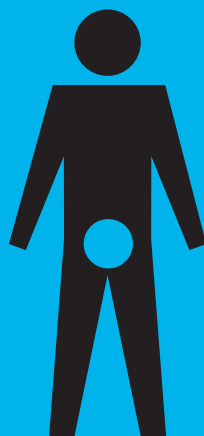


Early prostate cancer explained



EARLY PROSTATE CANCER EXPLAINED

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It is Prostate Scotland's aim to help all those affected by prostate disease and cancer, regardless of race, background, sexuality or gender identity.

This booklet is relevant for all patients diagnosed with early or locally advanced prostate cancer.

This will include men, trans women and some non-binary people, although we may use the terms man/men/male within this booklet.

The information that follows about treatment choices for prostate cancer is meant as general guidance. As procedures may vary between health boards, ask for more advice from staff at the hospital you are attending. If you have been given specific guidance by the hospital, it is important that you follow their instructions.

The information contained in this leaflet has been developed by Prostate Scotland and reviewed by its advisory group of health professionals and patients. This leaflet is not intended to replace medical advice or seeing a doctor for specific illnesses or symptoms.

SECTION 1: INTRODUCTION

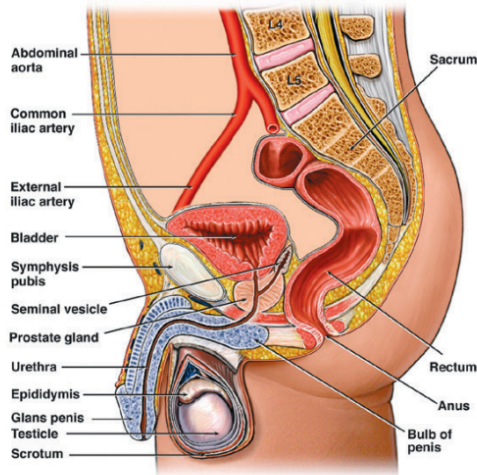
This section will explore what the prostate is and provide a brief explanation of prostate cancer including a look at risk factors, a guide to test results and an introduction to treatment options.

What is the prostate?

Only those born biologically male have a prostate. It starts out about the size of a pea then slowly grows to the size of a walnut by adulthood. Around the age of 40, it may start to enlarge, and this can cause problems when passing urine.

Where is it?

The prostate is inside the pelvis, just below the bladder and in front of the rectum (back passage). It wraps around the urethra, a tube which allows urine to flow out of the bladder and semen to pass out through the penis. The prostate can't be seen or checked from outside the body.



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What does the prostate do?

It supplies a thick, clear fluid that mixes with sperm to form semen. This fluid helps to nourish and protect sperm during sexual intercourse. The prostate also makes prostate specific antigen (PSA). PSA is a protein that makes semen more fluid and so helps sperm to move more easily.

What is prostate cancer?

Prostate cancer happens when the cells in the prostate become abnormal, multiply and grow faster than normal in an uncontrolled way. This causes a growth called a tumour. As the prostate is inside the body, this growth can't be seen and often causes no symptoms. Most prostate cancers grow slowly. Some people won't even know they have prostate cancer, as it may not cause any symptoms or shorten their life.

Prostate cancer may be:

- **Early or localised:** It is still within the prostate and has not spread to other parts of the body.
- **Locally advanced:** It has spread just outside the prostate through the capsule (covering) that surrounds the prostate or into the seminal vesicles that lie behind the prostate.
- **Advanced:** When cancer cells have spread away from the prostate through the bloodstream or lymph channels. On reaching a new site or sites, the cancer cells may start to grow causing another tumour or tumours. These are called secondary cancers (secondaries) or metastases. These metastases are most often found in lymph nodes in the pelvis or in bone.

What causes prostate cancer?

No one knows what causes prostate cancer even though it is the most common cancer for men in Scotland. However, the chance of getting prostate cancer increases with the following risk factors:

- **Age:** Prostate cancer becomes more common after the age of 50.
- **Family history:** Risk increases if your brother or father has or has had prostate cancer. If there is a strong family history of certain kinds of breast, ovarian or pancreatic cancer with the altered gene BRCA1 and BRCA2, the risk is greater.
- **Background:** Black men and those from an African/Caribbean background are more likely to develop prostate cancer and up to 5 years earlier.

Receiving a prostate cancer diagnosis

Your prostate cancer diagnosis will have been the result of several tests, such as PSA, digital rectal examination (DRE), MRI scan and biopsy.

The news that you have been diagnosed with prostate cancer will be a shock to you and your family. After being given your diagnosis, it's common not to take in everything the doctor has said.

It's normal to have a wide range of emotions – fear, worry, sadness, guilt, anxiety, stress, feeling very low and depressed. Although this is normal, it can have a huge impact on your life and on your family. The first step is to let someone from your healthcare team know that you're having difficulty coping.

The main message to hold onto is that treatments are available and, depending on your individual circumstances, treatments for early prostate cancer often have the potential to achieve a complete cure.

Waiting for results

Having multiple investigations and waiting for results can be very stressful. It can be worrying too, for partners, family members and close friends.

In some hospitals, there are specialist urology or oncology nurses, and it may help to talk to them. There are also telephone helplines that you can call. If there is a support group in your area, it may help to get in touch, as members will understand first-hand how you might be feeling. For a list of some sources of help turn to page 66.

It might also be a good idea to write down any questions you have so you can ask your medical team at your next appointment.

What do test results mean?

You will hear many different terms and numbers when your medical team discuss your results. These can be difficult to keep track of so you might want to record them in the Prostate Scotland logbook, a notebook or on your smartphone.

Gleason score / ISUP Grade

A doctor, called a pathologist, will be sent small samples taken from your prostate during your biopsy procedure. These are examined under a microscope to look at the cells.

Normal healthy prostate cells are roughly the same size and shape. As cancer grows, the cells change, become unusual and grow faster in an uncontrolled way. The more unusual or abnormal the cancer cells are, the more likely the cancer is to be aggressive or spread outside the prostate.

The pathologist decides which type of cancer cell is most common and which is second most common. Each of these two cell types is given a number/score from 3 to 5.

3 means these cells are the most normal looking or least aggressive, whilst cells scored as 5 are the most abnormal looking or most aggressive. These numbers are added together to give a final score out of 10. This is your Gleason score.

You may hear the Gleason score mentioned, but it has been replaced by the International Society of Uropathologists (ISUP) score. The ISUP score simplifies the Gleason score into 5 Grade Groups.

ISUP Grade 1 will be the least aggressive and least likely to spread to outside the prostate while Grade 5 will be the most aggressive grade of prostate cancer and more likely to spread.

Gleason Score	ISUP Grade
2-6	1
7 (3+4)	2
7 (4+3)	3
8 (4+4 or 3+5 or 5+3)	4
9-10 (4+5 or 5+4 or 5+5)	5

Staging

This is the word used to describe the size of the cancer and whether it has spread outside the prostate to the bones or other parts of the body. It is called the TNM system. It is made up of:

- The letter '**T**' for **tumour** followed by a number.
- The letter '**N**' for lymph **nodes**.
- The letter '**M**' for **metastasis** or metastases.



What does the T stage mean?

T1	The tumour is too small to be seen during a scan, and the doctor will not have been able to feel it when your prostate was examined during a DRE. This type of tumour shows up when the samples of tissue taken during the biopsy are looked at under the microscope. This is called early or localised prostate cancer.
T2: The tumour is still inside the prostate.	The tumour will be seen during a scan, and the doctor will have been able to feel a lump or hard area when your prostate was examined during a DRE. This type of tumour is still inside the prostate. This is also called early or localised prostate cancer.
T3a: The tumour has broken through the capsule of the prostate. T3b: The tumour has spread into the seminal vesicles.	The tumour is breaking out through the wall of the prostate. This will be seen during a scan or can be felt on examination. If there is no evidence that the cancer has spread elsewhere in the body, then this is called locally advanced prostate cancer.
T4: The tumour is invading other organs or bone.	The cancer has spread to nearby organs in the body, such as the rectum, bladder or pelvic side wall. This is called advanced prostate cancer. Where the cancer has spread to other areas in the body and started to grow, the new site is called a secondary site (secondaries) or metastasis. It is still prostate cancer.

What does the 'N' stage mean?

The 'N' stands for lymph nodes. Lymph nodes help fight infection. Prostate cancer can spread to lymph nodes near the prostate or to lymph nodes in other parts of the body. So, the 'N' shows whether cancer has been found in the lymph nodes. This is measured during an MRI scan.

As a guide:

- **NX:** the lymph nodes were not checked.
- **N0:** cancer cells have not spread to lymph nodes near the prostate.
- **N1:** the cancer has spread to the lymph node(s) near the prostate.

What does the 'M' stage mean?

The 'M' stands for metastasis (one other cancer site) or metastases (when there are several other cancer sites). This is the term used to measure the spread of the cancer in the body.

As a guide:

- **M0:** The cancer has not spread to other parts of the body.
- **M1:** The cancer has spread to other parts of the body e.g. lymph nodes away from the pelvis, bone or other organs.

CPG

You may also hear Cambridge Prognostic Group or CPG mentioned. To help with making choices about treatment, your ISUP score, your PSA and the stage of your cancer can be combined to give your CPG. The CPG categorises the likelihood of the cancer spreading and whether the cancer may shorten your life. Other prognostic tools are available but this is the most commonly used and is endorsed by the National Institute for Health & Care Excellence (NICE).

The following table summarises the Cambridge Prognostic grouping.



Cambridge Prognostic Group	Criteria
1	Gleason score 6 (grade group* 1) and PSA less than 10microgram/L and Stages T1–T2
2	Gleason score 3+4=7 (grade group* 2) or PSA 10–20microgram/L and Stages T1–T2
3	Gleason score 3+4=7 (grade group* 2) and PSA 10–20microgram/L and Stages T1–T2 or Gleason 4+3=7 (grade group* 3) and Stages T1–T2
4	One of: Gleason score 8 (grade group* 4), PSA more than 20microgram/L, Stage T3
5	Two or more of: Gleason score 8 (grade group* 4), PSA more than 20 microgram/L, Stage T3 or Gleason score 9–10 (grade group* 5) or Stage T4

In addition, the clinicians involved in your care may discuss or show you the Predict Prostate tool, which can be used to calculate individual prognosis for men with prostate cancer. Such tools can be used to help with decision making around the benefits and potential risks of various treatments.

What happens after the results are known?

Once the medical team has all your test results, several issues will be considered before deciding which treatment(s) may be most suitable for you. They will look at:

- Your ISUP/Gleason score or CPG.
- Your MRI scan.
- The stage of your cancer.
- Your PSA level.
- How old you are and your symptoms.
- Whether you have any other medical conditions.
- If the side-effects of the treatment would have greater impact on your quality of life than the cancer.

Your results will be discussed in a multidisciplinary team meeting (MDT). The MDT is made up of urologists, oncologists, radiologists, pathologists, clinical nurse specialists (CNS), physiotherapists, pharmacists, many of whom will be involved with your care and treatment.

