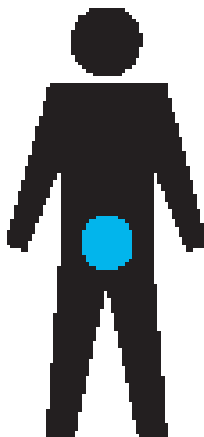




**SPOTLIGHT ON
PROSTATE CANCER SURGERY**

Minimal access radical prostatectomy for prostate cancer



Introduction

Our aim is to help all those affected by prostate problems whether it is the benign condition BPE (an enlarging prostate), the benign disease prostatitis or prostate cancer. It is anticipated that most of our information will be suitable, relevant and helpful for men and those born biologically male who still have a prostate. However, there might be times when your health care (such as appointments and treatment(s)) may be slightly different from our information. Our information will not be as applicable for those men not born with a prostate. Most of our publications will use the term 'you' but there may be times that we will have to use the terms man, men or male.

It might be helpful if you are comfortable and willing to make your healthcare team aware of your gender identity so that they can provide the most relevant information and appropriate health care for you.

You may just have been told that you have prostate cancer and are now facing the decision on which treatment might suit you best. Whilst this may sound daunting to you at first, it has been shown that the more you and your family are involved in helping to make the decision about treatment, the more confident and satisfied you will feel with your treatment choice. It doesn't mean that you need to make this decision on your own; your urologist, clinical nurse specialists (CNS) and other men who have been in this same position will give you information, help and support along the way.

The news that you have been diagnosed with prostate cancer may have come as a shock to you and your family and something that you were not expecting to hear. After being given your diagnosis, you perhaps didn't hear or take in another word that was said. It may be helpful when going to future appointments with the urologist, oncologist or clinical nurse specialist (CNS) if you can have someone go along with you so you can both listen, ask questions and get the most out of your appointment. You may find the Prostate Scotland Cancer Navigator App helpful as, with permission from your health care team, you can record and playback the appointment as many times as you like.

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That is not to take away from how you and your family are feeling right now. It's normal to have a wide range of feelings or emotions – fear, worry, sadness, guilt, anxiety, stress, feeling very low and depressed. Although all these feelings are quite normal, they can have a huge impact on your life and on your family.

The first step is to let someone from your health care team know that you're having difficulty in coping with everything that is going on. There is lots of support out there to help you and your family deal with and cope with your diagnosis. There is more information and some helpful contacts from pages 37- 44.

The main message to hold onto is that treatments are available and, depending on your individual circumstance, some treatments for early prostate cancer can be with curative intent.

This booklet is to help you, your partner and your family understand more about minimal access surgery to remove the prostate. This is called robotic assisted radical prostatectomy (RARP). There are 4 centres of excellence for RARP, so the vast majority of operations in Scotland to remove the prostate will be robotic.

Laparoscopic radical prostatectomy (LRP)

There are some surgeons in Scotland offering laparoscopic radical prostatectomy LRP, sometimes called keyhole surgery.

This procedure has become less common as more robotic systems have become available.

It differs from a RARP as the surgeon will be standing beside the man, directly

using the special keyhole instruments to perform the operation. Most of the information in this booklet will also apply to patients undergoing LRP.

RARP

The booklet covers what RARP is, who it's suitable for, what happens and the advantages and drawbacks of this type of treatment. It may help you decide if this might be the right treatment decision for you. It is intended for those men who have been diagnosed with cancer that is still contained within the prostate. Radical prostatectomy is offered as a cure for cancer that is contained within the prostate. It is called radical because it means the whole prostate is removed by surgery along with part of the urethra that lies within the prostate. At the same time the seminal vesicles that lie next to the prostate are also removed along with the vas deferens. (The seminal vesicles are two sac-like pouches below the bladder and behind the prostate that hold the liquid that mixes with sperm from the vas deferens to form semen.) You may also hear or read about partial or focal gland therapy, which is not a standard of care in Scotland (or indeed the rest of the UK or Europe) but may be offered to some suitable men as part of a clinical trial or a prospective registry study (as per EAU guidelines 2023).

There are other treatments available for prostate cancer, but treatments must be tailored to each individual and some of the following may or may not be suitable in your particular circumstances; active surveillance, external beam radiotherapy (EBRT) and prostate brachytherapy. Your urologist or CNS will talk over which treatments may be suitable for you.

About your prostate

The prostate starts out about the size of a pea then slowly grows reaching the size of a walnut when the man is in his 20s. Around the age of 40, it starts to grow or enlarge again, and this may cause problems for a man when passing urine. Only men and those born biologically male have a prostate. It's found inside the pelvis, just below the bladder and in front of the back passage. It wraps around the tube, called the urethra, which allows urine to flow out of the bladder and for some men semen to pass out through the penis.

Therefore, the prostate can't be seen or checked from outside the body. It supplies a thick, clear fluid that mixes with sperm to form semen, called the ejaculate. This fluid helps to nourish and protect sperm during intercourse. The prostate also makes Prostate Specific Antigen or PSA. This is a protein that makes seminal fluid more liquid to help sperm swim more easily, so is important in reproduction. PSA can be detected with a simple blood test which allows doctors to assess certain conditions of the prostate.

About prostate cancer

Prostate cancer happens when the cells in the prostate develop abnormalities, multiply and grow faster than normal. This causes a growth or a tumour. As the prostate is inside the body, this growth can't be seen and often causes no symptoms in the early stages. To see a diagram of where the prostate sits, please go to the inside back cover, page 47.

Why might a radical prostatectomy be suggested?

- As a primary/main treatment for prostate cancer when the cancer is localised and contained within the prostate;
- When the cancer has not spread (metastasised) to other parts of the body;
- After a period of active surveillance if there are signs of the cancer growing;
- When the cancer is thought to require treatment rather than surveillance;
- For men who are medically fit for surgery;
- For men who are otherwise healthy and are fit enough to have a general anaesthetic;
- As a last line curative treatment if radiotherapy or brachytherapy fails, although the side-effects are significant, and you are less likely to be offered this treatment as a result.

Surgery to remove the prostate

Robotic assisted radical prostatectomy (RARP). This is a more precise type of keyhole surgery. It usually means that there will be 5 or 6 small cuts (incisions) made in the lower part of the tummy, most about 1 cm long whilst the one where the prostate is removed is usually about 4cm.

A trolley with the robot and the robotic arms will be positioned next to the man. The instruments and camera needed to perform the operation are attached to the robotic arms. The instruments to do the operation are inserted through the small cuts.

The surgeon will be seated at a console away from the patient but has direct control of the instruments on the robotic arms at all times through the special console.

To see a film about this procedure, go to www.prostatescotland.org.uk/help-and-support-for-you/surgery-remove-prostate or <https://www.prostatescotland.org.uk/robot-assisted-prostate-cancer-surgery>

The aim of this booklet is to provide more information on robotic assisted laparoscopic radical prostatectomy.

Expected advantages of RARP:

- A shorter stay in hospital, usually only 1 day. And for some men, operated on as a day case.
- Smaller scars.
- Faster recovery time.
- Usually, returning to work more quickly.
- Less bleeding and fewer men requiring a blood transfusion.
- The catheter to drain urine may be taken out more quickly
- Studies suggest there may be better continence and erectile function rates.
- No requirement for hormones to be used therefore avoiding the short- and long-term side-effects of this medication.
- Far lower risk of long-term bowel related side effects.
- For the small percentage of patients whose cancer recurs, surgery provides a rapid easy to understand definition of recurrence which helps quick referral for a second treatment.

