter as this pull can be very uncomfortable.





How long might I have the catheter?

This will really depend on the reason why you have the catheter. The urologist, CNS, nurse on the ward, or GP will most likely chat this over with you and give you an idea when the catheter is likely to be taken out. Some catheters are more suitable for only a short time whilst others can be left in place for anything up to 12 weeks.

What might be some of the early side-effects of having the catheter put in place?

It's quite common to feel a bit uncomfortable or a bit sore when the catheter is first put in place, and you may still feel you need to pass urine. If you come across these troublesome side-effects they shouldn't last for too long.

You may notice a little pinkness or slight staining with blood in the drainage bag when you first have the catheter. If the urine becomes heavily blood stained or you notice blood clots you should contact your CNS, GP, NHS 24 or any specific number you have been given by the medical team at hospital.

Sometimes you might feel strong contractions of the bladder muscles (called bladder spasms) that can be quite painful, making you feel like you need to go to the toilet. Bladder spasms may cause a little urine to leak out alongside, rather than through, the catheter. Let the CNS, urologist or nurse on the ward know as they can give you some medicine to help relieve the spasms.

You may be asked for a sample of urine to check for a urine infection.

It's not unusual to see a milky coloured discharge around the catheter, so don't be concerned about this.

Particularly if you have had surgery on the bladder or prostate it may be expected that there could be some blood in the urine.

What is a drainage bag?

The outer end of the catheter is usually attached to a drainage bag to collect urine. There are two types of drainage bag:

 A leg bag. This might be worn on your thigh or lower down your leg on your calf. Some people prefer to have a longer length drainage tube that can be worn on the calf so it's not so noticeable and the bag can be emptied easily;



Overnight bag. These are larger bags that hold more urine so that you
don't need to get up during the night to empty the bag. These are
attached to your leg bag. Once you've attached the overnight bag to your
leg bag, don't forget to leave the leg bag tap open so urine can drain into
the overnight bag. Always make sure that the connections are tight so you
avoid any leaks or the connections coming undone during the night.

Before going home, the nurse will show you how to join the two bags together.

You will be given an elastic strap or special net bag to hold the drainage bag in place so that the weight of the bag doesn't pull on the catheter as this can be very uncomfortable.

Catheter valves

You may be offered the choice of having a catheter valve. When you have a catheter valve, urine will stay in your bladder until you open the valve, and you may have the sensation of having a full bladder. This is not suitable for everyone and your urologist or CNS will decide if this is an option for you. The valve is fitted at the outer end of your catheter and can be held in place with leg straps or can be loose. It acts like a tap that can be turned on or opened to drain urine from the bladder and can be turned off or closed to stop urine flowing out of the tube. When the valve is open, urine can be drained into the toilet, a container or into a drainage bag.

You should open the valve every few hours or when you feel your bladder is full then remember to close the valve again.

The possible benefits of having a valve are:

- It may allow you to get around more easily
- It's not as noticeable and may be more comfortable
- It preserves the normal filling and emptying cycle of the bladder so helps keep the bladder in good condition and maintains bladder tone (or keeps the bladder muscles healthy, fit and ready to use).

Like the drainage bags, the valve needs changed once a week. To help prevent infection it's important to follow the steps given in the section on how to empty the leg bag, or follow the instructions that you were given by staff on the ward.





How often should I empty the bag?

The leg bag should be emptied when it is about half to a maximum of twothirds full, so it doesn't become too full and heavy and pull on the catheter.

The overnight drainage bag just needs emptied in the morning.

If you are using a catheter valve, then open the valve every few hours or when you feel your bladder is full.

What position should the drainage bag be in?

The leg bag should be attached to the leg below the bladder whether you are lying, sitting, standing or walking.

How is a drainage bag attached to my leg?

It's important that the bags are well supported so they don't pull on your catheter. Not only can this be uncomfortable, but it may cause some problems. You will usually be given either elastic straps or a net sleeve to hold the bag in place.

When you connect the overnight bag to the leg bag you can either loosen the elastic straps or take them off completely.

