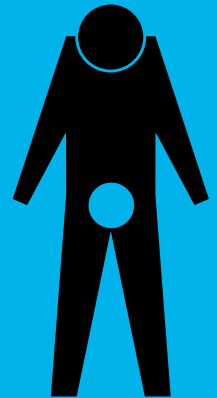


# Early prostate cancer explained



## Introduction

This booklet is to help you, your partner and your family understand about the prostate, prostate cancer, tests, investigations, treatments and treatment choices and to help you decide on the treatment that suits you best. While this may sound daunting to you at first, it has been shown that the more you and your family are involved in helping to make the decision about treatment, the more confident and satisfied you may feel with your treatment choice. It doesn't mean that you need to make this decision on your own; doctors, nurse specialists and other men who have been in this same position will give you information, help and support along the way.

This booklet has been written first and foremost for men who are being investigated for, or who have been diagnosed with, early (localised) or locally advanced prostate cancer who will potentially benefit from radical treatment with a curative intent. However, your family and friends may also find this booklet helpful.

Being told by the doctor or specialist nurse, "You have prostate cancer", can come as a shock and are words that you and your family didn't want to hear. In fact, you may not have heard another word that the doctor or specialist nurse said to you. For some people this is very upsetting, they find it hard to think about anything else for a while and it may take some time before you take it in. Don't worry, there will be time to ask questions or talk about what it means for you later.

If prostate cancer is found early enough, it is usually curable. However, many men can live with it and lead a full, active and happy life for many years, so it doesn't always need curative treatment.

### How to get the most out of this booklet:

The aim is to give you and your family information about prostate cancer - from the first visit to your GP through to making the decision about treatment. You may hear this called your 'cancer journey'.

For some men it helps to have lots of information right from the start and so you may choose to read the booklet from cover to cover.

Others may want only a little information at first and may prefer to dip in and out of the booklet to read the sections that are relevant, gradually taking in the information and enabling them to come to a decision about treatment.

The booklet is quite detailed and may give more information than you need. If this is the case, it may help you to look over the guide overleaf at the various sections so you can choose which are most relevant for you. You will also find that there is a brief summary at the start of each section giving the key information in that section followed by the detailed explanation.

Although you may not need all the information in the booklet right away, it is there if you or your family need it in the future.

### Please note:

Throughout the booklet, information is given as a guide on various tests, examinations, procedures and treatments. However, as there is more than one approach to tests, procedures and treatment, if you are given specific information by your GP, consultant or specialist nurse, then it is important that you follow their instructions and guidance.

## Section 1

### Introduction to the prostate and prostate cancer – page 10

#### **This section explains:**

- What the prostate is, where it is and what it does
- A brief introduction to prostate cancer
- The risk factors
- The possible symptoms and signs of prostate cancer

#### **Who might find this useful:**

Men and their families who are new to the topic and want some background information.

#### **Who might find this least useful:**

Men and their families who already have this information and may have known about their condition for some time.

## Section 2

### What might happen at the GP surgery? – page 14

#### **This section explains:**

- The questions your GP might ask
- Blood tests your GP might do
- The PSA test and PSA levels
- Digital Rectal Examination (DRE)
- Who you may be referred to in hospital

#### **Who might find this useful:**

Men who have had a recent appointment with their GP and need to understand what the tests were/are for and what the results mean.

#### **Who might find this least useful:**

Men who have already had these tests, understand what they are and may already be attending a urology department.

## Section 3

### Referral to the urology department - tests you may have in hospital – page 17

#### **This section explains:**

- Trans Rectal Ultrasound; what it is and what happens
- Prostate biopsy; what it is, the different ways that a biopsy may be done, what happens in each different type, and what the biopsy may show

#### **Who might find this useful:**

Men who are being referred to the hospital or who have recently seen the urologist.

#### **Who might find this least useful:**

Men who have already had these tests, understand what they are and may already be further along their cancer journey.

## Section 4

### Test results and what they mean – page 24

#### **This section explains:**

- The Gleason score; information on what it is and what the Gleason score means
- The prognostic grade group; information on this new grading system explaining what it is and what it means
- Staging; information on what this is and what it means

#### **Who might find this useful:**

Men and their families who want to know and understand more about what these results are and what they might mean.

#### **Who might find this least useful:**

Men and their families who already understand what the Gleason score, the prognostic grade group and staging means.

## Section 5

### Further investigations which may be done – page 30

This section explains:

- Bone scan; what it is, why it's done, what happens and getting the results
- MRI scan (Magnetic Resonance Imaging); what it is, why it's done, what happens and getting the results
- CT scan (Computerised Tomography); what it is, why it's done, what happens and getting the results

#### **Who might find this useful:**

Men and their families who want to know more about why these investigations are done, what happens and what the results might mean.

#### **Who might find this least useful:**

Men who have already had these investigations, understand what they are and may already be further along their cancer journey.

## Section 6

### The next step following the results of tests and investigations – page 35

This section explains:

- Waiting for your results
- What the results might mean for you
- The multi-disciplinary team (MDT); who they are and what they do
- What your diagnosis might mean for your family
- Intimacy and your diagnosis

#### **Who might find this useful:**

Men and their families who want to know who will be involved in their care and how the MDT reach their decision about treatment after seeing the results of the tests and investigations.

#### **Who might find this least useful:**

Men who have already had the results of tests and investigations and may be in the process of deciding which treatment may be best for them.

## Section 7

### Treatment choices – page 38

This section explains:

The different ways of treating prostate cancer:

- **Active surveillance or monitoring;** what it is, who it is suitable for, advantages and drawbacks, questions to ask your doctor
- **Radical prostatectomy – laparoscopic, robotic assisted laparoscopic, open and perineal;** what they are, who they are suitable for, what happens, advantages and drawbacks, questions to ask your doctor
- **Radiotherapy – external beam radiotherapy (EBRT) and brachytherapy;** what they are, who they are suitable for, what happens, advantages and drawbacks, questions to ask your doctor
- **Hormone therapy;** what it is, when it might be used, how it is given, side effects
- **Brief overview of the newer experimental treatments;** high intensity focused ultrasound (HIFU) cryotherapy, high dose rate brachytherapy (HDR Brachytherapy)

#### **Who might find this useful:**

Men and their families who want to know more about the treatment choices available, side effects and what effect this treatment may have on their quality of life. This section gives lots of information to help the man and his partner make an informed choice as to which treatment may be best for him.

#### **Who might find this least useful:**

Not all the treatment choices are suitable for all men. Those who have already been offered or made their treatment choice may decide to read information only about that particular treatment.

## Section 8

### Managing some of the potential side effects of the treatments – page 81

This section explains:

- Urinary incontinence (not being able to control the bladder/leakage of urine)
- Erectile dysfunction (not being able to have or maintain an erection)

#### **Who might find this useful:**

Men who want to know more about the specific side effects that can happen with some of the treatments.

#### **Who might find this least useful:**

Men who have chosen a treatment that does not have these particular side effects.

## Section 9

### Deciding on treatment: a step on your journey – page 89

This section explains:

- Who you can talk to, to help you make your decision
- What you need to think about to make your decision
- Tips when talking to doctors and nurses

#### **Who might find this useful:**

All men and their families who want to be involved in deciding the most suitable treatment for them.