Your case will be discussed by the MDT and then you will be seen in clinic by your own medical team (urologist, oncologist or CNS) to talk through the results and:

- Suggest which treatment(s) may be most suitable.
- Talk to you about the advantages and drawbacks of the treatment(s) offered, including potential side-effects.
- Ask which type of treatment you would prefer.

What might your diagnosis mean for your family?

After you've had time to come to terms with your diagnosis, you may start to wonder what the risks are for other men in your family.

Prostate cancer can run in families. Men who have close relatives who have been diagnosed with prostate cancer may have an increased risk of developing prostate cancer. Although it may be difficult, you should consider letting men in your family know so they can discuss this with their GP. Depending on their personal circumstances, the GP may offer a PSA test.

At the time of writing (September 2026) there is not a screening programme for prostate cancer in the UK. However, guidance suggests that anyone over the age of 50 with a prostate, even with no symptoms, can have a PSA test following appropriate consultation by their GP about the benefits and risks.

If the person is at higher risk due to family history or ethnicity this conversation is recommended from the age of 45.



Intimacy after diagnosis and before treatment

Some men are concerned about intimacy with their partner after they have been diagnosed. There is no evidence that there is any risk of passing cancer on through sexual activity.

Other men have asked about frequency of sexual activity after being diagnosed. The advice is to continue as you would normally, with a frequency that you and your partner are comfortable with (after certain treatments you may be advised to wear a condom).

Deciding on treatment

The various treatment options which you may be offered are covered in separate sections in this booklet.

You may be faced with deciding on a treatment. Whilst this may sound daunting, it is likely that the more you and your family are involved in the decision, the more confident and satisfied you will feel with your choice.

You don't need to make this decision on your own. Your medical team and other men who have been in this same position can give you information, help and support.

Spend some time thinking about what is right for you. Prostate cancer is generally slow growing, giving men and their families time to make the decision.

Some men want to know what will cure their cancer fastest and then get on with their life. However, other men feel that everything is happening too fast and they are not being given enough time to think things through.

Talk to others and try not to get rushed into deciding too quickly. Try looking at the videos and information about treatment options on the Prostate Scotland website.

People to talk to

- Members of the medical team who are looking after you – consultant urologist, consultant oncologist and CNS.
- Your GP.
- Your partner.
- Your family and friends.
- A prostate cancer support helpline or support group. For a list of some sources of help turn to page 66.

Some things to think about when deciding on treatment

- How much your cancer is a threat to your health now and how it might affect your health and wellbeing in the future.
- Your medical team will explain which treatment choices are available and suitable for you. Make a list of these choices. Write down what you like and what you don't like about each one. Think about how important each of these points is to you and your family.
- If you are recommended only one choice, you can ask why other treatment choices are not suitable for you.
- Look over the advantages and drawbacks given in each treatment section.
- Look over the list of suggested questions given in each section. You might want to ask your medical team some of these or you may have questions of your own.
- Make sure you fully understand the possible side-effects of each treatment and think about how these could affect all parts of your life, e.g. your job, hobbies, social life, sex life, holidays or events. If you have a partner, ask them what they think.
- You may wish to speak to others who have had the treatments. This will give you an idea of what is involved and potential impact. However, remember that people have different ideas on what is important so will put different values on the possible outcomes of treatment. It's important to feel that you have made the best choice for you.



Tips on talking with your medical team

- If you are struggling emotionally, speak to the staff in hospital or your GP.
- Make a list of questions and take this with you to your appointments, as it is very easy to forget what you want to ask. You can write down answers to your questions so you can look back over them later.
- You may wish to audio-record appointments so that you can listen back to the conversation later. You can use the recording system on your smartphone or a digital audio-recorder. **You must always get permission from your medical team before making a recording.**
- You could ask the urologist, oncologist or CNS to write down any test results for you, as these will be important later when discussing your PSA level, Gleason score, CPG and staging of your cancer.
- As there is often a lot of information, it can be helpful if your partner, family member or friend sits in on your appointment, as they can also ask questions, take notes or just listen. Then you can talk this over with them later. Tell the medical staff that you would like someone to sit in with you.
- If you don't understand what you've been told, let the urologist, oncologist or CNS know right away so they can explain it again. Medical information is often not easy to understand so lots of people need another explanation and more time.
- You might feel that the urologist, oncologist or CNS is too busy to answer your questions, but it's important that you understand what will happen now and when treatment has started. You can ask for more time and don't feel you need to decide in too much of a hurry.

SECTION 2: TREATMENTS

A: ACTIVE SURVEILLANCE AND WATCHFUL WAITING

You may be offered active surveillance (AS) or watchful waiting (WW) to manage your prostate cancer.

What is active surveillance?

AS is a way to manage prostate cancer by careful medical monitoring. AS means that you won't have any immediate treatment, as treatment is postponed until you or your medical team feels it necessary because of your test results or you decide you no longer want to manage your cancer in this way.

When might AS be suggested?

- For patients in Cambridge Prognostic Group (CPG) 1 as a first choice of treatment.
- For patients in CPG 2 AS may be suggested alongside prostatectomy and radiotherapy options.
- For some patients in CPG 3, AS may be discussed if the patient wishes to defer treatment.
- For patients whose prostate specific antigen (PSA) is appropriate for the size of their prostate.
- For patients who are medically fit otherwise.
- For younger patients who have concerns that the side-effects of treatment may have a greater impact on their quality of life than the cancer.

See pages 4-7 for more information on Gleason, ISUP and CPG.

There may be additional local guidelines that you have to meet for AS to be considered a suitable management choice. Ask your urologist or clinical nurse specialist (CNS) if there are specific guidelines for AS in the hospital that you attend.

How is the cancer monitored?

Your prostate cancer will be carefully monitored through regular appointments with your urologist or CNS. Depending on your health board, appointments may be face-to-face or by telephone or video call.

As protocols or guidelines may vary throughout Scotland, a typical approach might be:

Timing in years after commencing AS	Tests
Year 1	Measuring PSA every 3–4 months. The offer of a digital rectal examination (DRE) around 12 months. An MRI scan around 12–18 months (possibly an abbreviated scan).
Years 2–4	Measuring PSA every 3–6 months. Possibly a DRE every 12 months. Possibly an MRI scan if there is concern the cancer may be progressing.
Years 5 +	Measuring PSA every 6 months (assuming everything appears stable). The possibility of a DRE every 12 months.

When would another form of treatment be needed?

If you change your mind about AS, you should speak to your urologist or CNS. They will then discuss alternative treatment options with you.

Being monitored regularly should show if the cancer starts to grow and become more likely to spread. These signs include:

- Your PSA level continuing to rise.
- A change in your ISUP, CPG or Gleason score.
- Changes to the prostate during a DRE.
- Changes on an MRI scan.
- A biopsy showing significant increase in volume of the cancer.

If the urologist or CNS thinks that the cancer is showing signs of changing, growing faster or spreading, then treatment can be started.

Treatment options might include radical prostatectomy, hormone therapy, external beam radiotherapy or brachytherapy.

Watchful waiting

You may also hear about watchful waiting (WW). This is another way of monitoring prostate cancer; it is not the same as active surveillance. Your urologist or GP may suggest WW when they think that:

- The prostate cancer is likely to be slow growing and would not affect how long you will live.
- You have another health condition which means that you wouldn't be well enough to have another type of treatment.
- You are of an age where there is no clear evidence that treating the prostate cancer would help you to live longer.

WW means that you wouldn't have any active treatment for the prostate cancer.

The GP, practice nurse or urology team will review your PSA level every 6–12 months. Alternatively, you may be on symptomatic follow-up only, where it is felt that PSA readings would not change the management of your care. This would be discussed with you by your team.

If tests show that the cancer is changing and starting to grow, then the GP, urologist or CNS may talk to you about treatment. The treatment would be aimed at controlling the cancer and managing symptoms, not curing it.

What advantages and drawbacks are there to think about with AS?

Advantages	Drawbacks
With AS your prostate cancer is carefully monitored and treatment is put off until it becomes necessary or you decide you no longer want AS.	AS does not treat your cancer but the urology team will carefully monitor your cancer to check if it is progressing. You will need to remember to make appointments and keep a record of test results, taking an active part in the monitoring of your cancer.
You avoid any risk of potential side-effects (incontinence, erectile dysfunction, bowel or bladder difficulties) that you might get from treatments aimed at curing your prostate cancer. You can carry on with everyday life as before without any impact due to your prostate cancer treatment.	You may be anxious that you are not doing anything. AS is not for everyone. You will have to be willing to live with some uncertainty and doubt about your cancer and what is going on.
Your prostate cancer may grow so slowly that other treatments may never be needed. Even if your cancer starts to grow, then there are still options for treatment to try to cure it.	There is a very small risk that a slow-growing cancer may suddenly grow and spread outside the prostate while you are on AS, so you could reduce the possibility of your cancer being treated with the aim of curing it. This could then reduce the types of treatment available for you, increase the risk of side-effects and may make it longer for you to recover after treatment.
While your cancer is being monitored new and better treatments may become available.	You will need to have regular check-ups which may include PSA tests, DRE, MRI scans or biopsies.

Questions you may wish to ask your medical team about active surveillance

- Is AS a suitable option for me?
- If I choose AS now, can I change my mind later?
- Is it safe for me to put off treatment?
- If I wait, will this limit my choices in the future?
- What indications are there about the aggressiveness of my prostate cancer?
- Can you explain what the risks are likely to be?
- Between check-ups, are there any signs or symptoms I should look out for?
- Which tests would I have to monitor the cancer?
- How often would I need to have the tests and who would do these?
- How would we know if my prostate cancer is getting worse?
- What treatment might be offered to me if the cancer starts to grow?
- Are there other suitable treatment choices that I could think about now?
- Is there someone that I can talk to who has made this choice?

To learn more, download our *Spotlight on: Active surveillance as a management for early prostate cancer* from www.prostatescotland.org.uk



SECTION 2: TREATMENTS

B: SURGERY

You may be offered surgery to remove the prostate – this is called a radical prostatectomy.

What is a radical prostatectomy?

A radical prostatectomy is an operation to remove the prostate, and the cancer cells within it, to stop it from spreading to other parts of the body. This is a fairly major operation, and involves removing:

- The whole prostate.
- The part of the urethra inside the prostate.
- Seminal vesicles next to the prostate – glands that store semen.

See page 1 for an illustration of the anatomy around the prostate.

Radical prostatectomy can be done in the following ways:

Robotic assisted laparoscopic radical prostatectomy (RARP): the most common minimal access surgical approach to radical prostatectomy. The operation is carried out using a surgical robot.

Laparoscopic radical prostatectomy (LRP): very similar to the operation explained above; the difference is that the surgeon will use surgical instruments, rather than the robot. This is largely being replaced by RARP.

The expected advantages of minimal access surgery compared to traditional open surgery are:

- Shorter stay in hospital.
- Smaller scars.
- Faster recovery time.
- Quicker return to work.
- Less bleeding and decreased chance of requiring a blood transfusion.
- Less time with a catheter.
- Better continence and erectile function rates.

When might a radical prostatectomy be suggested?