How do I empty the leg bag?

The CNS or nurses on the ward will most likely show you how to do this before you leave the ward. Because the catheter goes directly into your bladder it can be a way of infection (germs) getting into your bladder. Preventing an infection is important so it's best if you follow these simple steps:

- Before touching your leg bag, always wash your hands thoroughly with an un-perfumed soap. It might be best to use an anti-bacterial handwash from a pump dispenser and an alcohol-based hand gel. Make sure you carefully clean between your fingers and thumbs as these seem to be the areas most commonly missed
- Don't forget to rinse your hands well under running water. Use a clean towel, making sure your hands are properly dried
- Open the tap at the bottom of the bag and drain urine into the toilet bowl
- Close the tap
- Wash and dry your hands.



Some people may be asked to keep a record of how much urine they pass. This can be done by opening the tap on the leg bag or catheter valve and passing the urine into a measuring jug before flushing down the toilet.

What should I do with the overnight drainage bag?

The nurses on the ward will most likely explain all this to you before you go home. Again, it's important that you (or if someone is doing this for you) follow the simple hand-washing steps. The overnight bag is attached to the leg bag and should be kept lower than the bladder. As these bags can hold up to 2 litres, you shouldn't have to worry about getting up during the night to empty the bag. Don't allow the bag to lie on the floor, always support it on a stand or support hanger.

In the morning, disconnect the overnight bag then empty and dispose of the bag. Some bags can only be used once whilst others can be used for more than a week, so some hospitals may ask you to use the overnight bag again. If this is the case, empty the overnight bag, and store in a safe clean place. Ask the district nurse, ward staff or whoever is looking after your catheter, what you should do with your overnight bag.

How often should I change the leg bag?

The leg bag and/or catheter valve needs to be changed every 5-7 days. If you do this any more frequently then you may run the risk of introducing an infection into the bladder.

What do I do with the empty bags or catheter valves?

The emptied bags or valves can be wrapped in several sheets of newspaper or put inside 2 plastic bags, sealed and put into the non-recyclable household rubbish bin. You shouldn't try to burn these. Ask the CNS, nurse on the ward or district nurse for more advice on how to dispose of the bags and valves in your area, as this can differ from area to area.

How often might the catheter be changed?

To a large extent, this depends on the reason for having the catheter. Depending on the type of catheter it can stay in place for between 2-12 weeks before needing changed. If your catheter needs to be changed then often a district or community nurse will do this for you.



If you have a catheter following a radical prostatectomy (your whole prostate being taken out), then you should never allow anyone (even district nurses) to take out or change your catheter.

Contact your CNS or nurses on the ward that you were in for more help and advice.

Looking after your catheter

The most important thing that you can do is to keep your catheter, and the area around the catheter, very clean. This helps cut down the risk of any bacteria (germs) getting into the catheter that may lead to you developing an infection and helps keep your catheter working properly.

Take the following steps to cut down your risk:

- Always wash your hands thoroughly before and after handling your catheter (see handwashing details on page 8)
- Wash the area where the catheter enters your body and wash down
 the catheter tube about twice a day without pulling or tugging on the
 catheter. It may be a good idea to keep a separate cloth just for this
- If you have a foreskin, wash underneath, rinse well and dry thoroughly. Make sure you put the foreskin back over the tip of the penis. If you do not it may become swollen and painful. If your foreskin is too tight then don't try to pull it back as you could hurt yourself. If this is the case, then let your CNS or nurse on the ward know and they can advise on another way to clean under the foreskin
- You can have your normal daily bath or shower. Some people much prefer
 to have a shower when they have a catheter. Before showering or bathing
 empty your drainage bag, but don't disconnect it and then take off the
 support you use to hold your bag. Afterwards, dry the drainage bag and
 attach again with the straps or sleeve
- Don't use any ointments or creams (unless prescribed by your doctor),
 perfumed soap or talcum powder around the catheter area as this could
 cause an irritation or increase the risk of infection. In fact, some ointments
 may actually damage the catheter. If you are unsure of what you can use
 ask the CNS, district nurse, or your local pharmacist for more advice.