## Section 10

### Understanding locally advanced prostate cancer - page 94

This section explains:

- What is meant by locally advanced prostate cancer
- How locally advanced prostate cancer is treated; hormone therapy, external beam radiotherapy, watchful waiting



- Why a trans-urethral resection of the prostate (TURP) might be used to help ease one of the potential side-effects of locally advanced prostate cancer and how this is done

**Who might find this useful:**

Men (and their families) who have been told that they have locally advanced prostate cancer.

**Who might find this least useful:**

Men who have been diagnosed with localised prostate cancer – that is cancer that is still contained within the prostate.

## Section 1

### Introduction to the prostate and prostate cancer

#### A brief summary of information in this section

- The prostate is a small gland just below the bladder which produces the clear fluid that mixes with sperm to form semen.
- Prostate cancer happens when the cells in the prostate grow faster than normal causing a growth or tumour.
- The risk of developing prostate cancer increases as a man gets older, if his brother or father has or had prostate cancer; if there is a strong family history of certain kinds of breast cancer; or if the man is from an African/Caribbean background.
- Prostate cancer is now the most common cancer for men in Scotland and 1 in 10 men may develop prostate cancer.
- In the early stages of prostate cancer the man may not have any symptoms at all. Some signs are problems in or when passing urine, pain or stiffness in the lower back, hips or upper thighs - although these may not necessarily mean that the man has prostate cancer.

#### Chapter 1

##### What is the prostate?

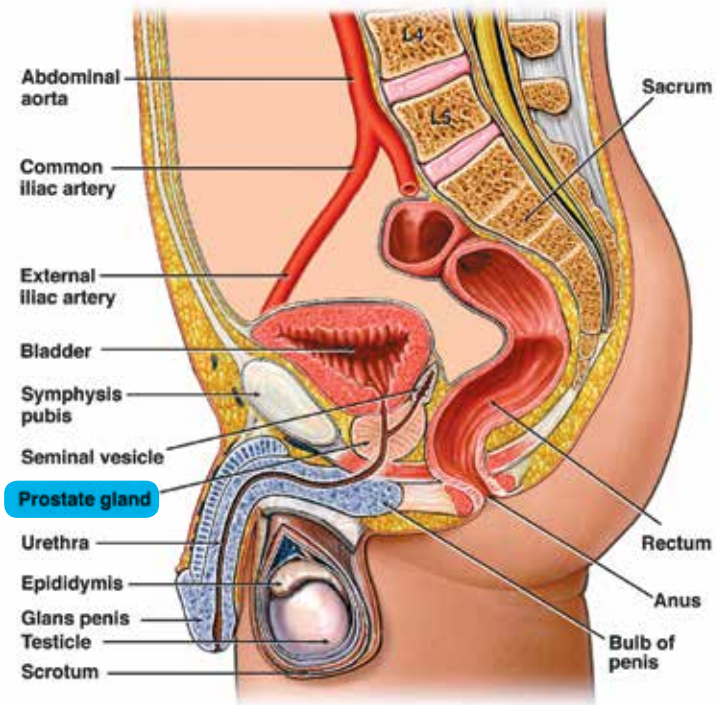
If you don't know what your prostate is, where it is or what it does, you're certainly not alone. In fact, most people don't know! Many men still find it uncomfortable or difficult to talk about the prostate as it plays a role in both passing urine and in sexual intercourse.

Only men have a prostate. It starts out about the size of a pea then slowly

grows to the size of a walnut until the man is in his 20s. Around the age of 40, it starts to grow or enlarge again and this may cause problems for a man when passing urine.

### Where is it?

The prostate is inside the pelvis, just below the bladder and in front of the back passage. It wraps around the tube, called the urethra, which allows urine to flow out of the bladder and semen to pass out through the penis. Therefore, 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, called the ejaculate. This fluid helps to nourish and protect sperm during intercourse. The prostate also makes Prostate Specific Antigen or 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 grow faster than normal. This causes a growth called a tumour. As the prostate is inside the body, this growth can't be seen and very often causes no symptoms.

However, most prostate cancers grow slowly. At the moment, it is not known why some prostate cancers grow more slowly and others grow more quickly.

Some men won't even know they have prostate cancer, as it may not cause any symptoms, have any effect on or shorten their life.

Prostate cancer may be:

- Early or localised; when it is still within the prostate and has not spread to other parts of the body.
- Locally advanced; when 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, but may appear in the lungs or liver.

This booklet is to help explain more to you about early or localised prostate cancer and locally advanced prostate cancer.

### What causes prostate cancer?

At the moment, no one really knows what causes prostate cancer even though it is now the most common cancer for men. However, the chances of getting prostate cancer increase with:

Age	As a man gets older – it mainly affects men over 65, but it can affect younger men from their 40s onwards.
Family history	If a man's brother or father has or had prostate cancer. This is especially important if more than one member of your close family was diagnosed with prostate cancer under the age of 70.  If there is a strong family history of certain kinds of breast cancer.
Background	If the man is from an African/Caribbean background then he is 3 times more likely to develop prostate cancer and up to 5 years earlier.

If you have a brother(s) or son(s) they may wish to talk over their risk with their GP. For more information there is a leaflet, '*Prostate cancer. Is it in the family*', available from Prostate Scotland.

### What are the symptoms or signs?

In the early stages of prostate cancer you may not have any symptoms at all. Having the symptoms below does **not** necessarily mean you have prostate cancer.

These symptoms can be similar in the other prostate diseases - benign prostatic hyperplasia (BPH) and prostatitis. See your doctor if you:

- Need to pass urine more often than before and more often during the night;
- Find it difficult to start passing urine;

- Need to get to the toilet quickly;
- Take longer to empty your bladder;
- Stop and start when passing urine;
- Have pain or stiffness in the lower back, hips or upper thighs.

Keeping a diary of visits to the toilet until you see the doctor would be helpful. A handy chart may be included with this booklet for you to fill in.

There is also a symptom self-test on our website at [www.prostatescotland.org.uk](http://www.prostatescotland.org.uk)

This does not give a diagnosis but points to the severity of symptoms.

The earlier symptoms are picked up and treatment, if any, started the better the outcome is likely to be.

## Section 2

### Guide to what might happen at the GP surgery

#### A brief summary of information in this section

- The GP will ask how you are feeling and take blood to check for any infections, to see that your kidneys are working properly and ask questions about passing urine.
- Prostate Specific Antigen (PSA) is a protein made in the prostate and some PSA normally leaks out of the prostate. A blood test to measure PSA levels may be done. High levels of PSA in the blood may point to something being wrong with the prostate and along with other tests and examinations helps the GP make a diagnosis.
- The GP may do a Digital Rectal Examination (DRE) to check the prostate for any hardened area, odd shape or unusual lump.
- Depending on the results of tests and examinations you may be referred to hospital to see a doctor who specialises in urology or for a prostate biopsy.

The information given about what your GP may do is meant as general guidance. Your GP may have a slightly different way of doing things.

### **What will happen at my GP?**

- The doctor will ask how you are feeling and ask some questions about passing urine;
- You will be asked for a urine sample to check for blood, glucose (a type of sugar) or for any signs of infection in the bladder or kidneys;
- A blood sample may be taken to check that your kidneys are working properly.

### **The doctor may suggest you have a Prostate Specific Antigen or PSA blood test**

PSA is a protein which is made within the prostate. It is normal for small amounts of PSA to leak out of the prostate into the bloodstream, so the PSA level can be checked by a simple blood test. This is called your PSA level. It is an important number to remember and you will hear it mentioned a lot. It may be a good idea to keep a notebook to jot down the date and your PSA level or use the Prostate log book that may be included with this booklet.