What happens?

(The information that follows on RARP is meant as general guidance. As procedures may vary slightly from hospital to hospital, ask for more advice from the individual surgeon carrying out your operation. If you have been given any specific guidance by them then it is important that you follow their instructions.)

When you and your medical team have decided that RARP is the most appropriate treatment in your particular circumstances, you will be asked to sign a consent form agreeing to go ahead with the treatment.

Pre-assessment

Most likely you will be asked to attend a pre-assessment appointment before you go into hospital for your operation. This appointment is to make sure that you are fit and healthy to have the operation. It will help you to understand what to expect before your surgery, may advise you on pelvic floor exercises, how long before your operation to stop eating and drinking and what to expect after your surgery. Your appointment may last an hour or so.

You will probably be asked to confirm your personal details, your medical history, if you have any allergies and any medication that you normally take at home.

The urologist or nurse will check on your general health and you will most likely have the following tests done to ensure that you are fit and healthy: blood and urine tests, clinical examination, an ECG to check on your heart and X-ray as required.

The operation will be explained to you, and you will have the chance to ask any questions. If you do have any questions or anything you would like to discuss, it might be beneficial to write these down before your appointment. You may be asked to sign the consent form at this appointment. You might find the Prostate Scotland Cancer Navigator App helpful as among other features you can add the list of medications that you take and use the notes section to write down any questions that you have. It's available on Google Play and the App store.

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for Apple app



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for Google Play app



As pelvic floor exercises are important to help regain continence after your operation, you might be given information on when to start and how to do pelvic floor exercises. You may also be referred to a physiotherapist who specialises in continence. Prostate Scotland has a helpful booklet 'Spotlight on pelvic floor exercises before and after surgery to remove the prostate (radical prostatectomy).



This is available on our website www.prostatescotland.org.uk or contact info@prostatescotland.org.uk or call for a copy.

There are helpful videos on our website by advanced practice physiotherapists on how to do pelvic floor exercises www.prostatescotland.org.uk/help-and-support-for-you/pelvic-floor-exercises



You may find it helpful to download the 'squeezy' app as a reminder to do your pelvic floor exercises. squeezyapp.com

Some hospitals may provide films or links to films on pelvic floor exercises.

Admission to hospital

You will be asked about any medication and possibly any herbal

supplements you are taking. You may already have been given advice on medication that you normally take at home by staff at the pre-assessment appointment. E.g. if you need to stop any of your routine medicines before surgery. Remember to tell staff about aspirin, warfarin, rivaroxaban, apixaban or any other pills you are taking and also about any allergies that you have. You may be asked to bring any medicines that you normally take at home into hospital with you.

You will have been given information about when to stop eating and drinking before the operation takes place.

On the morning of your operation, you may be given an enema or suppository depending on how recently you have opened your bowels. An enema/ suppository is a medicine, either as a liquid or capsule, which is put into your back passage to speed up your bowel movement and clear your bowel, making sure it is empty before surgery.

Once your bowel is clear you may be asked to have a shower, put on a hospital gown and special stockings. You may have to wear these stockings all the time whilst you are in hospital, although you can probably take them off to have a shower then put back on once you are dry. These help reduce the risk of blood clots in your legs.

An injection of Dalteparin under the skin will most likely be given to prevent any clots in the veins of your legs as well. You will likely be asked to self-administer this injection for 10-28 days when you go home. For a short film on how to do this you can watch www.youtube.com/watch?v=39sLVvZHEI4

Will I have an anaesthetic?

You will have a general anaesthetic, which means you will be kept asleep throughout your operation. The anaesthetist will see you on the day of your surgery. He/she will check over your pre-assessment information and chat over your anaesthetic. Of particular interest will be your general health, any previous anaesthetics, and your mouth and teeth.

What happens during the operation?

Once you are asleep, you will have a blood pressure cuff on your arm to measure your blood pressure and ECG leads attached to your chest to check on your heart throughout your operation. You will be given some oxygen during and maybe after your operation and you may also have a warming blanket.

Although you won't be aware of it, a breathing tube will be placed in your windpipe, and an extra monitor may be placed on the pulse on your wrist to accurately measure your blood pressure.

During your operation you will lie on your back in a slightly head down position. Being in this position can sometimes cause some puffiness of your face but this should disappear after the operation, and you may have a headache for a short time afterwards.

You may have an intravenous line (drip) that will stay in place until you are eating and drinking normally.

You will receive painkillers to keep you comfortable when you wake up.

Robotic assisted radical prostatectomy (RARP)



The abdomen (tummy) is inflated with carbon dioxide (a gas) to give the surgeons working space within the abdomen to do the operation. It is this gas that is responsible for the shoulder tip pain that patients often get after surgery. This will disappear within 48 – 72 hours.

In the operating theatre, a side cart with the robot is placed next to the operating table. Four robotic arms are attached to the robot on the side cart. The instruments the surgeon needs to carry out the surgery are then attached to these arms.

There are a variety of narrow (about 8mm in width) instruments that can be attached to the robot arms. The advantages of robotic instruments are that, unlike traditional keyhole instruments, in which the working bit of the instrument can only rotate in one axis (a bit like rotating the handle of a screwdriver can only rotate the tip), robotic instruments have articulated joints which allow the working bit (the tip) of the instrument to move in every direction.

In essence, robotic surgery allows the surgeon to operate as though they had their own hands inside your tummy, despite being keyhole surgery. The instruments and incisions being narrower than the surgeon's little finger.

Three of the four robotic arms have the instruments attached to them. One of the four arms has a 3D, high magnification camera attached which sends images from inside your tummy to the console/screen where the surgeon is sitting. The 3D image combined with high magnification gives the surgeon an all-round, very clear view of the prostate and means that he/she can carry out a very precise operation.

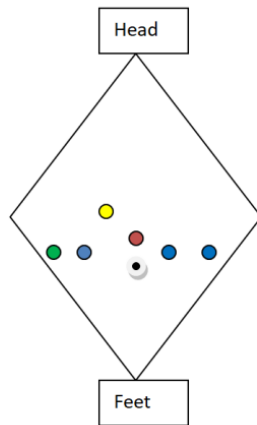
The instruments and camera attached to the arms are inserted into your body through special small plastic tubes called ports so that the operation can be carried out. The surgeon uses and controls these instruments on the robotic arms, instead of using instruments held in his/her hands.

The surgeon is in the same room as the man but sits away from him at a console or control panel. The surgeon controls and precisely directs the instruments to carry out the operation. The robot **does not and cannot** carry out the operation on its own.

Your prostatectomy by RARP

Diagram of likely incision sites and sizes:

- = <1cm
- = dependent on prostate size usually less than 4cm
- = 1.5cm |
- = bellybutton



As shown in the diagram small, special plastic tubes (called ports) are inserted at the colour sites.

Red port (site)

This is the usual entry point into the lower tummy and is 0.8 mm in length. It's where the camera and gas inflow are attached. The camera magnifies the prostate and surrounding area, making it look bigger and sending images to a screen. This ensures that the surgeon can see the area very clearly, which helps him/her perform the operation.

Three blue ports (sites)

These are 0.8mm in length and are used to insert the special instruments needed to perform the operation.

Green port (site)

This is an assistant port and is 1.5cms in length.

Yellow port (site)

This is an assistant port and is 0.5 mms in length.