Is there any special advice on drinking fluids?

It's recommended that you drink enough fluid each day, about $1\frac{1}{2}$ - 2 litres (about 6-8 large glasses) with water being best.

This helps:

- Make sure that the urine remains clear
- Your catheter drain properly
- Flush out the bladder and means urine is more dilute. This may help reduce the risk of infection
- Having enough fluid to drink each day can help if constipation is a difficulty.

If, for any reason, you are on a fluid restriction, then please ask the urologist, CNS or GP for more advice.

It's thought that cranberry juice may have a beneficial effect in helping reduce the risk of infection, but you shouldn't drink more than 2 small glasses spread throughout the day. You can also buy concentrated cranberry supplements. Before taking any form of cranberry, it's best to check with your urologist, CNS, GP or local pharmacist if this is suitable for you as cranberry can affect the way that certain medicines work. For instance, you should avoid cranberry if you take warfarin or if you suffer from irritable bowels. If you are diabetic, you need to be aware that cranberry contains natural fruit sugar, so it's probably best to avoid it.

Caffeine can irritate the bladder so it would make sense to cut down on the amount of caffeine that you drink. Caffeine is found in black tea, ordinary coffee, some herbal teas and to a much lesser extent green tea. Cola type drinks, energy and performance drinks and energy shots contain high amounts of caffeine.

Alcohol is a diuretic which means that it can increase the amount of urine produced. It can also irritate the bladder and should be avoided when taking certain medications. Ask your CNS, urologist, GP, nurses on the ward or local pharmacist for more advice about alcohol in your particular circumstances.



If constipation is a difficulty....

When you have a catheter and have problems opening your bowels or are constipated this can cause difficulty in two ways:

- 1. If your bowel is full, it can press on your bladder, stopping urine from draining and this may block your catheter
- 2. If you have to strain or push to open your bowels this can put pressure on your bladder and affect your catheter, potentially causing some leakage.

Avoid constipation by having a healthy well-balanced diet that includes at least 5 portions of fruit and vegetables each day. Having enough fibre in your diet helps too, so try to have wholegrain cereals and wholemeal bread as part of your diet. If constipation is a problem for you, let your GP, CNS or district nurse know as they may be able to prescribe a laxative to help.

What if I find I'm in pain?

If you find that you are in pain from your catheter, let your CNS, GP, district nurse or urologist know, and they may be able to prescribe something to help with any discomfort.

Is there anything else that I can do?

When you feel able, you may be advised to try some gentle exercise such as going for a walk as this may encourage the catheter to drain better. Always check with your CNS, district nurse or GP before beginning to exercise.

If you notice any discharge or leakage around your catheter, let the CNS at the hospital you attended, district nurse or GP know about this.

Check around the catheter area regularly for any signs of irritation or redness.

What if my catheter leaks?

- This may be caused by strong contractions of your bladder, called bladder spasms or cramps. These may be due to the bladder trying to get rid of the small balloon that is keeping the catheter inside the bladder. Let the CNS, district nurse or GP know as they may want to check your catheter, perhaps giving you a special medicine to help relax the bladder
- A small sample of your urine may be taken and checked for any signs of infection



- There may be a temporary blockage causing the leakage
- It may happen if you have to push or strain to pass a bowel movement
- If your catheter happens to leak, you may like to be prepared for those 'just in case' situations by having a waterproof sheet or pad on your bed or favourite chair. There are different types of pads that you can buy that will soak up leaks although these may not be specifically designed to help with leakage of your catheter
- Before going to bed check that all the connections are tight. Check that the connection between the leg bag and night bag is open.

What about intimacy if I have a catheter?

If you were having intercourse before you had your catheter fitted, then it's usually possible to have intercourse with a catheter in place, especially if you have a supra-pubic catheter.