The PSA level can be raised due to prostate cancer, but also for a number of other reasons such as an enlarged prostate or prostatitis. So, on its own, the PSA test doesn't diagnose prostate cancer, but it may highlight the need for further tests. Your doctor will take into account your PSA level along with other tests and examinations.

Generally, if the PSA level is very high then the chance of having prostate cancer is greater. If prostate cancer is confirmed, the PSA test is used to check whether the prostate cancer may be growing and if any treatment you are having is working.

### What is the normal level for PSA?

To some extent this depends on your age. The older you get, the higher your PSA level is likely to be. The doctor who gets your PSA results will take this into account. In some areas in Scotland there may be slight differences in the levels used and your doctor will explain this to you.

AGE	Suggested upper levels of PSA (ng/ml)
40 - 49	2.5
50 - 59	3
60 - 69	4
70 and over	5

(In March 2016, the revised Prostate Cancer Risk Management Programme for **NHS England** no longer uses age related PSA levels. <https://www.gov.uk/government/publications/prostate-cancer-risk-management-programme-psa-test-benefits-and-risks/prostate-cancer>. This indicates that men in England aged 50-69 with a PSA level of 3ng/ml or higher should be referred to a urology department. At the time of writing this does not apply to Scotland.)

Even if your PSA level is within the normal range on this occasion, if your GP has any concerns you may be asked to have your PSA level checked every 6 months.

### Digital Rectal Examination or DRE

This will usually be one of the first examinations your GP will do. It gives the doctor an idea of the shape, size and condition of your prostate. The doctor will be checking for any hardened area, odd shape or unusual lump. Having this examination along with a PSA test improves the chance of finding cancer early.

For this examination, you will be asked to lie on the bed on your side. The doctor will slide a gloved finger into your back passage or rectum to feel your prostate. It's much better for you and the doctor if you can manage to relax during the examination, even if you feel a bit embarrassed and a bit uncomfortable. Remember, the doctor has done this many times before and understands how you might be feeling.



### What happens next?

Your GP will explain the next steps to you. Depending on your PSA level and the DRE, you may be referred to the urology department in hospital to see a specialist doctor called a urologist or perhaps referred directly for a biopsy.

## Section 3

### Referral to the urology department - tests you may have in hospital

#### A brief summary of information in this section

#### Prostate biopsy

- A biopsy means that several tiny samples are taken from the prostate using a special needle. These samples are looked at very carefully under a microscope for any signs of prostate cancer. The results are usually sent to the hospital consultant within a few weeks.
- There are different methods of biopsy and it's important to be aware that you may not be offered, or are not suitable, for all types of biopsy or some types of biopsy may not be available in your area:
  - i. **TRUS biopsy** which is a trans-rectal ultrasound and biopsy.  
A small ultrasound instrument is passed into the back passage to provide images of the prostate so the urologist or CNS can guide a special, small needle to take tiny samples of tissue from your prostate. The whole procedure takes about 15 minutes. Taking each biopsy sample only takes a matter of seconds. Up to 12 samples may be taken during the procedure.
  - ii. **MRI guided TRUS biopsy** (MRI means magnetic resonance imaging)  
This type of biopsy is very similar to that above but also involves overlaying (or fusing) a recently taken MRI high definition picture onto the live images on screen from the ultrasound scan. This gives a detailed 360°, 3D picture of the prostate. The advantage being the biopsy needle can very accurately be targeted to specific areas in the prostate.

iii. **Template guided prostate biopsy** (or trans-perineal biopsy)

This type of biopsy is a surgical operation so you will have an anaesthetic. It also uses an ultrasound scan but in addition involves placing a special grid, which has holes every 5mm, against your perineum (the skin between your scrotum and back passage). Very fine biopsy needles are then targeted at specific areas in the prostate taking about 30-50 tiny samples. The operation takes about 20-40 minutes.

iv. **Trans-perineal biopsy using MRI and trans-rectal ultrasound fusion biopsy**

This type of biopsy is very similar to that above but also involves overlaying (or fusing) a recently taken MRI high definition picture onto the live images on screen from the ultrasound scan. This gives a detailed 360°, 3D picture of the prostate. The advantage being the biopsy needle can very accurately be targeted to specific areas in the prostate taking about 30-50 tiny samples.

**Why is a prostate biopsy done?**

- If your PSA level is raised;
- If an unusual lump or hardened area is found in your prostate during a DRE;
- If your prostate is not a normal shape or size;
- If you have previously had a normal biopsy result but your PSA levels remain raised;
- If you manage your cancer by Active Surveillance, a biopsy will check if the cells in the prostate are changing.

(In some centres, certain patients may be asked to have an MRI scan before their biopsy.)

(The information given about tests and examinations is meant as general guidance. As tests and examinations may vary slightly from hospital to hospital, ask for more advice from staff at the hospital you are attending.)

### Prostate biopsy

This is done in hospital by the urologist, clinical nurse specialist (CNS) or occasionally by a radiologist. A biopsy means that several tiny samples are taken from the prostate using a special needle, these samples are then looked at very carefully under a microscope.

There are 4 types of biopsy:

- i. TRUS biopsy which is a trans-rectal ultrasound and biopsy
- ii. MRI guided TRUS biopsy
- iii. Template guided prostate biopsy (or trans-perineal biopsy)
- iv. Trans-perineal biopsy using MRI and trans-rectal ultrasound fusion biopsy

It's important to be aware that you may not be offered or may not be suitable for all types of biopsy and some types of biopsy may not be available in your area.

### Before having a prostate biopsy, tell the urologist, CNS or radiologist:

- If you have any problems with bleeding;
- If you have an allergy to any medicines like antibiotics;
- About any medicines, herbal pills or herbal supplements you are taking;
- If you take any drugs to thin your blood such as warfarin, clopidogrel, rivaroxaban or apixaban. You should have been asked to stop these before the biopsy so ask when you can start to take these again;
- If you take aspirin, ibuprofen or other non-steroidal anti-inflammatory drugs;
- If you have been unwell with any other medical condition in the past few days.

Most likely you will need to sign a form agreeing to have the biopsy done. You can ask the doctor or CNS any questions about the biopsy, or let them know if you have any worries about having the biopsy and what the result might mean for you.

## The different types of biopsy explained

### TRUS biopsy (trans-rectal ultrasound biopsy)

This is usually the standard way to have a biopsy if you have a raised PSA and/or the doctor has concerns when she/he examined your prostate. It involves taking tissue samples from your prostate through the wall of your back passage. Occasionally, the trans-perineal (through the skin between your scrotum and back passage) method can be used if there are difficulties reaching your prostate through the back passage.

The urologist or CNS might ask you to take antibiotics before and after the biopsy. This is to help prevent you getting an infection.

You will be asked to lie on your left side with your knees bent up towards your chest. The doctor or CNS gently passes a small, lubricated, ultrasound instrument into your back passage up to your prostate. The instrument is about the size of a thumb and works by releasing sound waves. The echoes from the sound waves give a clear picture of the shape and size of your prostate on a screen. This part of the examination is used to guide the standard sampling procedure, and may highlight other specific areas which need to be sampled.

Once the doctor or CNS has a clear picture of your prostate, a special small needle is guided to take between 10–12 tiny samples of tissue from your prostate and you will be given a local anaesthetic to stop you feeling any pain. You might feel a short, sharp pain or stinging as the special needles take these samples and there will be a 'clicking' noise as the samples are taken. The whole procedure takes about 15 minutes. Taking each biopsy sample only takes a matter of seconds.