- As a primary treatment for prostate cancer when the cancer is localised and contained within the prostate.
- When the cancer has not metastasised (spread) to other parts of the body.
- For patients in Cambridge Prognostic Group (CPG) 1 active surveillance (AS) is the preferred option but surgery may be considered where AS is not acceptable to the patient.
- For patients in CPG 2 and 3 surgery should be offered alongside radiotherapy.
- For patients in CPG 4 and 5 surgery may be offered in some circumstances. This will be discussed with you if appropriate.
- After a period of AS if there are signs of the cancer growing and needing treatment.
- For men medically fit for a general anaesthetic.
- Very occasionally, RARP may be done if you have had previous treatment for prostate cancer such as radiotherapy or brachytherapy and the cancer has recurred but has not spread outside the prostate gland.

Planning for a radical prostatectomy

- You will likely go to a pre-assessment clinic to have some tests, the operation explained and any questions answered. The tests are to make sure you are fit enough to have the operation. You may be asked to sign a consent form at this appointment.
- You will be given information about eating and drinking before the operation takes place.
- In some centres you will be seen by a clinical nurse specialist (CNS) to discuss possible continence and erectile function issues.
- In some centres you may have the opportunity to watch a film or attend a class called 'surgery school' before your operation.
- Your CNS or a specialist physiotherapist will advise you on a programme of pelvic floor exercises to do before your operation.
- You will be asked what medication you are taking. Remember to tell staff about aspirin, warfarin, clopidogrel, rivaroxaban, apixaban, ticagrelor and edoxaban, or any other pills you are taking.
- On the morning of your operation, you may be given an enema or suppository depending on how recently you have opened your bowels.
- You will be seen by an anaesthetist prior to or on the day of your operation.



The operation

- You will be given a general anaesthetic, which means you will be asleep during the operation.
- You will be lying on your back with your head in a slightly down position:
 - i. With RARP the robotic machine will be placed next to the operating table. Robotic arms will be attached to the robot. The surgeon sits at a console a short distance away and controls the robotic arms and instruments from the console.
 - ii. You will have 5 small cuts across your lower stomach. 4 cuts will be around 1cm long and there will be a small plastic tube placed inside. Each cut serves a different purpose during the operation: 1 is used for a camera to magnify inside; 3 others are used for the instruments to undertake the operation.
 - iii. The final cut is about 2–3cm to allow the surgeon to insert the instruments needed to take the prostate out.
 - iv. With laparoscopic radical prostatectomy, you will have the 5 small cuts as described above. Instead of using a robot, the surgeon will directly work inside your body using instruments to do the operation.
- If the surgeon thinks that there might also be cancer in the lymph nodes then he/she may discuss removing the lymph nodes with you. These will be taken out during your prostatectomy, called a lymph node dissection.
- After the prostate is taken out, the urethra is joined back on to the neck of the bladder. Because part of the urethra has been taken out, it will shorten the urethra and so your penis may appear shorter.
- You will be given oxygen during and possibly after your operation and you may have a warming blanket.
- You may have an intravenous line (drip) that will stay in place until you are eating and drinking normally.
- Some men require a blood transfusion following the operation, although this is less likely with RARP.
- The operation usually lasts between 2 and 4 hours.
- You will be given painkillers on the ward to help with any pain or discomfort.

Having a catheter

- When you get back to the ward, you will have a catheter (a long, thin, flexible tube) in your bladder. This tube drains urine out of your bladder into a drainage bag outside your body. This allows the area to heal.
- The catheter will usually stay in place for 1–2 weeks but this can vary in different hospitals.
- You may have a tube drain in place for 1–2 days to drain any excess blood into a bag.
- Some men find their catheter might leak and for some this leakage can happen quite frequently.
- If you experience strong spasms in your bladder, speak to your CNS or nurses on the ward. They may want to check the catheter and may be able to prescribe a medicine to help.
- You will probably go home with the catheter in place and will be given advice on how to care for it. You may also be given a 'Take home pack' and a 'Urinary Catheter Care Passport'.
- 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 urgently contact your GP, NHS 24 or go to an A&E department.
- Your medical team will arrange the removal of the catheter.

If you have a catheter because you have had a prostatectomy, then you should not try to take the catheter out or change it yourself, unless you have express permission from your surgeon or CNS.

Further information about catheters can be found on pages 50–51.

To learn more, download our *Spotlight on: Caring for your Indwelling Catheter at Home* from www.prostatescotland.org.uk



Will I have to stay in hospital?

Yes, you will have to stay in hospital, but this is usually for a short time. Getting home will depend on a few factors:

- You can move around as well as you did before your operation.
- You have had a bowel movement.
- You know how to care for your catheter.
- Your pain is well controlled by medication.

Your urologist will see you after your operation and discuss with you when you can go home. Most men are discharged 1 or 2 days after the operation. This might be dependent on travel arrangements and the hospital you are in.

Going home and after care

- It's a good idea to wear some loose-fitting, elasticated-waist trousers for going home so that you feel comfortable.
- Some hospitals may provide you with a Prostate Scotland Prospank. This contains practical items such as continence pads, antibacterial hand gel and wipes.
- If you were asked to stop taking some of your usual medication before your operation, ask your urologist or CNS 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 may help to flush out any excess blood.
- It's quite common to find swelling and/or bruising to your penis or scrotum but this usually settles within a week.
- To help with pain and discomfort, it is good to have suitable painkillers at home. Ask your urologist or CNS if you are unsure about this.
- While you have a catheter, it is best to shower rather than bathe, if your wound is healing well.
- If you have a dressing this may need to be changed.
- If you have some leakage around the sides of the catheter, you may need to use pads. Pads will also help with any leaks after your catheter is taken out.

- Once your catheter is out, you will likely be advised to continue with your pelvic floor exercises to help with continence. Ask your CNS or physiotherapist for more information.
- At first, discomfort around the area of your wounds will stop you from doing too much. Avoid strenuous activity in the first few weeks, then start some light exercise and gradually increase as you recover. Remember not to pick up anything heavy as this puts a strain on your wound. Further advice on returning to activity will likely be given to you by a physiotherapist.
- After surgery, you should be able to go back to driving after 2–3 weeks, but you should discuss this with your urologist or CNS for more specific advice and let your car insurance company know.
- You may be able to return to work after 3–4 weeks. Again, speak to your urologist or CNS for more specific advice.
- When you are able and it feels comfortable, you may wish to become sexually active again. The ability to have normal spontaneous erections cannot be guaranteed – see further information below.
- 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.

Complications from radical prostatectomy

There are potential risks and complications with any kind of surgery. Your urologist or CNS will take you through these before you sign the consent form. Some of the potential complications are listed below.

Excessive bleeding: This is not very common but can happen during or after surgery. On rare occasions, this may lead to you having a blood transfusion.

Blood clots: Because of sluggish blood flow in the legs, blood clots can form. Again, this is quite rare, and measures to avoid this are taken during the operation. During recovery, surgical stockings help maintain a continuous blood flow in the legs. As soon as you feel able after your operation, you will be encouraged to walk to pump blood from the legs to the heart. While you're in hospital you may be prescribed enoxaparin, clexane or dalteparin to help prevent and treat blood clots. In some hospitals you will continue the injections for a short period after going home.

Urinary tract infection (UTI): This can be an infection in the bladder or kidneys. Signs include a burning feeling when passing urine, smelly and cloudy urine, and feeling you need to pass urine often even if only a little dribbles out. You will be given antibiotics if necessary; remember to finish the full course of tablets.

Injury to the rectum (back passage): Although this is a possibility, it is not common. Because the wall of the rectum lies so close to the prostate, there is a risk that it may tear during your operation. If the injury is recognised during the operation, it will be stitched and generally no further treatment is needed. Sometimes, a short-term colostomy may be needed to allow the rectum time to heal. A colostomy is surgery to make an opening in the lower stomach that connects part of the bowel to a pouch or bag outside the body to collect faeces.

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. They will need to be removed 4–6 weeks after your operation. This is done via a small, flexible camera passed into the urethra under local anaesthetic and as an outpatient. You will be advised if this is relevant to you whilst 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.

Leak in the join between the bladder and urethra: If the join between the urethra and bladder has not healed properly after 7–9 days then the catheter to drain urine will need to stay in longer, perhaps an extra 1–2 weeks. In some hospitals, you may be given a type of x-ray, called a cystogram, to check how quickly your catheter can be taken out. A cystogram is not done in all hospitals so you can ask your consultant if you are likely to have one.

Wound infection: Change your dressings and keep the wound site clean as instructed by your surgical team or CNS. If your wounds become red, painful, hot or have an unpleasant smell you may have developed an infection and should contact your CNS or your GP for advice as you will likely need antibiotics.

Abdominal bloating / shoulder tip pain: Gas is put into the abdomen during robotic surgery in order that your surgeon has room to do the surgery. They will remove as much as possible after the operation. However, you may still feel bloated for a few days. Some patients will experience shoulder tip pain as the gas can stretch your diaphragm, again this should settle in a few days.

Lower limb swelling: You may notice this, particularly if lymph nodes have been removed during your surgery. It should settle in a few weeks; however, some men will go on to require lymphoedema management from a specialist lymphoedema service. This can involve compression garments or specialist lymphatic drainage massage, as directed by the specialist.

Side-effects of radical prostatectomy

There are potential side-effects with all treatments for prostate cancer. This will vary from person to person. Some of the potential side-effects are listed below.

There is help available for many of these side-effects so if you are impacted by any of them it is important to talk to your urologist, CNS or GP so you can get advice.

Urinary incontinence: This means that you may not be able to hold urine inside your bladder after the catheter is taken out. It may be difficult to stop some urine leaking out when you cough, laugh, get up from a sitting position or when walking.

Although a common side-effect, it is usually temporary with most men regaining full continence over time.

You may also experience some urgency when you need to go to the toilet. Your urologist or CNS may suggest medication to help with this.

Some men will have severe urinary incontinence after a prostatectomy that may require a small operation to insert an artificial urinary sphincter.

You can get help and support for incontinence from the continence advisory service (CAS) in your area. These services are usually run by nurse specialists called continence advisors. Every health board has a CAS of some kind, although they might work slightly differently. Your CNS or GP will be able to guide you to the appropriate service.



Further information about continence issues can be found on pages 52-53.

To learn more, download our *Spotlight on: Urinary incontinence as a symptom of prostate problems* from www.prostatescotland.org.uk

Difficulties with erections: When a man has trouble getting or keeping an erection firm enough to have sexual intercourse, it is called erectile dysfunction (ED). Not being able to have an erection can affect men at different ages and stages in their life and for different reasons.

After a radical prostatectomy, it is usual for men to be unable to have an erection. This is because the nerve bundles and blood vessels, that are needed to have a normal, natural erection, lie close to the prostate and may be stretched/damaged during the operation.

For some men, it is possible to save these nerves with nerve sparing surgery. For others, to make sure that all the cancer is removed, it isn't possible to save these nerves and blood vessels. In this case, it is no longer possible to have a natural erection but there are treatments available to help. You can ask the urologist if nerve sparing surgery is a possibility for you.

Further information on erectile dysfunction can be found on pages 54-57.