The prostate can be removed through any of the sites, but it is usually done through the red or green port site, by increasing the length of the incision (cut) to 3-4cms.

Do note however, that the picture is just an illustration; whilst the positions of the incisions (cuts) are relatively standard, individual surgeons may have their own preferences regarding which instrument is used through which port.

How the surgeon reaches the prostate

The prostate lies in a small area called the retropubic cavity. This is the area between the pubic bone and the bladder.

Trans-peritoneal access

Throughout Scotland most RARPs are done by trans-peritoneal access. This means that the abdominal cavity is opened then expanded using carbon dioxide. Once the space has been created the surgeon will cut the peritoneum then drop the bladder down allowing entry to the retropubic cavity and so the prostate.

Nerve sparing procedure

The nerves and blood vessels necessary to have an erection run very close to and along the sides of the prostate (like the outer skin of an onion) and may be damaged or stretched during this operation. A nerve sparing operation involves a careful balance of "peeling this onion skin" whilst accidentally not peeling into the prostate or the cancer.

The possibility of nerve sparing depends on your erectile function before your operation, the type of disease you have (your Gleason

score, PSA, T stage), as well as where the cancer has shown up on your MRI scan. Your surgeon will have reviewed your case, to decide if you are suitable for nerve-sparing.

You should ask your individual surgeon for their nerve-sparing rates. You can also ask your surgeon or CNS for more information about nerve-sparing if this is a concern for you.

Reconnecting your water-pipe (urethra) to your bladder

Because the small part of the urethra inside your prostate will have been taken away, stitches are needed to re-join the urethra to your bladder. A watertight join is the goal of the operation (and is achieved in the vast majority of cases). The reliability of this join is checked during the operation by performing a leak test.

For most men this join will be watertight and won't leak and further treatment for a leak is uncommon. However, a very small number of men may need to have a catheter for an additional period of time if the join (anastomosis) is slow to heal and to become watertight.

Possibility of having a drain

For a very few men and under certain circumstances, the surgeon may decide to place a drain during the operation. If you do have a drain then you'll notice this will come out of your tummy below your belly button on the right or left side of your tummy/abdomen, and will be removed before you go home.

Removal of pelvic lymph nodes

There is a possibility that prostate cancer may have spread to the lymph nodes in the pelvis. (Lymph nodes filter tissue fluid. Antibodies and white blood cells that fight infection are found in lymph fluid.) The risk of lymph nodes being affected by prostate cancer may be confirmed before your operation by looking at such things as your PSA level, the Gleason score or prognostic grade group, the findings on an MRI or bone scan. Depending on this risk assessment and if the surgeon thinks that there might also be

cancer in the lymph nodes, it is sometimes necessary to remove some lymph nodes during the operation. Lymph nodes may be removed if you have intermediate or high-risk cancer. This is called lymph node dissection.

If the lymph nodes are removed, they will be examined by a pathologist and if found to contain cancer, further treatment will be required in most cases. Removal of lymph nodes for most people has no longer term side effects. The risk of long-term lymphoedema (leg swelling) is less than 5%.

How long does the operation take?

The operation usually lasts 1.5 up to 3 hours depending on circumstances but you will not be aware of this as you will be asleep. There are a number of circumstances which will determine the length of your operation. For instance, if the surgeon finds it necessary to do lymph node dissection this can add another 30 - 45 minutes to the operating time but should still fall within the 1.5 - 3 hour range. If you require more information about how long your operation might take, then you should discuss this with your surgeon.

Will I have 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. During the operation you will have a catheter put into your bladder to help divert urine whilst the initial swelling settles and the join heals. It's important that you avoid handling or pulling on the catheter. Sometimes you may leak urine around your catheter, and this may be related to your bladder being irritated by the catheter. If this is a significant problem, occasionally a medicine called an anti-cholinergic or mirabegron may be prescribed.

The catheter will usually stay in place for about 1-2 weeks so you will most likely go home with the catheter in place, but this can vary in different hospitals.

Catheters can cause some discomfort to the tip of the penis, but most men cope well with the catheter. Side-effects of having a catheter may

sometimes include a urine infection or UTI.

If you notice the following signs, then you should speak to your urologist, CNS or GP.

- Your urine seems cloudy and has a strong unpleasant smell.
- You feel hot and feverish with a high temperature.
- You feel shivery.
- You feel unwell, feel sick, have a headache or low back pain.

If you have a UTI, you will be given a course of antibiotics to take. It's very important to take all the tablets as directed, even if you feel better before you finish all the tablets.

Keeping the catheter clean, but minimising contact with the catheter and only changing the bag as instructed can help reduce this risk. You will be given advice by the ward staff on caring for your catheter before you leave hospital. For more information, please see https://www.baus.org.uk/_userfiles/pages/files/Patients/Leaflets/Catheter.pdf

You should not try to change or take the catheter out, nor should anyone else including District Nurses. For more help please contact your CNS or nurses on the ward where you had your operation done.

You can shower as normal if the wounds are healing well but avoid having a bath for 2 weeks. It's best not to use soap around the area of the catheter or the wounds.

If you notice that urine is not draining from the catheter into the catheter bag and you feel uncomfortable with a strong urge to pass urine, you should contact your GP, or NHS 24, or go to an accident and emergency department.

When the consultant decides that you no longer need the catheter, you will possibly be given an appointment to have this taken out. You may hear this called 'TWOC' or trial without catheter. Sometimes this is known as TOV trial of voiding.

For more information, Prostate Scotland has a booklet called 'Spotlight on caring for your indwelling catheter at home'. This is available on our website www.prostatescotland.org.uk or email us for a copy at info@prostatescotland.org.uk or call us.

Will I have to stay in hospital?

Yes, you will have to stay in hospital. Most patients spend around 23 hours in hospital following their operation. Some centres are starting day case surgery (ask your surgeon if you are eligible) and some men will require to stay longer than 23hrs.

Getting home depends on a few factors:

- You are able to move around as well as you did before your operation.
- You know how to care for your catheter.
- Your pain medication is controlling any pain.

If recovery goes well, most men are well enough to be discharged the day after their operation. However, this might also be dependent on travel arrangements etc.

After your surgery

After surgery you may spend a few hours in the recovery area where your pain will be managed, drowsiness monitored, your catheter is draining, and your wounds checked.

Once you have been checked and all of these are satisfactory, you will be transferred to the general urology ward. When you arrive back on the ward and wake up, you will find that you have a catheter in place, (for a minority of men there may be a small drainage tube from your tummy) and a drip to give you some fluid until you start eating and drinking.

You will have stitches, staples or glue closing the small incisions (cuts), as well as small plasters or dressings covering these. Your urologist, CNS or nurse will tell you if these will dissolve or need to be taken out. Remember to tell ward staff if you have an allergy to plasters. You may have some

discomfort or pain when you wake and you should let the staff know about any pain, as they can give some pain relief medicine.
The nursing staff will often try to get you sitting out of bed and going for a walk (with supervision) to help improve your recovery.
Depending on the routine practice at your hospital you will have your catheter removed. 7-14 days after your operation.

You may have to attend the hospital for a special X-ray (cystogram) to check on the join between your urethra and bladder to find out how quickly your catheter can be taken out.
If there are no leaks from the join between the bladder and urethra (water pipe) then the catheter will be taken out.
If there is a leak at the join, then the catheter will be left in for another week or two to allow healing.
To help with your continence (not leaking urine), you can start pelvic floor exercises after your catheter has been taken out.
A cystogram may not be done in all hospitals prior to your catheter being taken out so you can ask your consultant if you are likely to have one.