After the biopsy you may be asked to pass urine before you go home. You may also be given a date to come back to see the doctor or CNS.

### **MRI guided TRUS biopsy**

This type of biopsy is similar to that above but also involves overlaying (or fusing) a recently taken MRI (MRI means magnetic resonance imaging) high definition picture onto the live pictures of your prostate on the screen from the ultrasound scan.

Once these two types of specialist diagnostic techniques are fused together by special computer software, they provide a detailed 360°, 3D picture of the prostate. The advantage being the biopsy needle can very accurately be targeted to specific areas in the prostate.

This type of biopsy may not be available in all hospitals.

### **Template guided prostate biopsy (or trans-perineal biopsy)**

This type of biopsy involves placing a special grid against your perineum (the skin between your scrotum and back passage) and taking tissue samples from your prostate through the perineum. This may be done in certain circumstances and perhaps is becoming more common now.

The urologist or CNS might ask you to take antibiotics before and after the biopsy. This is to help prevent you getting an infection.

This is a surgical operation, so you will most likely be given information from the hospital as to how long before your operation you should stop eating and drinking. You will most likely be admitted to hospital on the day of your operation.

You may be given a general anaesthetic (to make you sleep during your operation) or a spinal anaesthetic (which makes you numb from the waist down).

Once you are in theatre, your legs will be placed in supports so the special grid can be placed between your legs.

The 'thumb-sized' ultrasound probe will be slid into your back passage showing images of your prostate on a screen, and a small flexible tube, called

a catheter, will be placed into your bladder via your urethra (water-pipe). The catheter normally stays in your bladder until the following day. In some hospitals, a catheter may not be used, and the procedure is performed as a day-case.

The special grid (or template) which is used has holes every 5mm and is placed against your perineum. The very fine biopsy needles are targeted at specific areas in the prostate where the ultra-sound scan shows areas of concern.

Tiny samples of tissue are taken very quickly in a regular, organised way throughout the grid. About 30–50 tiny samples are taken.

Once all the samples have been taken, the grid is taken away and a firm dressing is applied and a pair of disposable pants will help keep this in place. The operation takes around 20-40 minutes.

### **What is trans-perineal biopsy using MRI and trans-rectal ultrasound fusion biopsy?**

This is very similar to the procedure above. However, this type of biopsy also involves overlaying (or fusing) a recently taken MRI high definition picture onto the live images of your prostate on screen from the ultrasound scan.

Once these two types of specialist diagnostic techniques are fused together by special computer software, they provide a detailed 360°, 3D picture of the prostate. The advantage of this type of biopsy is that the biopsy needle can very accurately be targeted to specific areas in the prostate.

(This type of biopsy may not be available in all hospitals.)

### **Then what happens?**

The samples of tissue are sent to a lab to be examined for any signs of prostate cancer.

### **Are there any potential side effects from having the biopsy?**

There may be some slight side effects, but even if you get them they don't usually last very long.

Side-effects may include:

- Blood in your urine;
- Blood in your semen;
- Blood when you pass a motion;
- A dull ache in the area between your scrotum and back passage;
- Difficulties in passing urine. Occasionally this can lead to not being able to pass urine at all, called urinary retention. If this happens you should seek medical attention;
- It is best to avoid sexual intercourse for 3-5 days.

### Infection

After a biopsy, a small number of men may be at risk of developing an infection. If you start to pass a large number of blood clots, can't pass urine at all, have a burning feeling when passing urine, are in severe pain or develop a high temperature then you should contact your GP or NHS 24 straight away.

### Going home

- If you have had a **TRUS biopsy or MRI guided TRUS biopsy**, you should be able to drive home, but, as you might feel a little uncomfortable, it may be best to have someone drive you home.
- As you will have had a general or spinal anaesthetic if you have had **Trans-perineal biopsy or Trans-perineal biopsy using MRI and trans-rectal ultrasound fusion biopsy**, you should ask the doctor or ward staff if you can drive home and you may need to check cover with your insurance company. As you might feel a little uncomfortable, it may be best to have someone drive you home.
- If you are given antibiotics to take at home, it is important that you finish the full course of tablets.
- If you are in a lot of pain, then you can take over-the-counter painkillers such as paracetamol or ibuprofen. Ask the doctor, CNS or your local pharmacist if you are unsure what to take.
- Take it easy for the rest of the day.
- Try to drink plenty of fluids to help flush out any possible infection.
- Try not to move your bowels immediately after the procedure.

### How long before I get the results?

The results will be sent to your consultant around 2-3 weeks after the biopsy. This may vary from area to area, so ask the doctor or specialist nurse who did the biopsy when you are likely to get your results. If you don't hear, then there is no harm phoning the hospital to ask about your results.

Because the biopsy needles take very small samples from different areas in the prostate, it is possible to miss very small areas of cancer. So, you might find that even if your biopsy test didn't show any cancer, your urologist, CNS or GP may still want to check your PSA level again in a few months.

For more information, there is a booklet entitled '*Spotlight on prostate biopsy*' available to download from [www.prostatescotland.org.uk](http://www.prostatescotland.org.uk) or by calling Prostate Scotland and a copy will be sent to you.

## Section 4

### Test results and what they mean

#### A brief summary of information in this section

- **Gleason score**

This is the scoring system that has been used for many years to report on how aggressive your prostate cancer might be.

This score/number gives an indication of how quickly the cancer is likely to grow and spread; in other words, how aggressive the cancer is likely to be. A pathologist examines the samples of prostate tissue taken during the biopsy and reports on the findings to give a Gleason score. The higher the score, the more aggressive the cancer may be and is used to help categorise whether the cancer is likely to be low, medium/intermediate or high-risk.

This reporting system will be phased out over the next few years as a newer prognostic grade group system is introduced.



- **Prognostic grade group**

A new grading system has been put forward and now accepted as a way to grade prostate cancer. This new system will grade prostate cancer from **Grade 1 to Grade 5**. However, until this becomes widely accepted it is likely that Gleason score and prognostic grade group will be reported together.

- **Staging of the cancer**

This is done by the letters TNM and a number where T stands for tumour, N for lymph nodes, M for metastases. It describes the size of the cancer, whether it is within the prostate, has spread just outside the prostate wall or has spread to the bones or other areas in the body. This indicates whether the cancer is early or localised, locally advanced or advanced.

### What do the results mean?

If your results show that you do have cancer then the urologist or specialist nurse (CNS) will talk to you about how slowly or quickly the cancer is likely to grow, what stage your prostate cancer is or if it might spread.

The doctor or CNS will talk to you about a few things:

- **Your Gleason score.** This is a number usually between 6 and 10 and gives an idea of how aggressive the cancer is likely to be.
- **Your prognostic grade group.** This means that all prostate cancers will be divided into 5 groups, from Grade 1 to Grade 5, according to what the pathologist sees in the cells from your prostate biopsy.
- **The staging of the cancer.** This is done by the letter T and a number between 1 and 4 e.g. T2. This is used to describe the size and whether the cancer is inside the prostate, has spread just outside the prostate or has spread to the bones or other areas in the body.

### Gleason score

A doctor, called a pathologist, will be sent the samples taken from your prostate. The samples 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 and become unusual in shape and size. The

more unusual or abnormal the cancer cells are, the more likely the cancer is to be aggressive or spread outside the prostate.