To learn more, download our *Spotlight on: Prostate conditions and erectile dysfunction* from www.prostatescotland.org.uk

Infertility and dry ejaculation: Due to the vas deferens and seminal vesicles being removed during a radical prostatectomy you will no longer produce semen when you ejaculate. If you were considering adding to your family, you can ask your team about sperm banking before the operation.

Although you will feel the same pleasure that accompanies an orgasm, orgasms will usually be 'dry', meaning little or no semen is produced. It is also common to leak a little urine as the muscles relax at the point of orgasm, known as climacturia. Some men worry about the effect this will have on their partner, but for most partners this is not a problem.

Constipation: Constipation is a temporary but common side-effect after radical prostatectomy, and it may take time to get back to your normal pattern. Being constipated can be painful, uncomfortable and may affect healing if you strain too hard on the toilet.

A gentle laxative will help. Ask your urologist, CNS, GP or pharmacist for advice on what kind to use and how long for. It is also advised to eat a well-balanced diet with plenty of fruit, vegetables and fibre, and to drink approximately 2 litres / 4 pints of fluid per day.

Follow-up

You should get an appointment to attend the urology outpatient department about 6–8 weeks after surgery.

It is recommended that you get a PSA test before this appointment, so the medical team have an up-to-date level. Arrangements to have this PSA test vary between health boards, and it could be done at your GP or in the hospital. It's best to check arrangements with the urologist or CNS.

At your clinic appointment, you will be asked how you are, hear about your results and have your wound examined.

Your urologist may mention positive surgical margin(s). This 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.

You will continue to have regular check-ups and monitoring of your PSA levels. After a radical prostatectomy, your PSA should drop quickly and should be undetectable. If it does not drop this low or starts to rise, then the urologist may want to discuss further investigations.



What advantages and drawbacks are there to think about with a radical prostatectomy?

Advantages	Drawbacks
Can offer a cure for cancer still within the prostate. You may be reassured to know that your prostate and so the cancer within it has been removed.	This operation is suitable for the majority, but not all patients. For a small number of cases there may be a positive surgical margin following surgery that increases the risk of requiring additional treatment in the form of radiotherapy or hormone therapy later.
Information can be gathered about the stage of your cancer when the prostate tissue is studied in the lab. Long-term cure rates are well proven and are comparable with other treatments such as radiotherapy.	It is still a major operation, and you need to be in hospital for a few days. 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. As with all treatments, there is no complete guarantee of cure. There is a very small risk of severe bleeding and rectal injury linked with the operation.
Although there may be unwanted side-effects such as stress incontinence and ED, treatments for these are available and well-defined.	In some cases, incontinence and/or ED may be long-term issues.
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.	
After the operation, you may still be considered for radiotherapy if this is necessary.	Radiotherapy can have side-effects and these may be more troublesome if you have had previous surgery.
If you previously had problems passing urine, then a radical prostatectomy can solve these.	

Questions you may wish to ask your medical team about radical prostatectomy

- Is radical prostatectomy a suitable option for me to think about?
- Could it cure my cancer?
- Which type of radical prostatectomy would you suggest?
- How familiar is the surgical team in performing the surgery?
- Are there any outcome results available?
- Is nerve sparing surgery an option for me and what would be the impact on my erections if not?
- Can you explain what the risks and side-effects are?
- After having a radical prostatectomy, roughly how many men do you find have problems with incontinence and ED and for how long?
- When and where would the surgery be done?
- How long will I have a catheter for?
- Will I have to wear incontinence pads, and, if so, for how long?
- Is there anything I could do to help with the side-effects?
- When and how will we know whether the radical prostatectomy has been successful?
- If the radical prostatectomy is not successful, what would my options be?
- Are there other suitable treatment choices that I could think about?
- Is there someone that I can talk to who has had the same surgery that I am thinking about?

For more information you can download our *Spotlight on: Minimal access radical prostatectomy for prostate cancer* from www.prostatescotland.org.uk



SECTION 2: TREATMENTS

C: RADIOTHERAPY AND BRACHYTHERAPY

You may be offered radiotherapy, with the aim of destroying the cancer cells inside your prostate. There are a few ways that radiotherapy can be given:

- External beam radiotherapy (EBRT)
- Stereotactic body radiation therapy (SBRT)
- Brachytherapy
- Combination treatment

More detailed information on each type of treatment is provided below.

External beam radiotherapy

EBRT is a treatment that uses high energy x-rays to destroy the cancer cells.

It is an extremely localised treatment meaning that it accurately targets the prostate, and if required the seminal vesicles and nearby lymph nodes.

The prostate is accurately targeted so the dose to nearby healthy tissues is minimised.

EBRT is usually received as an outpatient, so most people won't need to stay in hospital.

Stereotactic body radiation therapy

This treatment may also be called stereotactic ablative body radiation (SABR) but throughout this booklet we will use the term SBRT.

Delivered in the same way as EBRT, this type of radiotherapy treatment uses larger doses of radiation in a shorter period, usually over 3–5 days.

There are specific indications for offering SBRT depending on your staging and grade of prostate cancer, and your medical team would explain this to you.

When might EBRT or SBRT be suggested?

Radiotherapy may be offered as treatment for prostate cancer:

- Patients in Cambridge Prognostic Group (CPG) 1 who decline active surveillance could be offered EBRT.
- Radiotherapy can be a suitable treatment for all types of early prostate cancer but the exact treatment type will vary depending on your CPG. This will be discussed with you by your oncologist as appropriate.
- After a period of active surveillance.

- For patients who are medically fit for and will benefit from treatment.
- For patients with recurrence following a prostatectomy.
- As part of a clinical trial.

Hormone therapy with radiotherapy

Some men may be given hormone treatment for several months before radiotherapy treatment. This can improve the effectiveness of the treatment as hormone therapy lowers the production of testosterone which can lead to the prostate shrinking. By making the prostate smaller, the area that receives radiotherapy is smaller which in turn can lead to a reduction in side-effects. Hormone therapy can also make the cancer cells more sensitive to radiation which can make the radiotherapy treatment more effective.

Further information on hormone therapy can be found on pages 46-49.

Planning for EBRT and SBRT

Before starting your radiotherapy, you will have appointments to create your individualised treatment plan. This may start a few weeks before your radiotherapy begins.

Fiducial marker insertion: In some centres, tiny gold pellets known as fiducial markers may be inserted into the prostate gland prior to the planning scan. These markers are not radioactive but are used to better visualise the prostate gland on the pre-treatment imaging.

You will be asked to stop any blood thinning medicines, such as clopidogrel, aspirin, apixaban or warfarin, before the markers are inserted. The amount of time you need to be off your medication depends on which drug you take, so you will need to discuss this with your medical team. If blood thinners are not stopped as required, the team will be unable to proceed with the marker insertion.

Inserting the seeds is a similar procedure to a transrectal biopsy. You will have a local anaesthetic and the procedure should take about 30 minutes. You will be asked to take antibiotics before and after the procedure.

Some radiotherapy centres may not use gold fiducial markers as they use a different type of pre-treatment imaging to ensure treatment accuracy. A rectal hydrogel spacer might be placed to minimise radiation exposure to the rectum (back passage).

CT planning scan: Prior to radiotherapy starting, you will have an appointment for a CT planning scan. This is a type of imaging that uses X-rays to produce detailed 3D images of the body. The CT scan is used to visualise the prostate and surrounding structures. This defines the size, shape and position of your prostate. This scan does not give any diagnostic and staging information. The process is usually as follows:

- In some hospitals, you may have an enema or suppository to clear your bowel before the scan.
- In some cases, you will need to have contrast for the scan. This involves a cannula being inserted into your arm through which a special dye is administered.
- You will be asked to drink water before the scan, so your bladder is comfortably full.
- You will lie on your back on the scanning couch, and the therapeutic radiographers will make you comfortable in the correct position. This is the position you will lie in to have your radiotherapy treatments, so it is important you are as comfortable as possible. You will have to lie still and breathe normally.
- To make sure that the therapeutic radiographers can set up you up in the same position every time you come for treatment, very small tattoos will be marked onto your skin.
- The scan will take about 20 minutes.
- Your CT scan will be downloaded into a planning system and overlaid with your previous MRI scan to allow the oncologist to accurately target the area to be treated.
- Your MRI and CT scans are used to create your individual radiotherapy treatment plan. You will probably start your radiotherapy treatment about 1–2 weeks after the scans.

Before your treatment

- You will usually have EBRT treatment daily Monday to Friday as an outpatient. Most radiotherapy courses last for four weeks. If you are having SBRT treatment it will usually be given for 3–5 days.

- To prepare for your treatment and to make sure that your rectum (back passage) is in the same position every day, you will be given micro-enemas. You are required to take them prior to your CT scan, sometimes for the two days before and the day of your radiotherapy treatment. The number of days that you will need to use a micro-enema will depend on the number of radiotherapy treatments you are having; this will be explained to you by your medical team.

Having treatment

- Therapeutic radiographers deliver your radiotherapy treatments.
- Each day you will be given your daily dose of radiation, called a fraction. By breaking up the treatment like this, normal tissue which might be affected has time to recover between treatments, which means you will experience fewer side-effects. However, the cancer cells don't recover so easily. Each appointment is important as the treatment causes a little bit more damage to the cancer every time.
- To help minimise the side-effects on the bladder, you need to have a comfortably full bladder during treatment. You may be asked to empty your bladder then drink a specific amount of water.
- It is a good idea to identify the location of the nearest toilets at the treatment centre, so a visit can be made immediately after completing the session.
- You will lie on the treatment couch in the same position and using the same immobilisation equipment as your CT planning scan. The therapeutic radiographers will use the tattoos you were given to line you up in the correct treatment position.
- Once you are set up in the correct position, the therapeutic radiographers will leave the room to deliver the treatment. They will still be able to see you and talk to you.
- You will not need an anaesthetic as you will not feel anything when the treatment is being delivered.
- You will hear a buzzing noise as the machine moves around you to deliver the treatment. Although it comes close to you, it will not touch you.
- While you may be in the department for up to an hour, the treatment lasts about 10–15 minutes with the radiotherapy only being delivered over a couple of minutes.

Side-effects from EBRT and SBRT

While the treatment itself doesn't hurt, you may experience some side-effects.

There are short-term side-effects and long-term side-effects. Short-term side-effects usually appear towards the end of your treatment or soon afterwards. Many of these can be helped with fluid and dietary advice or with medications, if necessary, and usually settle a few weeks after your treatment has finished. Some side-effects are more long-term but can still be managed.

It is important that you let the therapeutic radiographers or your nursing team know if you are experiencing side-effects during treatment.

Fatigue: During radiotherapy your body uses a lot of energy dealing with the effects of radiation on normal cells. This can leave you feeling very tired, also known as fatigue.

Most people find that they can carry on with their usual daily activities, and most people continue working. Feelings of tiredness can build up over the course of treatments but should go away gradually when the treatment finishes.