Before intercourse you should both wash your intimate areas. You should empty the drainage bag. In **certain circumstances**, it may be possible to disconnect the drainage bag and use a valve to stop urine draining. Afterwards, remember to attach the bag so urine can start draining again. You should **not** attempt to take the catheter out by yourself unless you have been specially trained by the CNS or urologist how to do this safely.

Once you have an erection, fold the catheter tube along the shaft/length of your penis, tape the tube out of the way then roll a condom over both your penis and the catheter. You can use water soluble lubricating jelly (such as KY jelly) if you need to. This won't affect the catheter. You should not use Vaseline as this isn't water-based. If you need more advice on which type of lubricating jelly to use, ask the CNS, district nurse or local pharmacist.

Make sure you wash around your catheter after having intercourse.

If this is something that you want to find out more about, don't be embarrassed to ask for advice from the CNS, district nurse or your GP.



What should I do if urine stops draining into the bag?

- Check the tube to make sure it's not blocked, twisted or has a kink in it
- Check that any drainage bag (leg or overnight bag) is below the level of your bladder whether you are lying down, standing or sitting
- Check that you are having enough fluid to drink ($1\frac{1}{2}$ 2 litres), about 6-8 glasses or 8-10 cups of fluid every day
- Check your drainage bag doesn't need to be emptied.

After you have finished all the checks and if urine is still not draining into the bag there could be a blockage in your catheter. You should contact your CNS, district nurse or GP as a blockage needs to be treated urgently. Out of hours or at the weekend you should get in touch with NHS 24 on 111. This service is available 24 hours a day, 365 days a year. Calls are free from landlines and mobile phones.

What if my catheter is painful?

- Check that the catheter tube is held in place
- Check that the drainage bag is properly supported by the elastic straps or net sleeve so it's not pulling on the catheter tube
- Check that the drainage bag is not too full
- Don't tug or pull the catheter tube
- Check that your foreskin is in the right position
- Speak to the CNS, district nurse or GP as they may prescribe some anaesthetic jelly around the catheter at the tip of the penis.

Are there some signs I should look out for?

Even if you've followed all the advice given, some difficulties may still occur. Look out for:

- Urine not draining into the bag in the past few hours
- Your catheter appears to be blocked
- Your catheter has slipped back or fallen out
- You have a pain in your lower tummy (abdominal) area, and you feel that your bladder is full
- The entry area of the catheter becomes red, swollen or tender.



Who should I contact?

If you have any concerns about your catheter, you should get in touch with the CNS at the hospital you attended or where you had the catheter put in place, GP or district nurse.

Urinary Tract Infection (UTI)

Because your catheter can provide a direct path for bacteria (germs) to get into your bladder, you may develop a UTI. When you have a catheter, it's not unusual for your urine to be slightly cloudy and have a strong smell.

However, if you notice any of the following signs it's important to get in touch with your CNS, district nurse, GP or out of hours NHS 24 by calling 111 as a UTI needs to be treated:

- Your urine is cloudy and has a strong smell
- Your urine becomes very blood stained or you notice some clotted blood. It's quite common for your urine to be very lightly stained with blood
- Feeling feverish (shivering, shaking, sore muscles)
- A high temperature, above 37.5°C
- Chills
- Feeling sick
- Headache
- Low back pain
- Feeling unwell and very tired.

If your healthcare professional thinks it's necessary, then they may prescribe a course of antibiotics. It's very important to take all of the tablets, even if you feel better before you finish them.

Your catheter will most likely be changed too.

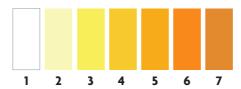




When checking urine in my catheter bag, what colour is urine normally?

Normal, healthy urine is a pale straw or clear yellow colour similar to colours 2/3.

What is the colour of your urine?



Some medications and foods can cause urine to be a different colour.

Going home

You will most likely be given a small 'take home' catheter and incontinence pack from the ward, that may include night drainage bags, long or short leg drainage bags, a catheter stand, net pants and a pack of incontinence pads.

If you need further supplies, then your GP may give you a prescription and the district nurse can also help advise on how you get additional items. Sometimes you can ask for these to be delivered from the pharmacy straight to your home.