The doctor looking at the cells decides which type of cell is most common and which is second most common. Each of these two cell types is then given a grade from 1 to 5. A grade of 1 means these cells are the most normal looking or least aggressive, whilst cells given a grade of 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 and it describes the grade of your cancer.

Because of modern biopsy techniques, grades of 1 and 2 are rarely used, so the lowest Gleason score likely to be reported is Gleason 6.

Your score is an important number to remember and you will hear it mentioned a lot. It may be a good idea to keep a notebook to jot down the date and your Gleason score or you can use the Prostate log book that may be included at the back of this booklet.

You can ask the doctor or specialist nurse to explain your score and what it might mean for you in more detail. Keep in mind though that with any cancer it is not always possible to foresee exactly what will happen. The Gleason score gives only a guide on how quickly the cancer might grow and spread.

The Gleason score is important as it helps the doctors decide which may be the best types of treatment to offer you.

### **Prognostic grade group**

A new grading system has been put forward for grading prostate cancer by Dr Jonathan Epstein. It has been accepted by the World Health Organisation (January 2016) and will be used to grade prostate cancer from now on. However, until everyone (pathologists, clinicians, CNS and patients) becomes used to the new prognostic grade grouping system and it is fully accepted by all healthcare professionals, it is likely that Gleason scores and prognostic grade groups will be reported together until prognostic grade groups become fully adopted into practice. This could take a few years.

The pathologist will still be sent the samples taken from your prostate and these will be examined under a microscope to look at the cell pattern. Using the new grading system guidelines, the pathologist will grade the prostate cancer by simply numbering the prostate cancer from Grade 1 to Grade 5 with each of the grades having a likely outcome. Grade 1 will be the least aggressive and least likely to spread outwith the prostate while Grade 5 will be the most aggressive grade of prostate cancer. This system has been designed to be a simpler, more accurate and understandable way of reporting, making it easier for men and their families to understand the likely aggressiveness of their cancer.

The prognostic grade group will be an important number as it will help the doctors and you decide whether it may be best to observe the prostate cancer and defer treatment or to offer treatment options straight away.

In practical terms this means:

<b>Prognostic grade group</b>	<b>Compares with Gleason of</b>
Grade 1	Gleason score 6
Grade 2	Gleason score (3+4) =7
Grade 3	Gleason score (4+3) =7
Grade 4	Gleason score 4+4, 5+3 or 3+5 =8
Grade 5	Gleason score 9 and 10

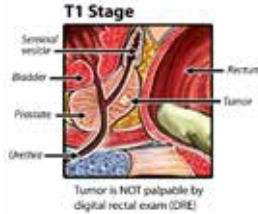
### Staging

This is the word you will hear to describe the size of the cancer and whether the cancer 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 and 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

#### T2a:

The tumour is smaller than half of one of the lobes in the prostate

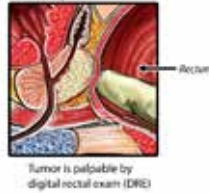
#### T2b:

The tumour is bigger than half of one of the lobes in the prostate

#### T2c:

The tumour is in both lobes but is still inside the prostate

### T2 Stage



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.

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 (cover) of the prostate

#### T3b:

The tumour has spread into the seminal vesicles

### T3 Stage



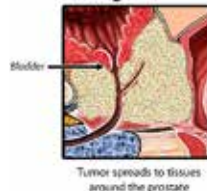
The tumour is breaking out through the wall of the prostate. This will be seen during a scan or can be felt by the doctor or CNS.

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 local structures

### T4 Stage



The fixed or invasive tumour has spread to nearby organs in the body, such as the back passage, 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.

**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

**Cancer risk scores compared**

Result	Low Risk	Medium Risk	High Risk
Gleason score	6	7	8-10
Prognostic grade group	1  The cancer is likely to remain in the prostate and grow slowly (be less aggressive)	2-3  There is an increased chance of the cancer breaking out of the prostate	4-5  There is a greater risk that the cancer will grow quickly (more aggressive) and may possibly have already spread outside the prostate
PSA level ng/ml	10 or lower	10-20	More than 20

## Section 5

### Further investigations which may be done

#### A brief summary of information in this section

- **Bone scan**

A bone scan may be done to find out if the cancer has spread to the bones, as prostate cancer, if it spreads, tends to spread to bones first of all. A very small amount of radioactive material is injected into a vein. After a few hours, a body scan is done to pick up any 'hot spots' which might indicate that a tumour is present. However, old fractures or arthritic changes can also show up as hot spots. The scan is examined by a specialist doctor in radiology who will send a report to the urologist.

- **X-ray**

An x-ray may be done to check out normal wear and tear on bone and joints.

- **MRI scan (Magnetic Resonance Imaging)**

An MRI scan uses magnets rather than x-rays to produce detailed pictures of the prostate, surrounding tissues, bones and other organs. It is usually done after a prostate biopsy has found cancer in the prostate. In some areas and in certain circumstances an MRI scan may be done prior to biopsy. It shows whether the cancer remains within the prostate or has spread to other organs or tissues and helps doctors decide on what may be the most suitable treatment.

- **CT scan or CAT scan (Computerised Tomography)**

Although done less often now, a CT scan combines special x-ray equipment with advanced computers to take many pictures in lots of different views inside your body. These pictures can be studied on a screen to see if the cancer has spread outside the prostate to the lymph nodes or areas around the prostate.

(The information given about the tests and examinations is meant as general guidance. As tests and examinations may vary slightly from hospital to hospital, ask for more advice from staff at the hospital you are attending.)

### **Bone scan**

Your doctor may suggest that you have a bone scan to check if the cancer has spread outside the prostate. This is because prostate cancer tends to spread to bones first of all. However, if your PSA level was low and the doctor said your cancer was low-risk, you will probably not need to have a bone scan.

Some hospitals may send or give you information about the bone scan, so it is important that you follow their guidelines. However, some information on bone scans is given below.

### **What happens?**

You will probably be asked to go to the hospital a few hours before your scan is due. A tiny amount of a radioactive material is injected into a vein in your arm. Although this may sound scary, the amount is so small that it won't harm you. It may make you feel a bit hot or flushed for a minute or two. Your scan will take place a few hours later because the radioactive material is slowly taken into your bones.

After this injection you may be able to leave the department, but you will be given a time to come back in a few hours (always check with the department you are attending). During this time, you can eat or drink as you normally would. Your bladder doesn't need to be full, so you can go to the toilet as often as you need. You will possibly be asked to empty your bladder when you get back to the department.

When you go back, you will probably be taken to a scanning room. In some places, you may be asked to put on a hospital gown, but in other hospitals you will not need to do this. You may also be asked to take off any metal jewellery or metal fasteners. Then you will lie down on a narrow bed and be asked to lie still. This can be a bit uncomfortable as you need to lie still in one position for about 15-20 minutes. Your whole body is then scanned by a special camera for any 'hot spots'. Hot spots are areas that take up a lot of the radioactive material and this may point to a tumour being there. However, old fractures or arthritic changes can also show up as hot spots, so it is worth telling your doctor or radiographer about them. As the radioactive

material doesn't cause any side effects, you will be able to go home afterwards and some men drive themselves to and from the test. You may be advised to drink plenty of fluids to help get rid of the small amount of radioactive material still in your body.

Afterwards, it may be wise not to be in close contact with pregnant women, babies or young children until the day after the scan. Ask for more advice on this at your bone scan.