You can help manage your fatigue by resuming as many daily activities as possible. It may help if you:

- Save your energy by resting a bit more than previously.
- Try to get a good night's sleep and have a short rest during the day.
- Think about work. Do you need some time off? Can you work for fewer hours or work from home? Some people are well enough to continue to work full-time and organise their treatment to fit in.
- Do light exercise such as going for a walk.
- Remain hydrated and eat a well-balanced diet.

Urinary symptoms: The bladder is located directly above the prostate, and you may experience some bladder side-effects such as:

- Needing to pass urine more often – urinary frequency.
- Needing to pass urine in a hurry – urinary urgency.
- Needing to pass urine more often during the night – nocturia.
- Experiencing a slight burning feeling when passing urine – dysuria.

Many of these bladder side-effects can be self-managed by ensuring that you are drinking plenty of fluid (approximately 2 litres / 4 pints of fluid per day is recommended). However, it is important that you avoid/reduce bladder irritants such as caffeine, alcohol, energy or carbonated drinks.

Simple painkillers, such as paracetamol, can also help if you experience short-term bladder side-effects.

Urinary symptoms often settle within a few weeks of treatment finishing but for some patients they can be longer lasting.

Some men may experience urinary incontinence. There are often ways to help with this, and your oncologist or clinical nurse specialist (CNS) will be able to give you more advice.

Further information on urinary incontinence can be found on pages 52-53.

To learn more, download our booklet *Urinary incontinence as a symptom of prostate problems* from www.prostatescotland.org.uk

Urethral stricture: For a very small number of men, scar tissue may form after radiotherapy treatment. This causes narrowing of the urethra, called a urethral stricture. This can lead to symptoms such as urgency, frequency and incontinence. Should this happen the oncologist or CNS would speak to you about possible treatments.

Bowel symptoms: The bowel is located directly behind the prostate, and you may experience some bowel side-effects:

- Needing to open your bowels more often.
- Changes in your bowel motions – motions may be looser or in some cases you may find it difficult to open your bowels.
- Having a feeling of urgency to open your bowels.
- An increase in passing wind, sometimes with stomach cramps.
- You may notice some blood in your bowel motions. If this happens let the oncologist, CNS or therapeutic radiographer know.

Many of these bowel side-effects can be self-managed by adjusting your diet and keeping well hydrated.

If your bowel motions become loose, you should reduce the fibre in your diet and follow the dietary advice given to you. It is important that you keep your normal diet and only make changes if you notice side-effects.

You may also be prescribed some medication to help your bowel side-effects, such as Fybogel.

Bowel habits: Some men find that their bowel habits change permanently. It might be small changes like opening your bowels more often, having slightly looser motions or passing more wind.

If you find that changes in your bowel habits are affecting your quality of life speak to the oncologist or CNS, especially if you have bleeding from your rectum.

Proctitis: Proctitis is an inflammation of the lining of the rectum and may be troublesome towards the end of treatment and for a few weeks after your treatment has finished. You may notice:

- A frequent or continuous feeling that you need to have a bowel movement.
- Some bleeding and pain from your rectum.
- Diarrhoea.
- Pain with bowel movements.

If this is affecting your quality of life, speak to your oncologist or CNS.

Difficulties with erections: After radiotherapy, approximately 60% of men may have difficulties in getting and keeping an erection. The blood vessels and nerves needed to get an erection lie very close to the prostate and can be affected by radiotherapy. There are medications and treatment to help with erectile dysfunction.

Further information on erectile dysfunction can be found on pages 54-57.

To learn more, download our *Spotlight on: Prostate conditions and erectile dysfunction* from www.prostatescotland.org.uk

Follow-up

After you have had radiotherapy, the oncologist, CNS or advanced practitioner radiographer will review you with regular check-ups.

The PSA blood test is used to assess the effectiveness of your treatment. You will need to get a PSA test approximately 1 week prior to each follow-up appointment. This test will usually be done at your GP practice.

After radiotherapy, your PSA levels will change – this could happen quickly or gradually as every patient reacts differently.

There may be occasions where the PSA may ‘bounce’ or ‘spike’. This doesn’t necessarily mean that your treatment isn’t working and your oncologist or CNS will talk this over with you to see if further tests are needed.

What advantages and drawbacks are there to think about with EBRT and SBRT?

Advantages	Drawbacks
It is minimally invasive.	If there is local recurrence in the prostate despite radiotherapy, then salvage surgical treatment carries more potential side-effects such as incontinence and erectile dysfunction.
It does not require a general anaesthetic and does not usually require a hospital stay.	Salvage focal re-irradiation with either EBRT or brachytherapy seeds may be an option for some men. Cryotherapy and HIFU are other options that may be considered. (HIFU is only available in Scotland as part of a clinical trial.)
It offers cure rates comparable to surgery and brachytherapy.	For some men observation and delayed hormone therapy may be more appropriate.
Less likely to have erection difficulties than with surgery.	Late effects from radiotherapy can occur several months or years after treatment and may be permanent.
Less likely to have long-term urinary incontinence than with surgery.	It can cause urinary symptoms such as frequency and urgency. It can cause proctitis leading to diarrhoea and urgency of bowel motions.
Treatment is painless at the point of delivery and can be done as an outpatient. It is suitable for men of any age.	A small number of men have persistent symptoms including rectal bleeding that may need further treatment.
Minimal or no time off work is possible, and normal activities can usually be continued.	It potentially needs to be done 5 days a week usually for 4–8 weeks, although SBRT, if suitable, is done over 3–5 days.



Advantages	Drawbacks
It may also be suitable for men whose general health and fitness would rule out surgery.	The PSA level should continue to fall but can take some time to reach its lowest level. It is not possible to know how successful the treatment has been until after a period of follow-up. There is a very small increased risk of a radiation-induced cancer 5–10 years after treatment in the pelvic area. Most are early tumours of the bladder or bowel that are treatable and curable, but a very small number of patients may develop incurable secondary cancers. It is not recommended for men with inflammatory bowel disease e.g., Crohn's or colitis.

To learn more, download our *Spotlight on: External Beam Radiotherapy for Prostate Cancer* from www.prostatescotland.org.uk

Brachytherapy

Brachytherapy is a form of internal radiotherapy, where the cancer cells are treated from inside the body rather than from outside.

Prostate brachytherapy is only available in 2 centres in Scotland – The Edinburgh Cancer Centre and The Beatson West of Scotland Cancer Centre in Glasgow. As these are national services, if you choose brachytherapy, you would be referred to one of these centres. There are 2 types of brachytherapy available:

Low dose rate (LDR) brachytherapy: This is a type of permanent brachytherapy. It is suitable for patients with CPG 1 and 2 prostate cancer, and for carefully selected patients with CPG 3 disease. It can be given as a primary treatment which means it is the first treatment given with the intention of curing the prostate cancer.

High dose rate (HDR) brachytherapy: This is a form of brachytherapy which delivers a very high dose of radiation over a short period into the prostate. This is combined with EBRT but rarely can be used to salvage a local recurrence within the prostate after previous radiotherapy.

It is suitable for patients with unfavourable risk prostate cancer, i.e. CPG 3 (carefully selected), 4 & 5 prostate cancer. It can be given as a primary treatment, meaning it is the first treatment used with the intention of curing the prostate cancer.

This booklet will concentrate on LDR brachytherapy which will be referred to as LDR.

When might LDR be suggested?

- When the cancer is small, contained within the prostate, that are categorised as CPG 1, 2 or some selected 3 prostate cancers. Patients should have good urinary symptoms.
- For men who are medically fit for treatment.
- When the PSA level is below 20ng/ml.
- For men who have a strong flow of urine.

What is LDR?

This is a method of delivering radiotherapy where tiny metal seeds which emit radiation are placed into the prostate, working to kill cancer cells from inside the body. The seeds are placed throughout the prostate to match the shape and size of the prostate. This is to try to make sure that the radiation reaches all the cancer cells with very little radiation reaching healthy tissue around the prostate.

About 60–120 seeds will be placed into the prostate. Each seed is smaller than an uncooked grain of rice. The exact number of seeds used will vary according to the size of the prostate itself and the size and location of any focal lesion.

The seeds stay in the prostate, slowly giving out radiation for around 9 months, until they are no longer active.

Planning for LDR

During the planning stage the size and shape of the prostate will be measured. You may hear this called your prostate volume. This provides accurate imaging of your prostate, including size and location, which is then used by your oncologist and medical team to plan how many radiation seeds are required and where to put them. This is different for every patient.

Hormone therapy with brachytherapy

Some men may need hormone therapy before brachytherapy. If your prostate is too large for the seed implant, your doctor may decide to give

you hormone treatment for a few months to shrink your prostate prior to your brachytherapy. Your prostate will be measured after about 3 months to check if the prostate has shrunk enough to allow the implant to go ahead. Further information on hormone therapy can be found on pages 46-49.

Having treatment

The operation

- You will usually have a general anaesthetic, and the operation will take about 1–2 hours. Very occasionally, a spinal anaesthetic may be used instead of a general anaesthetic.
- You may be given an enema to empty your bowel.
- A urinary catheter will be put into your bladder.
- An ultrasound probe will be put into your rectum to help the oncologist visualise the needle placement.
- Using a metal grid or template in front of the perineum (the area behind the scrotum and in front of the rectum) the seed implants are inserted. About 20–35 very fine, hollow needles containing the radioactive seeds are pushed through the skin.
- Approximately 60–120 seeds are used depending on the size of your prostate, either as individual seeds or as strands with several seeds joined together. When the seeds are in the correct place, the needles are withdrawn, leaving the seeds behind.
- The seeds stay in the prostate, slowly giving out radiation until they are no longer active.

After the operation and back in the ward

- You may be given an ice pack to deal with any swelling between your legs.
- It is likely the catheter will be removed once you are settled in the ward.
- Drinking plenty of water will help to flush out the bladder and reduce the risk of blood clots.
- You will likely be given a medicine to help you pass urine and may have to continue this at home.
- Initially you will be asked to pass urine into a bottle or use a commode rather than the toilet just in case you pass a seed. This is nothing to worry about. Don't empty the bottle down the toilet, let the ward staff know. You will be given advice on what to do should this happen at home.

Will I have to stay in hospital?

You may have to stay in hospital overnight. In some hospitals, you may be discharged on the day the implant was done. Ask the CNS or oncologist what usually happens in the hospital you are attending. It's a good idea to wear some loose-fitting trousers for going home so that you feel comfortable.

Tips when at home

- You may experience some discomfort for a short period after the procedure. Simple painkillers, such as paracetamol or ibuprofen, will help with this.
- Rarely, men may be asked to take antibiotic tablets for about 10 days. If you are given these, remember to take all the tablets as directed.
- You may be given a tablet (tamsulosin) to help you pass urine. This might continue for 3–6 months and occasionally for longer term.
- Drinking approximately 2 litres / 4 pints of fluid per day helps to flush out the bladder and reduce the risk of blood clots.
- For the first few days, you should not do any heavy lifting or strenuous exercise, but you can likely return to your normal day-to-day activities in a few days.
- You can likely go back to work a few days afterwards. If your job involves a lot of physical activity, it might take longer.
- You should not drive for 24 hours after the operation, and some men wait for a few days before driving. Check with your insurance company.