Potential side-effects of RARP

Most men who undergo RARP have few side-effects some of which will be mild and reversible, but others may go on for a longer period of time such as incontinence and erectile function issues. When side-effects/complications occur then it is likely to be within the first 30 days following your operation rather than appear potentially years later.
Most complications are “mild” and do not require hospital re-admission and are managed as an outpatient.
The risk of being readmitted into hospital varies by hospital but it is usually less than 5%. The risk of needing another procedure to correct a side-effect is less than 2%.

The following lists set out some of the potential side-effects:

Potential mild/reversible side-effects	
Risk of infection	The risk of developing an infection is around 10 in every 100. Most infections are likely to be Urinary Tract Infections (UTI) and are treated with a course of antibiotics by your GP.
Bleeding	This happens in every patient but the risk of a blood transfusion for heavy bleeding is very low (under 1 in 100 men).
Hernias through wounds/groin	This is uncommon (Less than 5 in 100 men), no heavy lifting for 4 weeks after the procedure helps to prevent this.
Deep vein thrombosis (DVT) or Pulmonary embolism (PE)	This is uncommon (1 in 100 men) but varies for each man. Most units give men blood thinning injections to prevent these.
Injury to bowel/rectum	The risk of this varies between every surgeon, ask your surgeon their rate. This occurs very uncommonly and there is a higher risk in men who have had extensive pelvic surgery or radiotherapy to the pelvis previously.
If a lymph node dissection is required	There is a rare (1 in 200) risk of injury to adjacent structures (bloods vessels, nerves). The risk of permanent leg swelling (lymphoedema) is less than 5 in 100.

Ureteric stents.
In some cases, it may be necessary to place small plastic tubes into the drainage pipes from the kidneys during the operation. This is usually if the pipes enter the bladder very close to where the stitching will take place. These plastic tubes are called stents.

These will need to be removed 4-6 weeks after your operation. This is done via a small, flexible camera passed into the water-pipe (urethra) under local anaesthetic and as an out-patient. You will be advised if this is relevant to you while in hospital. These stents can cause irritation of the bladder which may be noticeable when your catheter is removed. This irritation will improve once the tubes are removed.

Problems arising from positioning

Possible results (although these are not common): skin irritation or damage, pressure sores, nerve damage (with associated muscle weakness), and very rarely glaucoma (if you are predisposed to it).
It is common to have a sore head for a few hours after the operation as a result of being positioned 15° – 30° degrees head down for the operation.

Leakage of the carbon dioxide gas into tissues

If this happens you may have some discomfort in one or both of the shoulders, but any discomfort will soon disappear as the gas is re-absorbed by your body usually within 48-72hrs.

Potential longer-term side-effects

Incontinence

Please see pages 24-27 for more information.

Erectile dysfunction

Please see pages 27-30.

Potential uncommon/rare side-effects

Injury to adjoining structures (rectum/bowel, ureter, blood vessels and nerve)

Very rare complication.

Injury to the bowel. As the prostate lies close to the bowel, there is a small risk of injury to the bowel

Ask your surgeon what the risk is, but it is usually less than 1 in 100.

Changing from minimal access operation conversion into an open operation. This might happen in cases of severe adhesions or major bleeding.	This is a very rare event.
Bladder neck narrowing. This results in difficulty in passing urine.	Rare complication (<1%) occurring some time after the operation, which can be dealt with by performing an endoscopic operation

Care considerations after your operation

Problems with your catheter

Some men find their catheter might leak (urine by-passes the catheter) and for a few this leakage can happen quite frequently and can be very upsetting. This could be caused by strong tightenings or contractions in your bladder called bladder spasms. If this is severe, get in touch with your CNS or nurses on the ward that you were in. They may want to check the catheter and may be able to prescribe a medicine to help.

Before you are discharged from the ward you may be given a catheter and incontinence **'Take home pack'** that may include:

- i. Night drainage bags.
- ii. Long leg drainage bags (sometimes short leg drainage bags may be provided).
- iii. A catheter stand.
- iv. Net pants.
- v. Packs of incontinence pads. These come in midi and mini sizes and usually the midi size is provided.
- vi. You may be provided with a small take home pack from Prostate Scotland

which includes amongst other items a small pack of pads. This may be provided as a physical pack or as a voucher for you to redeem.

The CNS will let the District Nurse Community Team know about your discharge from hospital and that you have a catheter in place.

It is very important that you, or anyone else (including District Nurses), does not try to take the catheter out or change it. Always get in touch with the CNS for more help and advice.

A word about infection

If your urine looks cloudy, has a strong smell, you feel feverish and generally feel unwell it's important to get in touch with your GP or CNS for more advice.

Helpful booklets from Prostate Scotland:



'Spotlight on Caring for your indwelling catheter at home'
Scan QR Code



'Spotlight on Urinary Incontinence as a symptom of prostate problems'
Scan QR Code

Urinary Catheter Care Passport

If you are being discharged home with a catheter, you may be given a 'Urinary Catheter Care Passport'. It's 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.** (Eg. whether GP, CNS, Urologist or District Nurse).

So you (and your family) have all the necessary information on who will be looking after your catheter, the first section should be filled in giving 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. This enables everyone in the medical team to have an accurate and up-to-date record of what has happened, and this is why it's so important **to take the 'passport' to all your medical appointments.**

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

Urinary incontinence (not able to control when you pass urine)

This means that you may not be able to hold urine inside your bladder after the catheter is taken out and will leak some urine when you cough, sneeze or move about. Almost all men have some incontinence so it's nothing to feel embarrassed about and is likely to improve significantly in the first 3-6 months after your operation. It's because the valve (called the urethral sphincter), which controls urine flow, lies close to the prostate and its function may not work so well for a short time after surgery. Incontinence is usually managed effectively using incontinence pads and will improve as the healing process takes place.

Once your catheter has been taken out, it is essential that you continue with your pelvic floor muscle exercises (PFMEs). There is a very helpful film on our website which you can view by scanning the QR Code below.

Scan here to
view film



Scan here for our
PFME booklet



How long and how much incontinence will be troublesome for you is affected by several factors and varies from individual to individual. Although incontinence is a common side-effect, it's usually temporary with the majority of men regaining full continence (ability to control passing urine) over time. However, up to 2-3% of men will not recover their continence fully and may require a second operation to make them dry again.

While you may not like the idea of using pads, these can really help you manage the problem and carry on with your life. There are many different kinds available and the local continence service, CNS, nurses on the ward or perhaps your GP will advise you on which type of pad would be most suitable in your particular circumstances.

More information on incontinence and continence pads can be found in our booklet 'Spotlight on Incontinence as a symptom of prostate problems' which is available on our website www.prostatescotland.org.uk or email info@prostatescotland.org.uk or call for a copy.

Continence advisory services (CAS)

CAS are usually run by Nurse Specialists called Continence Advisors. They have specialist training and knowledge to provide help and advice for those who have problems controlling their bladder (and/or bowel.) Their main aim is to help improve your situation if incontinence is having an impact on you, and give you the confidence to get on with your life and get back to doing the things that you enjoy without being concerned about any leakage.