At the same appointment as your bone scan, you may be advised to have a normal x-ray or CT scan to check for any wear and tear in the bones and joints.

### **What about the results?**

You won't get the results right away and it may take a few weeks before you hear. A doctor who specialises in studying scans will look at your bone scan in detail and send a report to the doctor who referred you for the bone scan. Ask who you should contact and when you are likely to hear about the results.

### **MRI scan (Magnetic Resonance Imaging)**

#### **What is this?**

An MRI scan uses magnets rather than x-rays to produce detailed pictures of your prostate, surrounding tissues, bones and other organs. The pictures can be viewed on a computer screen, printed out or copied to a CD. The machine is like a long tunnel which covers most of your body.

Some hospitals may send or give you information about the MRI scan, so it is important that you follow their guidelines. However, some information on MRI scans is given below.

#### **Why is this done?**

Usually, this is done after a prostate biopsy has found cancer in the prostate. In some centres, patients may be asked to have an MRI scan before their biopsy.

An MRI scan is used to look closely at the cancer in the prostate. The pictures can also show if the cancer has remained within the prostate or has spread outside the walls of the prostate to other organs or tissues. It will help the doctor decide on the treatment choices most suitable for you.



### What happens?

- It is probably best to wear comfortable, loose-fitting clothing without metal fasteners, or you may be given a hospital gown to wear.
- You may be asked questions about your health and if you have any metal implants such as a pacemaker, but hip and knee replacements shouldn't cause any problems.
- It is very likely that the doctor or radiographer will go through a checklist with you, asking about metal implants to make absolutely sure the scan will not harm you in any way.
- If you don't like being in or have a fear of closed spaces or are unable to undergo an MRI scan for any other reason tell the staff about this.
- You will need to take off any jewellery or other metal objects.
- You will be asked to lie flat on your back on a narrow table and pillows might be used to help you stay still and in the correct position.
- Next, the table slides into the tunnel and you may find that the machine is quite noisy.
- The radiographer may ask you to hold your breath or lie totally still at certain points while the images are being recorded.
- The radiographer isn't able to stay in the room, but can see, hear and speak to you all the time during the MRI scan.
- You may be able to provide a music CD of your choice to the radiographer and ask if this could be played during your scan to listen to and perhaps help you relax.

The scan usually takes between 30 and 40 minutes. When the MRI has been completed, you will probably have to wait to make sure that the pictures are good quality so the doctor has sharp images to see what is happening in your body.

You won't get the results straight away, so ask when you are likely to hear about the results of the scan. You should feel free to contact the hospital to chase up your results.

### CT scan or CAT scan (Computerised Tomography)

This is done less often now and usually only if you suffer from claustrophobia (fear of being in an enclosed space).

### What is this?

A CT scan combines special x-ray equipment with advanced computers to take many pictures in lots of different views inside your body. These pictures can be studied on a computer screen, printed out or transferred to a CD.

Some hospitals may send or give you information about the CT scan, so it is important that you follow their guidelines. However, some information on CT scans is given below.

### Why is it done?

It can show if the cancer has spread outside the prostate to the lymph nodes or the area around your prostate.

### What happens?

- A special dye is injected into a vein, probably in your arm, to help make the pictures clearer. This might make you feel hot for a few minutes.
- You will be asked to lie flat on your back on a narrow table and keep quite still as any movement may blur the picture.
- At first, the table will move quickly through the scanner. Then, more slowly as the CT scan is done.
- You might hear slight buzzing, clicking and whirring sounds as the CT scanner turns around you as the pictures are taken.
- The radiographer isn't able to stay in the room, but can see, hear and speak to you all the time during the CT scan.

When the CT test has been completed, you will probably have to wait to make sure that the pictures are good quality so the doctor has sharp images to see what is happening in your body.

A CT scan usually takes about 30 minutes and most men will be able to go home after the scan.

You will probably get the results back in about 1-2 weeks. Ask how long it might take for your results to come back and if you have to phone to get them. Writing the date down or using the Prostate log book that may be included may help to jog your memory.

## Section 6

### The next step following the results of tests and investigations

#### A brief summary of information in this section

- Waiting for results can be a very stressful time for the whole family. It may help:
  - To speak to others such as the specialist nurse;
  - To get in touch with a support group in your area;
  - If someone attends your appointment with you;
  - To write down any questions so they can be asked at the next appointment.
- Following test results, the type of treatment offered will be based around the Gleason score/prognostic grade group, stage of the cancer, PSA level, your age, other medical conditions and whether the side-effects of treatment would have a greater impact on your quality of life than the effect of the cancer.
- As there is no clear cut answer on the best way to treat prostate cancer, a multi-disciplinary team (MDT), which includes specialists in urology and oncology, may be involved in your care and treatment. The decision made will also take into account the views of you and your family.

#### Waiting for the results

For many men being told that they have prostate cancer and then having a range of tests and examinations can be very stressful. This can be a very worrying time, too, for spouses, partners and the rest of the family. It may help if your spouse, partner or close family member goes along with you to appointments as you can both ask questions then talk it over afterwards. 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 contact the group, as members have the same diagnosis, have undergone the same tests, gone

through the anxiety of waiting for results and so understand first-hand how you and your family might be feeling.

It might also be a good idea to write down any questions you have so you can ask the specialist nurse or doctor at your next appointment.

### **What might the results of the tests mean for me?**

Once the doctor has all your test results, a number of issues will be taken into account before deciding which treatment(s) may be most suitable for you, based on whether you have low, intermediate or high-risk cancer (see page 29 to refresh your memory).

They do this by looking at:

- i. Your Gleason score/prognostic grade group or grade of your cancer - this is how the cells from your prostate looked under the microscope;
- ii. The stage of your cancer - this points to how big the cancer has grown or if it has spread;
- iii. Your PSA blood level;
- iv. How old you are and any symptoms you have that are troubling you;
- v. Whether you have any other medical conditions affecting your health;
- vi. If the side effects of the treatment would have greater impact on your quality of life than the effect of the cancer.

There is usually a multi-disciplinary team (or MDT) of urology surgeons, oncologists, radiologists, pathologists, and specialist nurses in urology or oncology, many of whom will be involved with your care and treatment.

They will:

- Have thought about these points and will talk them through with you;
- Suggest which treatment(s) may be most suitable and offered to you;
- Talk to you about the advantages and drawbacks of the treatment(s) offered;
- Ask which type of treatment you would prefer to have, taking into account the possible effect this may have on your life.

### **What might my test results mean for the rest of my family?**

If you've just been diagnosed with prostate cancer, this may have come as something of a shock. After you've had time to come to terms with your diagnosis, you may start to wonder if and what the risks might be for other men in your family.

It has been found that 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, when you're ready to talk about it, you should perhaps consider letting men in your family know about the increased risk so they can discuss this with their GP. Depending on their personal circumstances, the GP may then offer a PSA test.

At the time of writing (April 2016) there is not a screening programme for prostate cancer in the UK. Instead there is a Prostate Cancer Risk Management Programme and the guidance states that:

“Any man over the age of 50 who asks for a PSA test after careful consideration of the implications should be given one.”

However, if there is a strong family history of prostate cancer then the GP may ask the man to consider having a PSA test before 50.