Side-effects from brachytherapy

The amount and severity of side-effects vary from person to person. If you are concerned about any of the side-effects that you are experiencing then speak to your oncologist, CNS or GP.

Urinary symptoms: You may find passing urine causes some pain, you have a slow stream when passing urine and you may need to pass small amounts of urine but much more often. These symptoms tend to peak between 6–12 weeks after the procedure then begin to settle. It's also quite common to see traces of blood in your urine for several days after your operation. If you're concerned, contact your CNS.

Bowel symptoms: To help prevent discomfort caused by constipation, try to eat a well-balanced diet with plenty of fruit and vegetables, and fibre. Try to avoid straining when opening your bowels. Fybogel is often suggested to keep your bowel movements regular.

After brachytherapy it is very rare to pass blood from your rectum, but it can sometimes happen. If this happens speak to your oncologist or CNS as this may need to be investigated.

Difficulties with erections: You may find that you have difficulty in getting and keeping erections. If this is the case, speak with your oncologist or CNS as there are treatments that can help.

It's quite common for it to be slightly painful when you ejaculate and the ejaculate may be stained dark brown or red, but this should go back to normal in a few weeks.

When you orgasm, you might find that you release less or no fluid. This is quite normal.

Further information about erectile dysfunction can be found on pages 54-57.

Checking for seeds

At home, you may be asked to check your underwear and the toilet bowl for seeds which may have passed into your urine. The oncologist or CNS will likely give you more information on what to do with any stray seeds.

For the first 2–3 months (or for 6 ejaculations) you should use a condom during intercourse in case you pass a seed.

Follow-up

After 4–6 weeks you will likely go back to the hospital for a CT scan to check that the dose and position of the seeds are correct. When you go back to the clinic, let the staff know of any problems or if you have been having any side-effects from your treatment.

Your PSA after LDR

After LDR, your PSA will be checked regularly and will fall slowly, and it may take about 2 years to fall to its lowest level. Occasionally your PSA may 'bounce' or 'spike'. This doesn't necessarily mean that your treatment isn't working and your oncologist or CNS will talk this over with you to see if further tests are needed.



Contact with others

For the first 3 months after implant, it's recommended that:

- You don't sit babies / young children in your lap for long periods of time or sit very close to them. There's no harm in giving them a quick hug.
- You don't sit beside or be too close to women who are or may be pregnant.

Brachytherapy information card (BIC card)

After your implant you will be given an information card to always carry. The card has essential information for doctors and nurses, who may be treating you, to keep them safe.

You, the oncologist or CNS should fill in any blanks on the card with information about your treatment. If you're not given a card, it is a good idea to ask for one.

It's particularly important to carry this with you, if travelling away from home or going abroad. Some security monitors, such as at airports, are very sensitive and can detect low levels of radiation. To get over this difficulty, you can show your brachytherapy information card to security staff.

What advantages and drawbacks are there to think about with brachytherapy?

Advantages	Drawbacks
Offers cure rates similar to surgery and EBRT or SBRT.	If there is a local recurrence despite LDR, then salvage (potentially curative) treatment may still be an option. For some people this may be with re-implantation with more seeds (a focal salvage implant). For others, salvage prostatectomy may be a better option. However, salvage prostatectomy requires a higher specialist referral as it is not often performed and carries a risk of incontinence, ED and possible rectal perforation that may require further surgery.



	Cryotherapy may be considered for recurrent disease for some people. For other people, continued clinical follow-up and the use of intermittent cycles of hormone therapy when required may be more appropriate.
Short procedure under general anaesthetic with short hospital stay and catheter removed on the ward when the man wakes up. Minimal time off work and can continue normal activities soon after.	Some discomfort when the implant is done and for a short period afterwards.
Very low risk of incontinence and reasonable chance of maintaining erections.	Not suitable for men who have poor urinary function or an enlarged prostate. Discomfort, frequency and urgency in passing urine until the radiation has died down. Rarely retention of urine requiring a catheter (approximately 2%). Some difficulties with erections but treatments are available as with surgery. Infertility – although it has been known for pregnancies to occur following brachytherapy treatment.
Lower risk of bowel problems than with EBRT.	From the evidence there appears to be a very low risk of secondary cancers from brachytherapy on its own.

To learn more, download our *Spotlight on: Prostate brachytherapy* from www.prostatescotland.org.uk

Combination treatment

Sometimes patients are offered a combination of external beam radiotherapy and brachytherapy.

EBRT combined with LDR boost

This combines a course of EBRT (as explained above) followed by an implant of LDR brachytherapy seeds (as explained above) about 2 weeks after EBRT has finished.

EBRT with HDR brachytherapy boost

This combines a course of EBRT followed by 1 treatment with HDR brachytherapy either 2 weeks before or 2 weeks after EBRT has finished.

When might combination treatment be suggested?

- The aim of combining the 2 treatments is to treat cancers with a higher dose of radiation.
- It can be used very effectively to treat intermediate and high-risk prostate cancers, i.e. CPG 3 (carefully selected), 4 & 5 prostate cancer.
- As the radiation emitted from the seeds only travels a very small distance (about a couple of millimetres) within the body, a higher dose of radiation can be given than having EBRT on its own.

What does it involve?

- A 4.5-week course (23 fractions) of EBRT given for 5 days a week, Monday to Friday.
- A boost with brachytherapy seeds around 2 weeks after the course of radiotherapy has finished.

Side-effects

Potential side-effects are the same as those experienced by other radiotherapy or brachytherapy treatments.

Further information can be found on pages 33-35.

Questions you may wish to ask your medical team about radiotherapy or brachytherapy

- Is radiotherapy or brachytherapy a suitable option for me to think about?



- Is it available in my area? If not, would you consider referring me to another centre?
- Could it cure my cancer?
- Would I need to have hormone therapy before the treatment? And why?
- If I do, how long will this be for and what are the possible side-effects of the hormone treatment?
- Would I need to have both EBRT and brachytherapy?
- Can you explain what the risks and side-effects are likely to be?
- If I have brachytherapy, will anything happen if I go through airport security?
- After having radiotherapy or brachytherapy, roughly how many men do you find have problems with incontinence and erectile dysfunction and for how long?
- Is there anything I could do to help with the side-effects?
- When would treatment start?
- Where would I have the treatment?
- When and how will we know whether the treatment has been successful?
- If treatment is not successful, what would be my options?
- Are there other suitable treatment choices that I could think about?

SECTION 2: TREATMENTS

D: HORMONE THERAPY

You may be offered hormone therapy. This works by reducing the amount of testosterone in the body.

Prostate cancer grows in response to the male hormone testosterone. Without testosterone, prostate cells, including cancerous cells, will shrink or grow more slowly.

Hormone therapy, when used on its own, is not a cure for prostate cancer. However, it may be successful in keeping the cancer in check for several years.

If you are considering having external beam radiotherapy or brachytherapy, you may be given hormone therapy for several months before radiotherapy or brachytherapy starts. This is to shrink the cancer so that radiotherapy has a better chance of working or the prostate has shrunk enough so the seed implant can go ahead. It may also carry on after radiotherapy treatment as it has been shown to reduce recurrence rates and improve survival.

Further information on radiotherapy can be found on pages 29-45.

How is it given?

Hormone therapy can be given by an injection, by taking tablets or by both. The decision as to which is best for you will be discussed with you by your oncology team.

Some men will be given a tablet, which blocks testosterone from entering the cancer cells, prior to starting injections. The tablet is taken for a week or two before starting injections and may be continued for a week or so after your first injection.

Testosterone production is switched off by having an injection or an oral tablet (different to the one described above).

If an injection is used it will be administered just under the skin, usually in the stomach or the buttock. The injection may be given once a month, once every 3 months or once every 6 months. You will likely be given the injection by your GP or nurse at your local clinic.



Keep a record of your injection date and mark your calendar or diary when your next dose is due, so that you can book this with your practice. It is very important to have this injection on time.

Some men may be on tablets alone. If it is decided that you will go on an oral tablet, this is usually taken once a day, although 3 tablets might be taken on the first day to start the treatment. The tablets need to be continued until you are told to stop, so remember to add them to your repeat prescription.

What are the side-effects of hormone treatment?

Side-effects will vary from person to person and can occur with both tablets and injections. Some of the potential side-effects are listed below.

There is help available for many of these side-effects so if you are impacted by any of them it is important to talk to your urologist, clinical nurse specialist (CNS) or GP so you can get advice.

Injection reaction: You may get a reaction at the site of the injection that causes discomfort or redness.

Sweats and hot flushes: These are often one of the first, and most common, side-effects. A hot flush is a sudden strong feeling of heat in your face, neck, chest or back. A hot flush and sweating can last for a few minutes or up to a few hours.

Loss of libido: This is a common side-effect, as hormone therapy reduces the amount of testosterone. Because you have less testosterone, you may find that you have a reduced desire for sexual activity. Some men may lose their desire completely. Rather than trying to avoid the issue, talk to your partner about your worries and anxieties.

Difficulties with erections: Because hormone treatment works by switching off or blocking testosterone, not being able to get and keep an erection is a common side-effect. You can find further information on pages 54-57.

To learn more, download our *Spotlight on: Prostate conditions and erectile dysfunction* from www.prostatescotland.org.uk

Fatigue: Fatigue, or extreme tiredness, is a very common side-effect. Make a note of your energy levels across the day and plan your tasks and activities to take advantage of those times when you are feeling less tired.

Taking some regular exercise can help. Drinking plenty of fluid and eating a well-balanced diet can also be beneficial. If you haven't exercised for a long time, then you will need to build this up gradually. Always check with your CNS, urologist, oncologist or GP before starting exercise.

Muscle weakness and changes to body shape: A loss of muscle mass and strength is common and is caused by the drop in testosterone levels. Some men gain weight especially around their middle. Some men may notice that their penis and testes become smaller.

To help with loss of strength and weight gain, have a healthy well-balanced diet combined with regular, resistance exercise such as walking, swimming or using light weights.

Swelling and tenderness around the breast area: Hormone therapy can cause one or both breasts to swell (this is called gynaecomastia), become tender and can cause nipples to become sensitive. The amount of swelling can vary considerably. There are treatments which can include a one-off small dose of radiation, medication or surgery.

Bone thinning: Due to reduced testosterone, bones can thin, become weak and brittle, and may break more easily. Your team may recommend you have some additional treatments to combat this, based on how long you are on hormone therapy. Common additional treatments may be calcium supplements, Vitamin D or a medication called alendronic acid. However, these are not suitable for everyone so would be assessed by the medical team.

Hair loss: Men on long-term hormone therapy may notice a loss of hair on arms, legs, underarms and genital area.

Heart problems: Reducing testosterone levels can increase blood pressure, cholesterol levels and can cause weight gain. Taken together these can put you at greater risk of developing heart disease. This may be more of an issue with long-term hormone therapy.

Emotional impact: Although it doesn't always happen, feelings of anxiety or depression may increase as you go through your treatment. You may also have mood swings, get upset easily or feel tearful. Talk to your CNS, urologist, oncologist or GP, or you may like to join a prostate cancer support group. More information on dealing with these feelings can be found on pages 58-62.