Every health board has a CAS. Each service works in a slightly different way and provides different details and may not be called a 'continence advice/ advisory service'. For more information on the CAS in your area check www.prostatescotland.org.uk/continence-advisory-services

Recovery of continence is usually faster in younger, slimmer and fitter patients and is helped by bladder retraining and doing pelvic floor exercises on a regular basis. Indeed, before you had surgery you will most likely have been advised to start a pelvic floor exercise programme. Your consultant or CNS will usually advise on when to start pelvic floor exercises after your catheter is taken out.

You may also experience some urgency when you need to pass urine and your doctor may suggest that you take some medication to help with this.

Pelvic floor exercises (PFEs)

Pelvic floor muscles are like an elastic hammock that stretch from the pubic bone at the front of your body to the little bone at the bottom of your spine, your coccyx. They also stretch side-to-side across your body. Their task is to support the bowel and the bladder. When the pelvic muscles are in good condition, they help prevent leaking of urine and poo.

To do PFEs properly you first need to relax your abdominal (tummy) and buttock muscles. At first, you could begin trying pelvic floor exercises lying down but later while you are sitting or standing.

To identify the pelvic floor muscles, focus on the muscles that you would use to stop yourself from peeing and/or trying to stop yourself from passing wind. During this action you should feel the back passage opening contract. Steadily tighten the pelvic muscles and hold for as long as you can. Build up until you can manage to hold for a maximum of 10 seconds. Now relax the muscles for an equal amount of time to the time you held the contraction for. You should do the pelvic floor exercises between 4- 6 times every day. If you do not think you are doing the exercises properly, please let the urologist or CNS know as they may be able to arrange for you to see a physiotherapist who will help.

Using pelvic floor exercises, it may take up to 3-6 months for continence to return and improvement can continue to occur even up to 1 year following surgery.

There are helpful videos on our website by advanced practice physiotherapists on how to do pelvic floor exercises www.prostatescotland.org.uk/help-and-support-for-you/pelvic-floor-exercises.

Some hospitals may provide films or links to films on pelvic floor exercises.

How incontinence might improve

The majority of men (60-70%) will require 1 pad or less at 3 months after the operation and 85-90% will become completely continent (not leak urine) by 6 months to 1 year. A small number of men (approximately 2-3% depending on the surgeon) require a second procedure to make them dry.

Urinary control usually returns in three phases:

Phase 1. You are dry when lying down at night.

Phase 2. You are dry when walking or doing moderate activity.

Phase 3. You are dry when you rise from a sitting position or cough or sneeze. This is the last aspect of continence to return after surgery.

Your continence should improve given time and ensuring that you do your pelvic floor exercises as advised every day.

For more information, Prostate Scotland has the following booklets '*Spotlight on Incontinence as a symptom of prostate problems*' and '*Spotlight on pelvic floor exercises before and after prostate surgery*'. These are available on our website www.prostatescotland.org.uk or email us for a copy at info@prostatescotland.org.uk or call us.

Problems having erections.

Not being able to have an erection can affect men at different ages and stages in their life and for different reasons. When a man has trouble getting or keeping an erection firm enough to have intercourse, it is called erectile dysfunction (ED) or sometimes impotence. This can happen as a man gets older, with some kinds of medications and with some other illnesses.

After RARP, it is usual for men to be unable to have a natural, spontaneous erection.

A few things that may affect your erection:

- After the operation your body needs time to heal, with a gradual recovery that may in fact take a few years. Indeed, it is usual not to have an erection in the first six to nine months after surgery.

- Your age. Men under 60 tend to have better quality erections before surgery and, therefore, are more likely to recover erections after surgery.
- It can also depend on:
 - How good or firm your erection was before your operation.
 - How sexually active you were before your operation.
 - Whether the surgeon was able to save the nerves (nerve-sparing surgery) that lie very close to the prostate, and which are responsible for erections and potential recovery of function. You can always speak to your CNS for more information. In some hospitals when you have had nerve sparing surgery you may be prescribed Tadalafil (Cialis®) long-term when you are discharged.

Many doctors now think that after surgery the sooner you start having stimulation or trying to have intercourse may actually improve the chances of having the same kind of erection as you did before your operation. Touching, caressing, holding and massage can help. If you are able to regain a partial erection, then trying to have vaginal intercourse should be attempted as soon as reasonable. The use of a lubricant such as KY jelly may be helpful at this stage. Vaginal stimulation is a factor that can stimulate further erections. So, there is no need to wait to have a 'full' erection before trying to have intercourse. The return of erections occurs gradually and the ability to have a full erection often takes up to 2-3 years to recover fully, and in some cases may never do so.

You may notice that your penis will often appear shorter because the water-pipe (urethra) is shorter once the prostate has been removed.

You should be aware that there is no curative treatment for prostate cancer where maintenance of spontaneous erections can be guaranteed. As there are a variety of treatments available to help with this difficulty, most men can achieve satisfactory erections when spontaneous erections do not return.

There are a few options for trying to make the quality of your erections better.

Medication to be taken by mouth

Pills that can help include Avanafil (brand name Spedra®), Sildenafil (brand name Viagra®), Vardenafil (brand name Levitra®), Tadalafil (brand name Cialis®).

These work by increasing the blood flow to the penis to help you have an erection and work best if the nerves are still intact.

Vacuum pumps

If tablets or injections don't help, or if you prefer another option, then you can try a vacuum pump. This works by suction drawing blood into the penis. In some hospitals, a vacuum pump may be provided at an early stage alongside tablets.

MUSE - medication by an applicator

MUSE stands for medicated urethral system for erections. The medicine is given by a small applicator that has a thin tube inside it.

Vitaros cream

This is a cream that is applied into the opening and around the tip of the penis.

Medication that is injected

A treatment that is injected into the penis is very successful for some men and can be effective even if the nerves are not intact. If this treatment is recommended, you will be taught how to do the injection. The medicine makes the blood vessels in the penis swell and allows it to fill with blood and so become erect.

Dry ejaculation or orgasm

Because your prostate, vas deferens (tube that carries sperm) and seminal vesicles (these supply the majority of fluid that makes up semen) will have been removed, you will not produce any semen. So, although you will feel spasms and pleasure that accompany an orgasm, you will not ejaculate.

Some men may notice leakage of a small amount of urine as they climax. This is called 'climacturia' and is not something you need worry about as the urine is sterile and harmless. Some men worry about the effect this will have on their partner, but for most partners this is not a problem.

You may find that the sensation of orgasm may be lessened, changed or just different than previously.

Infertility

Because the tubes carrying your sperm need to be sealed during the operation and the seminal vesicles have been taken away, you will not be able to conceive children in the normal way. If this is an issue, then ask your consultant or CNS about the possibility of storing sperm.

For more information, Prostate Scotland has a booklet called 'Spotlight on prostate conditions and erectile dysfunction'. This is available on our website www.prostatescotland.org.uk or email us for a copy at info@prostatescotland.org.uk or call us.

Getting home after RARP

- If you were asked to stop taking some of your usual medication before your operation, ask the urologist or nurse about restarting these when you get home.
- It's usual for you to pass some blood or small clots for up to 10-14 days after the operation. Increasing your fluid intake just after your operation may help to flush out any excess blood.
- To help with any pain and discomfort, it is best to be prepared and have some suitable painkillers at home. Ask the nurse or urologist in hospital if you are unsure about this.
- At first, discomfort around the area of your wound will stop you from doing too much. Avoid vigorous activity in the first few weeks, start off with some light exercise and then gradually increase. For the first 2 months after your operation, or as advised by your urologist or CNS, you should avoid sports that put a strain on your perineum such as cycling, horse riding. (The perineum is the skin between your scrotum and back passage.) If you develop any pain in the area, you will need to get in touch with your GP or CNS.
- Remember, too, not to pick up anything heavy as this puts a strain on your wound.
- You should be able to go back to driving in about 2-3 weeks, but you should chat this over with your own consultant for more specific advice. You should be able to do an emergency stop without feeling overly

cautious about it and without it being painful. It's wise to check with your insurance company to make sure you are covered to drive.