There is more information about Risk Factors and the PSA test on our website or you can download the following leaflets or get in touch and a copy will be sent to you:

*'Prostate cancer. Is it in the family? Is it time to check it out?'*

*'PSA the knowledge'*

*'PSA explained'*

### **Intimacy after diagnosis and before treatment**

Some men are concerned about intimacy with their wife/spouse or partner after they have been diagnosed with prostate cancer and worry that they might pass cancer on to them. There have been some studies looking into this that seem to suggest that there is no strong evidence that there is any risk of you passing cancer to your wife/spouse or partner through intercourse.

Other men have asked about frequency of intercourse after being diagnosed with prostate cancer; should they carry on with intercourse as before, should they stop having intercourse, should they increase the number of times they have intercourse and ejaculate to ‘exercise’ the prostate. The answer would seem to be to continue with intercourse as you would normally, with a frequency that you and your wife/spouse or partner are comfortable with. (There are circumstances after certain treatments when you may be advised to wear a condom.)

## Section 7

### Treatment choices

#### A brief summary of information in this section

There are three main ways to treat early or localised prostate cancer. However, not all of the treatments will be available in all areas. For some treatments it may be necessary to travel to other areas.

With early or localised prostate cancer there are generally three main choices of treatment. The treatment choices take into account your age, your general health, the risk to you from your cancer and which treatment you might prefer. The treatment choices are:

- Active surveillance or monitoring
- Surgery to remove the prostate
- Radiation treatment to kill the cancer cells - this may be by external radiotherapy or brachytherapy
- Hormone therapy may also be used in combination with radiotherapy or brachytherapy

#### • Active surveillance (AS) or monitoring

(If this is an option you are considering then there is more detailed information about this treatment and the procedure involved in this section.)

AS may be suggested if the cancer is low-risk or prognostic grade group 1 and if the side-effects of treatment will have a greater impact on quality

of life than the cancer. It may be an option for a small number of men with intermediate-risk prostate cancer or prognostic grade group 2. (Please see page 25-27 for more information on low and intermediate-risk and also prognostic grade groups.)

It means that:

- i. There is no immediate treatment of the cancer. Instead treatment is deferred/postponed until such times that treatment becomes necessary;
- ii. The urologist and CNS will keep a close eye on the man's health and cancer with regular check-ups, PSA tests, DRE, MRI scans and possible biopsies;
- iii. If the cancer shows signs of growing, becoming more aggressive or spreading then treatment can be started.

### ● **Radical prostatectomy (surgery to remove the prostate)**

(If you are considering a radical prostatectomy then more detailed information about this treatment, procedure and side effects are included in this section.)

Radical prostatectomy may be suggested as an option if the cancer is low-risk or prognostic grade group 1, intermediate-risk prognostic grade group 2, 3, or for a small number of men with high-risk prognostic grade group 4 prostate cancer. The operation removes the whole prostate, part of the urethra and seminal vesicles. Radical prostatectomy may be done by minimal access (keyhole) surgery, in some areas by robotic assisted minimal access surgery or less commonly now by an open procedure. Radical prostatectomy can be a cure for cancer which is contained within the prostate.

- Radical prostatectomy involves a short hospital stay, if recovery goes well, a general anaesthetic and a catheter for about 2 weeks. This can vary in different hospitals and with the type of surgery;
- After a radical prostatectomy, the PSA level should be practically undetectable;
- There will be regular check-ups and PSA levels will be measured after about 6-8 weeks.

## • Radiotherapy

(If you are considering radiotherapy, then more detailed information about this treatment, procedure and side effects is included in this section.)

This can be given in two ways:

### i. External beam radiotherapy (EBRT)

EBRT is suitable for prognostic grade groups 1-5.

High energy x-ray beams from outside the body accurately pinpoint areas to be treated in the prostate to kill the cancer cells. Treatments are carefully planned and will usually be given 5 days a week for between 4-8 weeks. Hormone therapy may be given in combination with radiotherapy. EBRT can be a cure for prostate cancer which is contained within the prostate.

### ii. Brachytherapy

Brachytherapy is suitable for prognostic grade group 1-3.

This is a type of radiotherapy where tiny metal seeds which emit radiation are placed into the prostate, working to kill cancer cells from inside the body. The position and exact number of these 'seeds' implanted into the prostate are worked out very carefully. The seeds are put in place during an operation with a general anaesthetic and possibly an overnight hospital stay. Hormone therapy may be given in combination with brachytherapy if the prostate is large, to make the implant technically easier. Brachytherapy can be a cure for prostate cancer that is contained within the prostate.

## • Hormone treatment

Hormone treatment works by reducing the amount of testosterone and as a result slows down the growth of the cancer or shrinks it. Hormone therapy may be given before radiotherapy so this has a better chance of working. It may be given before brachytherapy to shrink the prostate if the prostate is large. Hormone therapy can be given as a tablet and by injection.

## • Other treatments

There are some newer treatments, but these are still considered to be experimental and are not generally available in Scotland, unless participating in a trial.



- **High intensity focused ultrasound (HIFU).** This uses ultrasound waves to generate heat to kill cancer cells.
- **Cryotherapy.** This uses freezing to kill the prostate cancer cells. This is available in Glasgow as a national service.
- **High dose rate brachytherapy (HDR).** This combines 3-4 weeks of EBRT with 1-2 fractions of HDR. Very thin hollow tubes/ needles are inserted into the prostate then carefully controlled amounts of radiation treatments are given. The tubes are easily withdrawn and no seeds are left in the prostate. It is given in combination with 3-4 weeks of EBRT. This treatment is not available in Scotland.

There are several different ways to treat prostate cancer. Because of the way that prostate cancer develops, no-one knows for sure the best way to treat early or localised prostate cancer. Whilst the doctors will be able to advise you on what they feel may be the best treatment, the decision must take into account your views. So, the doctor or specialist nurse will listen to you and your family and help you come to a decision.

(The information given about the treatments and procedures is meant as general guidance. As treatments and procedures may vary slightly from hospital to hospital, ask for more advice from staff at the hospital you are attending.)

Not all the treatments will be available in all areas. This may be one of the issues that you will need to consider in your particular situation, as you may have to travel to another area and on more than one occasion. You can ask the doctor or specialist nurse about which treatments are available locally.

### **Active surveillance or monitoring**

What is active surveillance (AS)?

Active surveillance (sometimes called active monitoring) is a management option suitable for some men with prostate cancer. AS means that you won't have any immediate treatment, as treatment is deferred or postponed until your doctor feels it necessary to treat your prostate cancer because of your test results.

When might this be suggested?

- When cancer is found in the early stages, is still inside the prostate and is thought to be low-risk of progression or prognostic grade group 1. It may be an option for a small number of men with intermediate-risk prostate cancer or prognostic grade group 2;
- For men aged under 75 with a life expectancy of 10 years or more;
- For men over 70, as the cancer is unlikely to grow fast enough to cause problems during their lifetime;
- For younger men who have concerns that the side-effects of treatment will have a greater effect on their life than the cancer. They may prefer to put off the risk of side-effects for as long as possible (called deferred radical treatment).

There may be additional local guidelines you may have to meet to be considered for AS. Ask your consultant or CNS for more information.

Your prostate cancer will be very carefully monitored and you will have regular appointments with your GP, urologist or CNS for PSA tests and a DRE (digital rectal examination). In addition, repeat biopsy and/or repeat MRI scans may well be used as part of the monitoring process. To help keep track of your appointments, blood results, Gleason score, prognostic grade group and other test results you may find that the Prostate log book is very handy. You can ask your urologist or CNS for a copy, download from our website [www.prostatescotland.org.uk](http://www.prostatescotland.org.uk) or call us and a copy can be sent to you.