Questions you may wish to ask your medical team about hormone therapy

- Why do I need to take hormones and how do they work?
- Would you recommend that I have hormone therapy before radiotherapy or brachytherapy?
- When would this start and would I have this only up until my radiotherapy starts or when I have brachytherapy?
- How is hormone treatment given?
- Could having hormone therapy make me feel worse?
- Would hormone therapy go on after I have had my other chosen treatment?
- How long will I have to be on hormone therapy for?
- What are the most common side-effects and how likely am I to have them?

To learn more, download our *Spotlight on: Hormone Therapy for Prostate Cancer* from www.prostatescotland.org.uk

SECTION 3: MANAGING THE SIDE-EFFECTS OF TREATMENT

As covered in the previous sections there are usually some side-effects from all treatments for prostate cancer, whether this is for a short time or over a longer period. For some men, these side-effects can affect their quality of life. This section looks at three of the most common side-effects and gives more detailed advice on management:

- **Having a catheter**
- **Urinary incontinence**
- **Erectile dysfunction**

Post treatment recovery clinics

To help men and their families, some hospitals have recovery clinics. The services and the way these clinics work will vary depending on which hospital you attend. You may wish to ask your clinical nurse specialist (CNS) if there is a service available in your area.

Having a catheter

A catheter is a long, thin, flexible tube that is used to drain urine out of your bladder into a drainage bag outside your body. After prostate cancer surgery, you may go home with a catheter, to allow the area to heal.

Your urinary catheter will usually be draining the urine from your bladder via a soft tube coming out of your penis. However, some centres will insert a suprapubic catheter which means a small incision is made in your abdomen whilst you are under general anaesthetic to allow the catheter to be inserted straight into the bladder through the abdomen. This allows the bladder to drain while avoiding a catheter in the urethra and may make the transition back to normal urination more comfortable.

If you experience strong spasms in your bladder, speak with your CNS or nurses on the ward. They may want to check the catheter and may be able to prescribe a medicine to help.

You will likely be given a 'Take home pack' with night drainage bags, long or short leg drainage bags, a catheter stand, net pants and packs of incontinence pads.

Your medical team will arrange for the removal of the catheter at a later date. The small wound should heal quickly on its own but there may be a small amount of leakage for a few days. If you have any concerns, contact the CNS or ward staff for advice.

If you have a catheter because you have had a prostatectomy, then you should not try to take the catheter out or change it yourself, unless you have express permission from your surgeon or CNS.

Infection: Because the catheter can provide a direct path for bacteria to get into your bladder, you may develop a urinary tract infection (UTI). You can help to prevent this by drinking plenty of fluids, to flush any bacteria into the bag. If your urine looks cloudy, has a strong smell, you feel feverish and generally unwell it's important to get in touch with your CNS or GP for advice.

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

The passport is for you to keep while you have your catheter and it's very important that you take it to all your healthcare appointments.

The first section should be filled in with all the essential contacts that you may need. There's also an information guide on caring for your catheter.

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.

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

To learn more, download our *Spotlight on: Caring for your Indwelling Catheter at Home* from www.prostatescotland.org.uk

Urinary incontinence

This means that you may not be able to hold urine inside your bladder. It may be difficult to stop some urine leaking or dribbling out when you cough, laugh, get up from a sitting position or when walking. This is called stress incontinence.

After prostate cancer surgery most men will have some incontinence. Some men can control their bladder within a few weeks, whilst others take some months to recover. There is no way to forecast how long this will take for you, but most men will have recovered within a year.

A small number of men (up to 2–3%) may require a second operation to restore their continence.

Doing the recommended pelvic floor exercises before and after treatments can help greatly with symptoms of urinary incontinence (see below for further information).

Practical tips for managing incontinence:

- Wear an absorbent pad inside your underwear to help with leakage. These can help keep you dry, prevent any smell and protect clothing. Wearing pads may give you more confidence to carry on with your day-to-day activities. Ask your CNS on where to obtain pads.
- Limit alcohol and caffeine intake (caffeine is found in tea, green tea, coffee, cola type drinks and energy drinks).
- Try to drink about 2 litres / 4 pints of fluid daily, spaced out evenly throughout the day. Don't try to cut down the amount of fluid you drink each day to avoid passing urine frequently. This could make things worse.
- Empty your bladder before bedtime or before any vigorous activity.
- Maintaining a healthy weight may help improve bladder control.
- Stop smoking as smoking can cause chronic coughing leading to worse symptoms of stress incontinence.
- Avoid constipation as it can worsen symptoms of urinary leaking. If this is a problem for you discuss management strategies with your GP.

Being able to control your bladder usually takes three steps:

- Step 1: You are dry when lying down at night.
- Step 2: You are dry when walking or doing moderate activity.
- Step 3: You are dry when you cough, sneeze, laugh or stand up from a sitting position. It may take up to a year for you to reach step 3, as this is the final part of being in full control of your bladder.

Pelvic floor muscles and exercises: Pelvic floor muscles are sometimes described as being like an elastic hammock that stretches from your pubic bone at the front of your body through to the coccyx, the small bone at the bottom of your spine, and from side to side.

Before and after a radical prostatectomy, these muscles need to be trained to contract and relax, to have endurance, strength and coordination. This will allow you to develop an awareness of your pelvic floor, when it works and how it can work better. Retraining your pelvic floor can help you to achieve continence, sexual function and allow you to lead an unrestricted active life.

A specialised physiotherapist can provide you with a customised programme of pelvic floor exercises to be practised both before and after your radical prostatectomy. As surgery can change the fine dynamic of bladder support, manual assessment linked with dynamic ultrasound imaging may be used to assess and treat stress incontinence following a radical prostatectomy.

It is important to pace your pelvic floor exercises during the day, as over-exercising the muscles can lead to them becoming fatigued or overactive which can slow the recovery process.

Some men may also develop overactivity or tension in the pelvic floor muscles after surgery, which can contribute to pain, urgency or difficulty emptying the bladder. Specialist physiotherapy assessment can help identify this.

Contact your local physiotherapy department or Pelvic, Obstetric and Gynaecological Physiotherapy (POGP) at www.pogp.csp.org.uk for details of specialist physiotherapists in your area.

To learn more, download our *Spotlight on: Urinary incontinence as a symptom of prostate problems* and *Spotlight on: Pelvic floor exercises before and after surgery* from www.prostatescotland.org.uk

Erectile dysfunction

When a man has trouble getting or keeping an erection firm enough for sexual intercourse, it is called erectile dysfunction (ED). Not being able to have an erection can affect men at different ages and stages in their life and for different reasons. Whilst you may be upset and worried about this, there are many things that can be done to help.

After surgery, your body needs time to heal, with a gradual recovery of erections. It is common not to have an erection in the first 6–9 months after surgery, and it may take 2–3 years before you can have a spontaneous natural erection. For some men spontaneous natural erections may never return.

If you have external beam radiation therapy (EBRT), you may not notice any problems with erections at first, as ED happens gradually and can take up to 2 years before becoming fully apparent.

If you have brachytherapy, you may have difficulties with ED a few years after treatment.

Your age can have an impact. Men under 60 tend to have better quality erections before surgery and, therefore, are more likely to recover erections after surgery.

ED can also depend on:

- How good or firm your erection was before your treatment.
- How sexually active you were before your treatment.
- Whether the surgeon was able to save the nerves (called nerve sparing surgery) that lie very close to the prostate and which are responsible for erections.

Nerve-sparing surgery: You don't need to have a prostate to achieve an erection. However, the nerve bundles and blood vessels that are needed to have a normal, natural erection lie next to the prostate and may be stretched or damaged during surgery.

For some men, to make sure that all the cancer is removed, it isn't possible to save these nerves and blood vessels. In this case, it is no longer possible to have a natural erection, but there are options available. More information is listed below.

For some men, it is possible to save the nerves, and 50–80% of men will get back to their normal erection function within 2–3 years.



Treatment options: If you experience difficulties with erections, tell your urologist or CNS who may be able to suggest something to help.

ED is treated according to what suits the man best. So, once you've been diagnosed, your urologist will advise on the most suitable treatment, considering your wishes.

Many doctors now think that trying sexual activity soon after surgery may improve the chances of having the same kind of erection as you did before your operation. Touching, caressing, holding and massage can help. So, there is no need to wait to have a 'full' erection before trying.

Early penile rehabilitation may help preserve erectile tissue health and improve long-term erectile recovery for some men. There are a few options for trying to make the quality of erections better.

With all treatments, if your erection lasts for more than 3 hours, contact your GP or go to A&E as this is an urgent medical issue.

Oral medication:

- Tablets include sildenafil, vardenafil, tadalafil and avanafil. These work by increasing the blood flow to the penis so allowing it to become erect. They work best if the nerves in the penis are still intact.
- Your urologist or GP may prescribe these medications to be taken routinely even if you're not planning to be intimate; there is evidence to suggest that earlier treatment results in a better response to treatment.
- Possible side-effects include headaches, dizziness, nausea, blurred vision, flushing of the face, blocked nose and tummy upset. Men with heart problems should check with their doctor before using this type of medication.

Applicator medication – MUSE®:

- MUSE® stands for medicated urethral system for erections.
- This medicine, called alprostadil, works by widening the blood vessels going into the penis, allowing more blood into the penis.
- It is given by a small applicator that has a thin tube inside it. This tube holds a small pellet of medicine which is released into the penis. An erection develops in about 10 minutes and lasts for at least 30 minutes.
- Possible side-effects include a painful, long-lasting erection, pain and mild injury to the urethra. It may cause irritation for a small number of women.

Topical medication:

- Your urologist, CNS or GP may prescribe Vitaros® cream to apply to the penis. They will give you detailed instructions on the dose and how to apply the cream. An erection should develop within 5–30 minutes of applying the cream.
- Possible side-effects include dizziness, mild to moderate aching, burning, pain and redness of the penis, rash or itching. To prevent your partner experiencing any side-effects you should wear a condom.

Injectable medication:

- Treatment injected into the penis is very successful for some men and can be effective even if the nerves are not intact. When having these injections, you should not use any other medication for ED.
- There are 2 available medications, Invicorp® or Caverject®. Your urologist, CNS or GP will decide which one to prescribe for you.
- If this treatment is recommended, you will be taught how to do the injection yourself.
- It usually takes 5–10 minutes to get an erection, and it lasts for 30–60 minutes and will go on even after orgasm.
- Possible side-effects include bruising, mild pain/discomfort when injecting, scar tissue at the injection site, headaches or dizziness.

Vacuum pumps:

- If injections, cream or tablets haven't helped or don't suit you, vacuum pumps are another option.
- Sometimes using a vacuum pump is introduced much earlier into your treatment plan to 'exercise' the penis.
- These pumps are available on prescription from your urologist, CNS or GP. It is recommended that you do not buy a pump over the counter or online, as these ones could allow the pressure to build too high and cause injury to the tissues in the penis.
- A rigid tube is placed over the penis and sealed. A pump helps make a vacuum which draws blood into the penis, so it becomes erect. A band can be placed around the base of the penis to keep the erection firm for up to 30 minutes.