- You should be able to return to light work 3-4 weeks. Again, speak to your consultant for more specific advice.
- When you are able and it feels comfortable, you can begin to try to have sexual intercourse; but you should remember that recovery of erections after surgery is a process of rehabilitation that can take 2-3 years.
- If you find that you have some leakage around the sides of the catheter, you may be given some incontinence pads. Ask for more advice from staff on the ward.
- Constipation, and your bowels being sluggish, is a temporary but common side-effect after radical prostatectomy and it may take time to get back to what was normal for you. You will most likely be given medication to help with constipation after your operation and possibly be asked to continue with this at home for a time. That said, some men find constipation troublesome while others do not. Being constipated can be painful, make you feel very uncomfortable and may affect your wounds and healing if you strain or push too hard to pass a bowel movement. Before buying any over-the-counter medicines for constipation, check with your CNS, GP or local pharmacy what would be best in this instance. Including more fibre in your diet may be helpful so try to have at least 5 portions of fruit and vegetables each day and use wholegrain cereals rather than white refined varieties.
- Have at least 2 litres of fluid (about 8-10 cups) and try to include some glasses of water each day. Switching to de-caffeinated tea and coffee may be beneficial as well as avoiding fizzy drinks or energy drinks that have caffeine added.
- You may be provided with a small take home pack from Prostate Scotland which includes amongst other items a small pack of pads. This may be provided as a physical pack or as a voucher for you to redeem.

You should be given information from the ward on who to contact if you are worried or have problems after you go home. If not, then you should contact your GP or NHS 24.

Going back to the clinic

You will most likely get an appointment to attend the urology outpatient department in about 6-8 weeks approximately depending on availability, although this may vary from hospital to hospital.

At this appointment, your surgeon will ask you about how your recovery has gone, examine your wounds, ask about your bowel movements (constipation, pain). They will ask you about your urinary continence, pad usage, urinary flow and your erectile function.

You might be given a couple of questionnaires to fill in:

- i. About passing urine. This helps your urologist/CNS better understand any problems/difficulties you are having with your waterworks.
- ii. Ability to have an erection. This helps your urologist/CNS better assess your ability to get and maintain an erection and any problems/difficulties in having an erection.

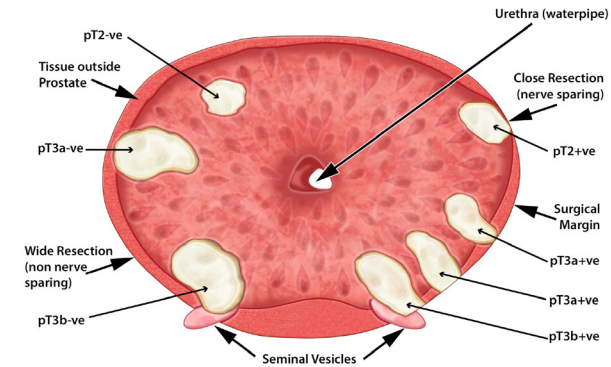
They will also discuss the pathology report with you such as T stage, Gleason score and margin status (positive or negative, size and location) and discuss the PSA results with you.

Your results and what they mean

The diagram overleaf is to help you understand what this means in your particular circumstances. It might be helpful if you take this booklet to the clinic with you.

Post Prostatectomy Grading, Staging and Follow Up

Picture courtesy of:
NHS
Highland



Your Gleason score is: _____ Grade Group _____

pT2-ve Tumour contained within prostate and is within the surgical margin.

pT2+ve Tumour contained within prostate but involves the surgical margin.

pT3a-ve Tumour has gone outside the prostate but is within the surgical margin.

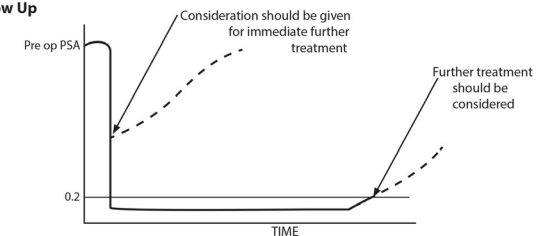
pT3a+ve Tumour has gone outside the prostate and involves the surgical margin.

pT3b-ve Tumour has invaded the Seminal Vesicles but is within the surgical margin.

pT3b+ve Tumour has invaded the Seminal Vesicles and involves the surgical margin.

The higher the Gleason score and / or pT number and / or the greater extent of surgical margin involvement increases the potential need for further treatment.

PSA Follow Up



PSA Follow Up Regime Unless Advised Otherwise

- 6 Weeks
- Year 1 and 2 - 3 Monthly
- Year 3 to 5 - 6 Monthly
- Year 6 to 10 - Annual

Positive surgical margin means that cancer cells were found close to the edge of the prostate and the urologist or CNS will discuss what this might mean for you. If the surgical margin is involved, this increases the risk of needing further treatment, but there is still a good chance that no further treatment will be required.

How do I know if the treatment has worked?

After you have had surgery, the urologist will want to see how you are with regular check-ups. Remember to make an appointment at your GP Practice to have a PSA blood test before you go to your urology appointment, so the urologist has an up-to-date result.

After RARP, your PSA should drop quickly and should be practically undetectable*. If it does not drop this low or starts to rise, then this suggests there may be cancer cells elsewhere in your body. Always ask your GP or Practice Nurse for the actual PSA level/result in ng/ml.

* In this case undetectable will mean at its lowest limit and will vary depending on the type of test used. You can discuss what undetectable means with the clinician or CNS.

Weighing up the decision? What advantages and drawbacks are there to think about with RARP?

Advantages	Drawbacks
Can offer a cure for cancer still within the prostate.	This operation is suitable for the majority, but not all patients.
You may be reassured to know that your prostate and so the cancer within has been removed.	For a small number of men there may be a positive surgical margin that increases the risk of requiring radiotherapy and/or hormone treatment at a later date.

The urologist can gather information about the stage of your cancer during the operation and more information when the prostate tissue is studied in the lab.	It is still a major operation, and you need to be in hospital for a day or so. As there may be some discomfort and pain, you will need to allow time for healing and recovery. You may be off work and have to stop other activities for a few months.
Long-term cure rates are well proven and are comparable with other treatments such as radiotherapy.	As with all the other treatments, there is no complete guarantee of cure.
Blood loss	There is a very small risk of severe bleeding.
Bowel concerns	Lower risk of long term bowel problems with surgery compared with Radiotherapy.
Although there may be unwanted side-effects such as incontinence and erectile problems, treatments for these are available and well-defined. After the prostate is removed, your PSA level should be undetectable. So, it is a simple way of checking whether your cancer has come back again.	There may be incontinence (usually temporary) or erectile dysfunction.
After the operation, you can still have radiotherapy if this is necessary.	Radiotherapy can worsen the side-effects if you have had previous surgery.

What might this mean for you when choosing treatment?

Any treatment for prostate cancer will have an impact on your quality of life. Recent studies have shown that for the majority of men whichever treatment is chosen for early prostate cancer there is an equal impact on the risk of dying from prostate cancer around 15 years after treatment.