In some areas there may be a continence advisory service. There's no harm in asking if there is such a service in your area. They can help with catheter and continence issues and help answer any questions. Your GP may decide to refer you to this service for specialist advice right from the start or you may be able to get in touch with them yourself.

How should I store all the supplies for my catheter?

It's best to keep all the catheters, drainage bags and any other equipment in the original packaging in a cool, dry place. It's probably best to store any spare catheters flat rather than standing upright. An ideal place to store these would be in a cupboard or wardrobe out of direct sunlight.



Who should I contact for help or if I have any concerns or questions?

Please follow any advice you were given from the ward on who you should contact if you have any difficulties. You may even have been given a number that you can call for help. Your CNS, district nurse or GP will most likely be able to help with any difficulties or answer any questions.

Urinary Catheter Care Passport

If you are being discharged home with a catheter, you may be given a 'Urinary Catheter Care Passport'. This is a booklet to help you and the whole medical team looking after you keep an accurate record of caring for your catheter and share/pass on important information to all those involved in looking after you and your catheter.

The passport is for you to keep while you have your catheter and very importantly **take with you to all your healthcare appointments**. (e.g. GP, CNS, urologist or district nurse).

The first section in your passport should be filled in with all the essential contacts that you may need. There's also a guide on what the catheter is and caring for your catheter on a daily basis.

The clinical section should be completed by any member of the medical team who has looked at or made any changes to your catheter, so everyone has an accurate and up-to-date record of what has happened. This is why it's so important **to take your 'passport' to all your medical appointments**.

Once you no longer need a catheter, please don't throw the passport out but return it to your GP, district nurse, CNS or urologist so it becomes a part of your medical records.

Trial without catheter – TWOC or TOV (trial of voiding)

When the CNS or urologist thinks or decides that you no longer need a catheter, you will be given an appointment to have the catheter taken out. You may hear this called **TWOC** or trial without catheter or **TOV** or trial of voiding (voiding means passing urine). This trial is to make sure that you can pass urine when the catheter is taken out. It will usually be done in a





day bed area in a hospital or clinic, so that urology staff can check on how things are going. For some people it may be carried out at the person's home with the community nursing team overseeing and managing this.

You should be well hydrated before your appointment so your bladder fills up reasonably quickly and you will also be asked to continue to drink while you are at the appointment or during the trial. It is best to avoid caffeinated drinks as these can irritate the bladder and make you feel like the bladder is full before it actually is.

You may be asked to attend a local hospital to have the TWOC or TOV done. If you're attending a hospital appointment, you may be required to stay until you have voided (passed) urine 2 or 3 times, so it could take a few hours.

Alternatively, some community nurse teams have a scanner, and these teams may even do the TWOC or TOV, removing the catheter in the morning then returning in the evening to do a scan.

You should ask at the clinic (your urologist or CNS) if you should continue with the medicines that you were taking previously.

The following is general information about how a TWOC or TOV might be carried out. If you have been given specific information from the hospital that you attend it is important to follow their guidance and instructions.

- It's not usual for you to be given antibiotics before removing the catheter.

 The hospital team may prescribe an antibiotic if they think it may be necessary
- Removing the catheter shouldn't be painful but may be a bit uncomfortable. The nurse will remove water from the balloon that is holding the catheter in your bladder. You won't feel this. The removal of the catheter will only take a couple of seconds
- If you are in a clinic, you will need to fill up your bladder and once you
 need to pass urine you may be asked to void (pass urine) into a flow
 machine. Then you may have your bladder scanned to see how well your
 bladder is emptying
- You may have a slight burning or stinging feeling when you pass urine for the first few times after the catheter has been taken out



- If you can pass urine and feel comfortable with it, you will probably be able to go home and you might be given a follow-up appointment for a few weeks. If you're having any difficulties passing urine, then you may need to have another catheter put in place
- You may be given some pads to take away to prevent and deal with any leakages.