- After sexual activity has finished, gently stretch the rubber ring so the blood trapped in the penis is released. This means that you will lose your erection and the ring can easily be taken off the penis. Remember: always take the ring off afterwards and don't go to sleep with the ring still in place.
- Vacuum devices may also help maintain penile length and tissue health during recovery.
- Don't be disappointed if a vacuum pump doesn't work for you straightaway – it may take a few tries to be able to use the pump correctly. If you are finding it difficult, speak to your urologist, CNS or GP for more advice.

To learn more, download our *Spotlight on: Prostate conditions and erectile dysfunction* from www.prostatescotland.org.uk

SECTION 4: THE EMOTIONAL IMPACT OF PROSTATE CANCER

In addition to managing the physical side-effects of prostate cancer and treatments, it can be hard to deal with how you are feeling.

You might feel worried about whether you are making or have made the right treatment choice, worried about side-effects or anxious about waiting for results.

Your moods might be affected as you go through treatment. It is also common to experience a fear of cancer returning after treatment, or a fear of cancer progressing if you have opted for active surveillance or watchful waiting. Increased fear around follow-up scans or PSA testing is also common. All these feelings are normal, and there are ideas below to help you cope.

If you feel overwhelmed by these feelings, or they are getting in the way of you living your life, make an appointment with your GP and tell them how this is affecting you emotionally.

How might you be impacted?

Low mood or feeling depressed:

- Persistent very sad or low feeling for most of the day.
- Not having the energy to do things that you took for granted before.
- Losing interest in hobbies, not taking part in activities that you used to enjoy, not feeling up to seeing family and friends.
- Feeling very tired yet having trouble sleeping.
- Having trouble focusing and perhaps not able to make decisions.

Feeling anxious:

- Feeling worried all the time and finding it difficult to let go of these thoughts.
- Difficulty carrying out everyday jobs and caring for yourself.
- Being very restless, on edge or jumpy.
- Feeling tired, short tempered or irritable.

Feelings of panic: Panic attacks are severe feelings of being anxious, scared or out of control, and these can be frightening. These can come on at any time for no apparent reason. 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, numb or tingly.
- You feel dizzy, light-headed or faint.
- You feel short of breath.

Coping with these feelings

Different people find different ways of coping with these feelings. For many people, taking back some element of 'control' over their prostate cancer journey can help them navigate the emotional impact. This could be:

- Taking an active part in treatment decision-making.
- Sourcing extra information online.
- Joining a support group.
- Volunteering to help others.
- Choosing to pursue a healthier diet.
- Taking gentle exercise.

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 will be for you but maybe give some a try.

Getting more information: Some men like to learn more about everything that is going on, to feel more in control, more knowledgeable at appointments and to have a better understanding of what medical teams are talking about. When searching for more information online use reputable websites such as:

- www.prostatescotland.org.uk
- www.cancerresearchuk.org
- www.macmillan.org.uk
- prostatecanceruk.org
- www.maggies.org
- www.samh.org.uk

Remember that your medical team can provide you with more information so don't be afraid to ask questions.

Talking it out: The important thing to realise is that you're not alone – others will have had similar feelings and thoughts.

For some men talking to their partner, family and friends provides the support they need. They feel comfortable and at ease showing how they feel.

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

There are prostate cancer support groups throughout Scotland where you can talk to other men who are on a similar journey. Some of the groups run a 'buddy scheme' and you can talk to someone who has had / is having the same treatment as you.

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

- www.maggies.org
- www.cancersupportscotland.org
- Prostate Cancer UK specialist nurses' helpline: 0800 074 8383
- Macmillan cancer support line call: 0808 808 0000
- Cancer Research UK nurse helpline: 0808 800 4040

Some men like to share their personal stories with others, often to stress the importance of early diagnosis and for men not to ignore symptoms and risks. This can be through talking to work colleagues, family, friends, or even sharing their story in the press.

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; videos on the website below allow you to listen without needing to join a group: **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. You can use a smartphone for this, or it can be as simple as keeping a notebook handy.

You could 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 for a short while help?

- Get 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 fancied.
- Visiting museums, art galleries, listening to music, trying to paint or sketch, writing short stories or poetry.
- Trying something new like dancing, yoga, meditation or Tai Chi.

Looking after yourself: It's all too easy to think 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 medical team if you're having trouble sleeping.

Some people may be tempted to try and escape by drinking too much alcohol or using drugs. This is never a good idea. Alcohol and unprescribed drugs may make you feel worse and might affect your treatment.

Consider attending one of our Living Well with Prostate Cancer courses run in partnership with Maggie's Centres throughout Scotland, and Ayrshire Cancer Support in Ayr and Kilmarnock.

Visit **lookgoodfeelbetter.co.uk** for support at every stage of your journey. They offer a range of workshops and classes providing advice around the physical changes you may experience while undergoing treatment.

Getting active: Speak to your urologist, oncologist, CNS or GP to make sure you are fit enough to exercise. Research has shown that exercising when you have prostate cancer might:

- Relieve some of the side-effects of treatment.
- Help slow the risk of progression of prostate cancer.
- Improve prostate cancer survival.
- Improve your mood and 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 or walking up the stairs instead of taking the lift.

In some areas we offer Prostate FFIT, a free 12-week exercise and wellbeing programme for men affected prostate cancer. This programme is run at football grounds in partnership with the SPFL Trust.

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

SECTION 5: UNDERSTANDING LOCALLY ADVANCED PROSTATE CANCER

Some men will have been told from the outset by the oncologist or clinical nurse specialist that they have locally advanced prostate cancer. This section is to help these men and their family understand what this means and gives an outline of the treatments that may be offered.

What is locally advanced prostate cancer?

Locally advanced prostate cancer means that the cancer has spread just outside the prostate through the capsule that surrounds the prostate, into the seminal vesicles or into lymph nodes within the pelvic area. The seminal vesicles are glands that lie behind the prostate and supply some of the fluid in semen.

What do test results mean?

Once the urologist, oncologist and MDT have all your test results, several issues will be considered before deciding which treatment(s) may be most suitable for you:

- Your ISUP grade group or Gleason score, and Cambridge Prognostic Group (CPG). For more information on this see pages 4-7.
- The stage of your cancer.
- Your PSA level.
- How old you are and how much your symptoms are troubling you.
- Whether you have any other medical conditions affecting your health.
- If the side-effects of treatment would have greater impact on your quality of life than the effect of the cancer.

How is locally advanced cancer treated?

Hormone therapy: Once prostate cancer has broken through the prostate capsule or wall and has spread to the seminal vesicles a treatment is needed that tackles all the prostate cancer cells. The most common way to do this is through hormone therapy that removes the male hormone testosterone. Prostate cancer cells need testosterone to grow. So, by reducing the amount of testosterone, cancer cells shrink or don't grow as fast. Hormone therapy can keep prostate cancer in check for many months and in some cases years.

Further information on hormone therapy can be found on pages 46-49.

To learn more, download our *Spotlight on: Hormone Therapy for Prostate Cancer* from www.prostatescotland.org.uk

External beam radiotherapy (EBRT): EBRT can be used to treat locally advanced prostate cancer using high-energy x-ray beams, which very accurately target the cancer in the prostate. The treatment can also cover a small area around the gland, including the seminal vesicles and lymph nodes in the pelvis.

Further information on EBRT can be found on pages 29-37.

To learn more, download our *Spotlight on: External Beam Radiotherapy for Prostate Cancer* from www.prostatescotland.org.uk

Watchful waiting: Watchful waiting is a way of monitoring your prostate cancer which avoids unnecessary treatment which may not be suitable for you due to other health problems or where it is felt your cancer may not cause you any issues in your lifetime. You would be monitored through PSA testing and careful assessment of symptoms.

Further information on watchful waiting can be found on pages page 14.

Surgery: This is called a radical prostatectomy. Although this is rarely used to treat locally advanced prostate cancer, in certain cases, your doctor may discuss surgery to remove your prostate, seminal vesicles and lymph nodes in your pelvis.

Further information on radical prostatectomy can be found on pages 17-28.

To learn more, download our *Spotlight on: Minimal access radical prostatectomy for prostate cancer* from www.prostatescotland.org.uk

SECTION 6: SUPPORT FOR YOU AND YOUR FAMILY

As you deal with the impact of your prostate cancer diagnosis you may find you and your family need extra support.

There may be a prostate cancer support group in your area where you can talk to other men (and often their families) who have been diagnosed with prostate cancer. These support groups may provide you with additional information and some groups run a buddy scheme. Often these men share their experiences of when they were diagnosed with prostate cancer and their treatment.

Your clinical nurse specialist or GP should be able to advise on what support groups there are in your area.

Prostate Scotland COMPASS support services

COMPASS is our comprehensive range of support services to help men and their families navigate prostate cancer. These services are specifically designed for all men affected by prostate cancer, wherever they are on their journey. They complement the excellent care received from medical experts and offer the opportunity to meet others in a similar situation.

Living Well with Prostate Cancer: Our Living Well with Prostate Cancer 6-week course is free and run in partnership with all Maggie's Centres across Scotland, as well as Ayrshire Cancer Support in both Ayr and Kilmarnock. Men meet others in a similar situation, while hearing from experts on all aspects of living with prostate cancer, from managing urinary problems to financial advice and everything in between.

Prostate FFIT: We've teamed up with the SPFL Trust to run our unique Prostate FFIT (Football Fans in Training). A free, 12-week health and wellbeing programme, it is an invaluable opportunity to meet others and share experiences. Men learn about different types of exercise, diet and nutrition, in a relaxed, fun environment.

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

Other sources of help

The following organisations also offer information, advice and support. Some offer nurse-led telephone helplines.

Cancer Research UK

www.cancerresearchuk.org
0808 800 4040

Look Good Feel Better

lookgoodfeelbetter.co.uk/workshops
01372 747500

Macmillan Cancer Support

www.macmillan.org.uk
0808 808 0000

Maggie's

www.maggies.org/our-centres
0300 123 1801

NHS 24

www.nhs24.scot
111

Prostate Cancer Research Infopool

www.theinfopool.co.uk
0203 735 5444

Prostate Cancer UK

prostatecanceruk.org
0800 074 8383

Scottish Action for Mental Health

www.samh.org.uk
0141 530 1000

UCAN

www.ucanaberdeen.com
01224 550333

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

Prostate Scotland Information resources

Active surveillance



Pelvic floor exercises
before and after
surgery to remove the
prostate



Brachytherapy for
prostate cancer



Prostate conditions and
erectile dysfunction



Caring for your
indwelling catheter
at home



Prostate logbook



Hormone therapy for
prostate cancer



Radiotherapy for
prostate cancer



Minimal access radical
prostatectomy for
prostate cancer



Urinary incontinence
as a symptom of
prostate problems



Videos

A guide to pelvic floor exercises



PROSTATE SCOTLAND

Our Work

All our awareness materials, introductory guides, explanatory guides and 'Spotlight on' guides 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 donating.

This booklet has been produced by Prostate Scotland with input and advice from its expert advisory group PAGES. All PAGES members have been asked to declare any potential conflict of interests. Further details can be requested by emailing jennifer.fallon@prostatescotland.org.uk

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