So, when deciding on which treatment to choose it's important that you consider both the short-term and longer-term side-effects, how much these will affect your lifestyle now and in the future and when these side-effects are likely to happen. Then you can choose the treatment that you consider will be the most appropriate and acceptable for you and on your life and lifestyle now and in the future.

When making a decision about which primary (or first) treatment to choose, men and particularly younger men may need to think about which other treatment(s) may be available to them if their first treatment isn't successful or cure their cancer and their cancer comes back again.

You may find the Prostate Scotland Cancer Navigator App helpful when making a decision on which treatment to choose. Not only does this provide information and compares treatments but also helps you consider what is important to you (and your family) in your life. It is to help you make the decision but does not advise on which treatment might be most suitable for you. The App is free to download on Google play or the App store.

Before choosing a RARP or LRP, you may have some questions to ask your urologist or CNS. A list of possible questions is given below. Think about what you would like to know, so perhaps you would need only to ask a few of these, or you may have questions of your own.

- Is there anything I could do to help with the side-effects?
- When and where would I have RARP?
- How long will the operation last?
- When and how will we know whether RARP has been successful?
- What check-ups would I have and how often would I need check-ups?
What would be done at the check-ups – PSA, scan, etc?
- If RARP is not successful, then what would my options be?

- Can I have radiotherapy after surgery and vice-versa?
- Are there other suitable treatment choices that I could think about?
- Why would RARP be better for me than external beam radiotherapy or brachytherapy?
- What is the outlook for me?
- Is there someone that I can talk to who has had the same surgery that I am thinking about?
- How urgent is it that I have this operation done?

The emotional impact of cancer.

In addition to managing the physical side-effects of prostate cancer and treatments, it can sometimes be hard to deal with how you are feeling. There are however many things that can be done to help you manage if you are affected. Everyone is different and not everyone will be affected, or by the same feelings.

Some people going through treatment or after treatment might feel worried about whether they are making or have made the right treatment choice, about the side-effects they are experiencing from treatment or about getting their PSA or scan results. Sometimes people's moods and how they are feeling can be affected as they go through treatment. And for some if their treatment has finished, they may feel relief, but also fearful of the cancer coming back. Some people may find their moods and how they are feeling may go up and down. All these feelings are normal.

What kind of feelings are we talking about?

Some people going through or after treatment may at times have:

Low mood or feeling depressed

How having a low mood or being depressed might make you might feel:

- Very sad, or very low for most of the day and these feelings persist.
- Not having the energy to do things that you took for granted before.
- Losing interest in hobbies, not taking part in activities you used to enjoy, not feeling up to seeing family and friends and perhaps losing your appetite.

- Feeling very tired yet having trouble sleeping.
- Having trouble focusing or concentrating and perhaps not able to make decisions.

Feeling anxious. Being anxious can affect you in many ways:

- Feeling very worried all the time and finding it difficult to let go of these thoughts.
- It can make it hard for you to carry out everyday jobs and not able to take care of yourself.
- Being very restless, feeling on edge for a lot of the time or jumpy.
- Feeling tired, short tempered, touchy.
- Feeling shaky or trembling

Feelings of panic

- Panic attacks are severe/strong feelings of being anxious or scared. You feel as though you have very little control over them and these can be scary
- These can come on at any time and sometimes for no apparent reason.

For instance, panic attacks may mean that:

- Your heart rate shoots up and you feel the beats almost pounding in your chest.
- You feel hot and sweaty.
- You feel shaky or numb or tingly.
- You feel dizzy, light-headed or feel you might faint.
- It's difficult to catch your breath and you take very small quick breaths or feel that you have difficulty in breathing

Coping with these feelings

Just like with everything else in life, people find different ways of helping them cope with these feelings. Some people try new activities that they never thought they would enjoy so don't rule anything out.

Here are some ideas for you to think about. Not all of these will be for you but maybe give some a go.

Getting more information.

For some men and their family, it helps to know more about everything that is going on, so they feel more in control and more knowledgeable when they go to see the urologist, oncologist, CNS or GP. They have a better grasp of what they are being told during their consultation and can ask questions about anything they don't understand. When searching for more information use reputable/trustworthy websites for example:

www.prostatescotland.org.uk

Prostate Scotland Cancer Navigator App is free to download from Google play or the App store

www.cancerresearchuk.org

www.macmillan.org.uk

prostatecanceruk.org

www.maggies.org

www.samh.org.uk

Remember too that your CNS, urologist, oncologist and GP can provide you with more information and answer your questions.

Talking it out

For some men talking to their partner or spouse or their family and friends provides them with all the support they need. They feel comfortable and at ease showing how they feel – sad, teary, angry etc.

Other men might find it easier to talk someone from the team looking after him – the CNS, urologist, oncologist and GP.

The important thing to realise is that you're not alone – others have had similar feelings and thoughts. There are Prostate Cancer Support Groups throughout Scotland where you can talk to other men who have already been on or still on the same journey as you are right now. Some of the groups run a 'buddy scheme' and you can talk to someone who has had/ is having the same treatment as you. (see the Prostate Scotland website for more details).

There are organisations who provide confidential support to let men talk about what they are going through, for example:

www.prostatescotland.org.uk

One-to-One support run in partnership with some Maggie's Centres

www.maggies.org

www.cancersupportscotland.org

Prostate Cancer UK Specialist Nurses tel 0800 074 8383

Macmillan cancer support line call 0808 808 00 00

Cancer research UK, Nurse helpline 0808 800 4040

Some men once they have come to terms with their diagnosis and treatment, like to share their personal stories with others, often to stress the importance of early diagnosis and for men not to bury their head in the sand. This can be through talking to work colleagues, family, friends, sharing their story in the press etc

Here you will find great examples of men sharing their stories. If you don't feel ready to talk about your own experience, it can still be useful to hear other men talk about their experience of prostate cancer, and the videos below allow you to listen without needing to join a group.

<https://www.theinfopool.co.uk/personal-stories>

Keeping track

Some men like to keep a record of their cancer journey from PSA test results to treatments and side-effects. If this is something you would consider then the Prostate Scotland Cancer Navigator App is free to download from Google play or the App store and has a special section where you can do just that including keeping track of your fatigue as well as levels of anxiety. For others it may be as simple as keeping a notebook handy or using the Prostate Scotland Log Book.

You could also try writing down your feelings, worries and concerns and think about any practical things you could do to help yourself.

Time out

Would time away and just forgetting about everything help for a wee while? Trying a new hobby that you've thought about doing for a long time but never got round to it?

- Getting back to a hobby or activity that you enjoyed before - a game of golf, bowls or darts.
- Mending the fence, cutting the grass, putting up the shelf.
- Visiting gardens or historical sites that you've always put off.
- Visiting museums, art galleries, listening to music, trying to paint or sketch, write short stories or poetry, go dancing.
- Trying yoga, meditation, Tai Chi.

There are so many things out there that you might never have tried so give them a go and have fun!

Looking after yourself.

It's all too easy to fall into the trap of thinking about your diagnosis so much that you forget to look after you. Try to have a good diet with plenty of fresh fruit and vegetables. Sleep is important too. Talk to your CNS, Urologist, Oncologist or GP if you're having trouble sleeping.

Some people may be tempted to try and escape it all by drinking too much alcohol or using drugs. This is never a good idea. Alcohol and unprescribed drugs may make how you're feeling worse and might affect the treatment that you are on.