Dealing with incontinence after the catheter is taken out

Once the catheter is taken out, it's quite normal to leak urine for a time. The type of leakage (how heavy it is) and how long it will go on for will vary from person to person. Straight after the catheter is taken out, this leakage can be sudden and can be quite heavy at first, but this may not always be the case.

It's quite common to pass urine frequently for the first couple of hours after the catheter has been taken out, sometimes as often as every half hour. This should settle down over a couple of days.

To help with any leakage, you will most likely need to wear pads inside your underwear. If you have difficulties with incontinence, then get in touch with the CNS, continence care or advisory team or your local pharmacy for more advice. Most people will become dry within a matter of weeks or months but for some people leakage can go on for longer.

You may find the following websites to be really helpful: www.continenceproductadvisor.org/prostatecancer/surgeryandacatheter www.continenceproductadvisor.org

Pelvic floor exercises

Pelvic floor muscles are sometimes described as being like an elastic hammock that stretch from your pubic bone at the front of your body through to your coccyx, the small bone at the bottom of your spine and from side to side. They play a role in supporting other organs inside your body and also play an important part in helping to control your bladder (and bowel), so stopping any leakage or dribbling.

After any operation on your prostate, to help with any leakage or dribbling of urine, you should start pelvic floor exercises (PFE) as soon as your



specialist physiotherapist, urologist or CNS recommends. You may even have been given information about how to do PFEs at your pre-assessment clinic, so you may have started PFEs before your operation. To find out more and how to do these see our booklet on 'Pelvic Floor Exercises' or go to our website https://www.prostatescotland.org.uk/wp-content/uploads/resources/Pelvic-floor-exercises-before-and-after-surgery-to-remove-the-prostate.pdf

The specialist physiotherapist, nurses on the ward or CNS will be able to give you more advice on PFEs if you're having any difficulties.

Online films of how to do PFEs

Two films by advanced practitioner physiotherapists at the Western General Hospital in Edinburgh explaining more about PFEs before and after prostate surgery are available on our website at https://www.prostatescotland.org. uk/help-and-support-for-you/pelvic-floor-exercises

Before using the pelvic floor exercises booklet or the films, please **always** check with your specialist physiotherapist, CNS, urologist, GP, or nurse on the ward that these are suitable for you.

Apps that may be helpful

Prostate Scotland

Prostate Scotland is currently developing an App, please check our website *www.prostatescotland.org.uk* for further details of when the App will be available. Within the App there will be the facility to set reminders of when to do PFEs.

Squeezy

There is an app available called Squeezy. This app reminds you when you need to do PFEs, and you can record the PFE you've done. It comes with a set of standard exercises but can be changed to suit you and fit into your lifestyle.

At the time of writing (September 2021) this costs £2.99 and is available for iPhones from the App store https://apps.apple.com/gb/app/squeezy-for-men-the-nhs-physiotherapy-app-for-pelvic/id929618748
For android phones it is available from Google play Squeezy https://squeezy-men-nhs-pelvic-floor.soft112.com/



Before purchasing or using any App, please check with your specialist physiotherapist, urologist, GP, CNS, or nurse on the ward to make sure that this is suitable for you.

Toilet card

You may find it helpful to get a 'toilet card' which explains that the holder has a medical condition and may need to use a toilet urgently.

https://www.bladderandbowel.org/help-information/just-cant-wait-card/https://www.ageukincontinence.co.uk/toilet-cardhttps://be.macmillan.org.uk/be/p-24952-macmillan-toilet-card.aspx

After your catheter is removed

Once you're home you should keep an eye out for the following signs:

- You need to pee frequently
- You only pass small amounts of urine when you go
- You have pain or a lot of discomfort in the lower part of your tummy
- You feel your bladder is full, but you can't empty it completely
- It's difficult to start to pee
- It's painful when you pee.

These could be signs that you are retaining urine, called urinary retention. You should contact your GP, CNS or NHS 24 for more guidance.

Getting more information

If you have any questions about your catheter and looking after your catheter at home then it may be a good idea to write these down and speak to the CNS, urologist, GP or district nurse.

Compass

Prostate Scotland is currently developing a range of support and wellbeing services to help people across Scotland navigate prostate cancer. It's called our COMPASS project and in time it will cover information, courses, exercise programmes, workshops and support services for people with prostate cancer and disease. Visit www.prostatescotland.org.uk/help-and-support-for-you to see what's available.





We currently offer the opportunity to speak to a Cancer Support Specialist through a joint initiative with Maggie's in some areas of Scotland. The Cancer Support Specialists have expert knowledge of prostate cancer and you can speak to them face-to-face at a Maggie's centre, on the phone or by video call.

Our special, online exercise programmes for people with prostate cancer can be found on our website https://www.prostatescotland.org.uk/help-and-support-for-you

Please check with your CNS, oncologist, urologist or GP that the programmes above are suitable for you before starting to exercise.

Whether it's talking through being diagnosed with prostate cancer, chatting about your treatment options, speaking about your symptoms and side-effects or the impact it's had on your life, this service can help.

We also offer a 'Living Well with Prostate Cancer' course for people undergoing treatment or when treatment has finished. We take a look at side-effects and how to minimise them, the practicalities of having prostate cancer along with many other topics.

For more information visit www.prostatescotland.org.uk/help-and-support-for-you.

Additional resources that you may find helpful:

Spotlight on incontinence as a symptom of prostate disease.

Spotlight on pelvic floor exercises before and after prostate surgery.

Early prostate cancer explained.



Our work:

All our awareness materials, introductory guides, explanatory guides and 'Spotlight on' guides such as this booklet are available free of charge to individuals and their families and all healthcare settings.

If you found the booklet helpful, you can help us reach many more people with awareness and information about prostate disease and prostate cancer by doing the following:

- Obtaining and wearing a Prostate Scotland badge
- Volunteering some of your time
- Taking part in or organising a fundraising event or making a donation.





This booklet has been compiled by Prostate Scotland with advice from PAGES (Prostate Advisory Group Prostate Scotland). Prostate Scotland acknowledges the help and support from the members of the group:

Professor Alan McNeill, Consultant Urologist, Western General Hospital, Edinburgh (Co- Chair of PAGES) Mr. Ben Thomas, Consultant Urologist, Western General Hospital/ Borders General Hospital, Edinburgh (Co-Chair of PAGES)

Mr Feras Al Jafarri, Consultant Urologist, NHS Fife

Dr David Astill

Derek Brown

Brian Corr, Urology Clinical Nurse Specialist, Raigmore Hospital, Inverness Alan Dickinson

Dr Andrew Dunlop, General Practitioner Principal, East Calder Medical Practice, West Lothian Sioned Hancock, Advanced Physiotherapy Practitioner, Western General Hospital, Edinburgh Scott Little, Clinical Nurse Specialist, Western General Hospital, Edinburgh Bill Taylor,

Ashleigh Ward, Lecturer, Dundee University
Prostate Scotland staff: Adam Gaines, Director. Mae Bell, Information and Advice Manager

The information contained in this leaflet has been developed by Prostate Scotland and reviewed by its Advisory Group of doctors, nurses and patients. This leaflet is not intended to replace medical advice or seeing a doctor for specific illnesses or symptoms.

Prostate Scotland gratefully acknowledges the generous donation from the Grand Lodge of Scotland for funding the Information and Advice Project in 2021.

The Information and Advice Project was originally funded in 2009 thanks to initial grants from the Scottish Government and Sir Tom Farmer through the Farmer Foundation.

Contact Us

Prostate Scotland, 14 Torphichen Place, Haymarket, Edinburgh EH3 8DU Tel: 0131 603 8660 (Choose option 1 for information) Email: info@prostatescotland.org.uk www.prostatescotland.org.uk

Date: Reviewed September 2021 @ Prostate Scotland

Prostate Scotland is a charity registered in Scotland (SC037494). Prostate Scotland is a company registered in Scotland (SC306268).