Look out for our 'Living well with prostate cancer' 6 week course run in partnership with some Maggie's Centres. www.prostatescotland.org.uk/help-and-support-for-you/living-well-with-prostate-cancer-course

This website is well worth a look as it is dedicated to giving support at every stage of your journey. They offer a range of workshops and classes providing advice and guidance around the physical changes you may experience while undergoing treatment.

<https://lookgoodfeelbetter.co.uk/workshops/>

Getting active

Speak to your CNS, Urologist, Oncologist or GP first to ensure that it is okay for you to exercise, but research has shown that exercising when you have prostate cancer can make a difference:

- It might relieve some of the side-effects of treatment.
- It may help slow the risk of progression of prostate cancer.
- It might improve prostate cancer survival.
- Overall, it may improve your mood, relieve some stress, tension and anxiety.

If you've been used to regular exercise, you might be keen to get going again. If exercising is completely new to you then doing a small amount of exercise is better than not doing anything so don't feel daunted about getting started.

Try going for a walk, playing golf or going bowling, washing the car, doing the weeding, walking up the stair – all these things and more count towards having some exercise.

Prostate Scotland have an exercise video on our website specifically designed for men with prostate cancer so grab your trainers and give it a go!
www.prostatescotland.org.uk/news/prostate-cancer-exercise-video

In some areas we also offer Prostate FFIT 12 week exercise courses for men living with prostate cancer www.prostatescotland.org.uk/help-and-support-for-you/prostate-ffit

Above all if you're struggling to cope then please talk to someone.

Your CNS, Urologist, Oncologist and GP are great sources of help along with the many voluntary organisations out there.



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 <https://www.prostatescotland.org.uk/help-and-support-for-you> or <https://www.prostatescotland.org.uk/support-services> to see what's available.

We currently offer:

- Prostate Scotland Cancer Navigator App available and free to download from the Apple Store or Google play. This includes information on treatment decision making, the ability to record your consultation (with permission), appointment and medication diaries, monitor side-effects and much more.
- 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. 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.
- A 'Living Well with Prostate Cancer' course. This is a 6 week course for those undergoing treatment or when treatment has finished. We take a look at fatigue, urinary problems, side-effects and how to minimise them, erectile dysfunction and relationships, eating well and the practicalities of living with prostate cancer.
- Our special online exercise programmes for those living with prostate cancer are particularly relevant for those on hormone therapy. Please check with your CNS, oncologist, urologist or GP that these programmes are

suitable for you before starting to exercise. Available on our website www.prostatescotland.org.uk/help-and-support-for-you/exercise-video

- In some areas of Scotland, we offer a 12-week programme to participate in (Prostate FFIT). This is a specially designed course for those with prostate cancer. Each week there is an exercise session but in addition, the course builds your knowledge on diet, nutrition and making healthier lifestyle choices. For more information check our website <https://www.prostatescotland.org.uk/news>
- There will shortly be a 'Treatment decision making' workshop. Check our website as to when this will be available.

For more information visit

prostatescotland.org.uk/help-and-support-for-you

Prostate Scotland

Other booklets from Prostate Scotland that you may find useful:

- **'Early prostate cancer explained'**
- Spotlight on **'Pelvic floor exercises before and after radical prostatectomy'**
- Spotlight on **'Prostate conditions and erectile dysfunction'**
- Spotlight on **'Incontinence as a symptom of prostate problems'**
- Spotlight on **'Hormone therapy for prostate cancer'**
- Spotlight on **'Caring for your indwelling Catheter at home'**
- Spotlight on **'Prostate conditions and erectile dysfunction'**
- **'Advanced prostate cancer explained'**

Maggie's Centres in Scotland

Maggie's Centres provide support for anyone diagnosed with cancer and also for their family.

To find a Maggie's Centre near you visit: www.maggies.org/our-centres/

Prostate Scotland works in partnership with some Maggie's Centres to run the Prostate Scotland COMPASS service providing the one-to-one support service or the 'Living well with prostate cancer' course.

Please note Prostate Scotland is not responsible for the content of any of the external websites.

Useful contacts

For more information:

If you have any questions, then you can speak to your CNS, urologist or GP. It may also help to look at the following websites or contact the organisation by phone or email. These organisations also have information leaflets available and some offer telephone helplines which you can contact for support or to answer your questions. There may be a prostate cancer support group in your area where you can talk to other people (and often their family) who have been diagnosed with prostate cancer. These support groups may provide you with additional information.

Often these people share their experiences when they were diagnosed with prostate cancer, how they decided on treatment and about the various types of treatment they are having or have had.

Organisation	Website	Contact number	Helpline available
Prostate Scotland	www.prostatescotland.org.uk	0131 603 8660	Telephone information service (not a helpline)
NHS 24	www.nhs24.com	111	✓
Prostate Cancer UK	www.prostatecanceruk.org	0800 074 8383	✓
Macmillan Cancer Support	www.macmillan.org.uk	0808 808 0000	✓
Cancer Research UK Cancer Information Nurses	www.cancerresearchuk.org	0808 800 4040	✓

Our work

All our awareness materials, introductory guides, explanatory guides and 'Spotlight on' guides such as this booklet are available free of charge to people 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:

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

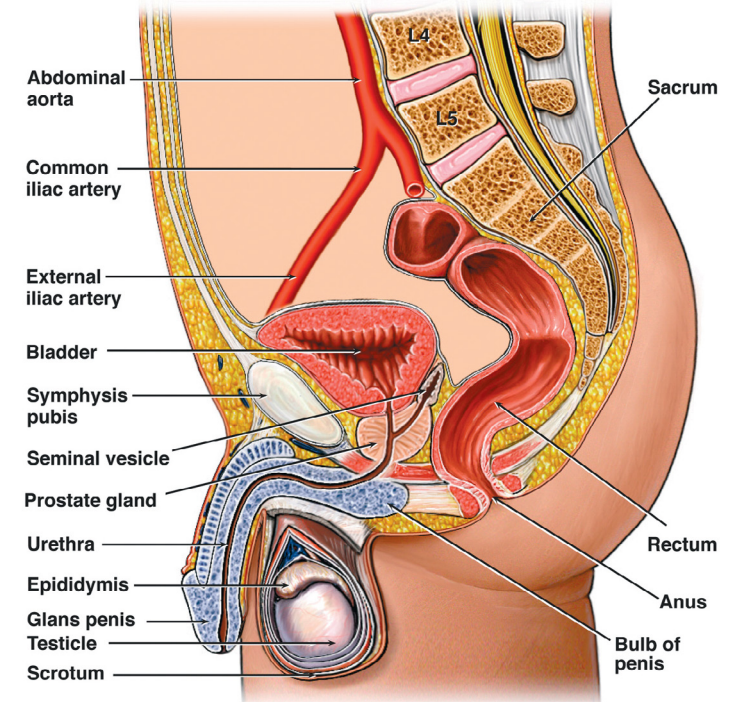


The prostate

The prostate sits inside the pelvis, underneath the bladder and in front of the back passage or rectum.

It wraps around the tube called the urethra (or water-pipe) which allows urine to pass out of the body and, for some men, semen to pass out through the penis.

The pelvic floor muscles are like an elastic hammock to support the bowel and the bladder. These stretch from the pubic bone at the front of the body through to the coccyx, the small bone at the bottom of the spine and from side to side.





This booklet has been compiled by Prostate Scotland with advice from PAGES (Prostate Advisory Group Prostate Scotland).
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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.

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