### **When will I need to consider another form of treatment?**

Having all the checks done regularly should show if or when the cancer starts to progress by becoming more aggressive.

Treatment can be started if you change your mind about AS or if the cancer shows signs of growing faster or looks as if it might spread outside the prostate. These signs include:

- Your PSA level rising very quickly;
- An increase in your Gleason score or prognostic grade group;
- Changes to the prostate during a DRE. This could be the prostate changing in size, shape or the doctor feeling a lump or hardened area;
- A biopsy shows significant increase in volume of the cancer.

If this is the case, then further treatment options will be discussed with you by your urologist or CNS. These might include radical prostatectomy, external beam radiotherapy or brachytherapy.

**What advantages and drawbacks are there to think about with active surveillance?**

Because you will not be having any immediate, active treatment for your prostate cancer and instead your cancer will be monitored by regular check-ups and tests, you may want to think about the advantages and drawbacks of managing your prostate cancer by AS.

Advantages	Drawbacks
<p>With AS your prostate cancer is carefully monitored and only treated if and when treatment becomes necessary, so avoiding potential side-effects of treatment that can impact on your quality of life and the risk of over treatment.</p>	<p>Although AS does not cure your cancer, the urology team carefully monitor your cancer to check if the cancer is progressing.</p>
<p>You avoid any risk of potential side-effects that you might get from other types of treatment.</p>	<p>You may worry that you are not doing anything. You will have to be willing to live with some uncertainty and doubt about your cancer and what is going on.</p>
<p>Your prostate cancer may grow so slowly that other treatments may never be needed.</p>	<p>There is a very small risk that a slow-growing cancer may suddenly grow and spread outside the prostate capsule while you are waiting and so you could reduce the possibility of your cancer being treated with curative intent. 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.</p>
<p>While your cancer is being monitored new and better treatments may become available.</p>	<p>You will need to attend your GP or hospital to have regular check-ups, PSA tests, DRE and prostate biopsies. You will need to remember to make appointments and keep a record of test results, in other words taking an active part in the monitoring of your cancer.</p>

For more information, there is a booklet entitled '*Spotlight on Active Surveillance as a management for early prostate cancer*' available to download from [www.prostatescotland.org.uk](http://www.prostatescotland.org.uk) or by calling Prostate Scotland and a copy can be sent to you.

Before choosing active surveillance, you may have some questions to ask your urologist or CNS.

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

- Is active surveillance a suitable option for me?
- If I choose active surveillance now, can I change my mind later on?
- 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?
- Between check-ups, are there any signs or symptoms I should look out for and let you know about?
- Why do you think this might be the best option for me?
- Can you explain what the risks are likely to be?
- Which tests would I have: PSA, DRE, biopsy, scans, anything else?
- How often would I need to have the tests or check-ups and who would do these?
- How would we know if my prostate cancer is getting worse?
- How quickly and to what level would my PSA need to rise before you would think about an alternative treatment for me?
- What treatment might be offered to me if the cancer starts to grow?
- How quickly would I be able to have the treatment?
- Are there other suitable treatment choices that I could think about now?
- Why would active surveillance be better for me than a radical prostatectomy, external beam radiotherapy or brachytherapy?
- What is the outlook for me?
- Is there someone that I can talk to who has made this choice?

## **Surgery for prostate cancer**

The operation to remove the prostate is called a radical prostatectomy. The aim is to remove the prostate, and so all the cancer inside it, and stop the cancer from spreading to other parts of the body. It is not a suitable option for all men who have prostate cancer.

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

### **What is a radical prostatectomy?**

If your doctor thinks this is an option, and you are thinking about it, then this section will give you more information about what happens, side-effects, advantages and drawbacks of the operation.

This is a fairly major operation and it involves removing:

- Your whole prostate;
- A part of the urethra (water-pipe) – the tube that allows urine to flow out of the bladder through the penis;
- Seminal vesicles next to the prostate – glands that store semen.

If you have had symptoms of an enlarged prostate, (benign prostatic hyperplasia, BPH), then having your prostate taken out may relieve these symptoms.

There are a few ways that a radical prostatectomy can be done:

### **Minimal access surgery**

Keyhole and robotic assisted surgery are becoming the most common way of removing the prostate.

#### **1. Laparoscopic radical prostatectomy (LRP - also called keyhole surgery)**

This has become a much more common way of taking out the prostate and may be a treatment choice for some men.

In this operation, you will have five small cuts across your lower tummy. Four of these cuts will be around 1cm long with the final cut being slightly longer, about

3-4 cms to allow the doctor to insert the special instruments needed so that the prostate can be taken out.

## **II. Robotic assisted laparoscopic radical prostatectomy (RALRP - keyhole surgery)**

RALRP is now available in Aberdeen, Edinburgh and Glasgow.

This is similar to the laparoscopic operation already described and is becoming the most common minimal access surgical approach to radical prostatectomy. The difference being that there is a trolley with the robot, robotic arms and instruments next to the operating table. The surgeon very precisely directs the small robotic instruments attached to the robot arms from a console with a control panel.

The expected advantages of minimal access surgery are:

- Usually a shorter stay in hospital;
- Smaller scars;
- Faster recovery time;
- Usually returning to work more quickly;
- Less bleeding and fewer men requiring a blood transfusion;
- The catheter to drain urine may be taken out more quickly;
- Several studies suggest there may be better continence and erectile function rates.

For more information about minimal access surgery to remove the prostate, Prostate Scotland has available a booklet '*Spotlight on Prostate Cancer Surgery Minimal Access Radical Prostatectomy for Prostate Cancer*'. This is available on our website. For a copy to be sent to you please call or email [info@prostatescotland.org.uk](mailto:info@prostatescotland.org.uk)

## **Open radical prostatectomy (called retropubic radical prostatectomy)**

This may be the operation recommended to some patients, depending on their individual features, by some surgeons in Scotland.

This means that you will have one quite large incision (cut) in your lower abdomen, from your tummy button to the pubic bone. This will often be about 7-10 cms (about 4 inches) long. However, the greater the distance between your tummy button to your pubic bone, then the longer the cut is likely to be.

Over the next few years, open radical prostatectomy is likely to be phased out in Scotland with minimal access surgery becoming the surgery of choice.

### **Radical perineal prostatectomy**

This means that an incision is made in the area between the scrotum and the back passage and the prostate is taken out through this cut. Although this is very rarely recommended in Scotland, it may be the operation of choice for certain men.

### **When might a radical prostatectomy be suggested?**

- As a primary/main treatment for prostate cancer when the cancer is localised and contained within the prostate;
- When the cancer has not spread (metastasised) to other parts of the body;
- When the cancer is thought to be low-risk or intermediate-risk according to your Gleason score or prognostic grade group; however it may be done in some men who have high-risk prostate cancer;
- After a period of active surveillance if there are signs of the cancer growing and is thought to need treatment;
- For men who are expected to live for at least 10 years;
- For men who are otherwise healthy and fit enough for a general anaesthetic;
- If you have had previous treatment for prostate cancer and the cancer has not spread outwith the prostate, such as radiotherapy, but the cancer has recurred.

### **What happens?**

#### **Radical prostatectomy**

- You will most likely have to go to a pre-assessment clinic to have some tests done, the operation explained to you and any questions answered. All of this is to make sure that you are fit enough to have your prostate taken out. You may be asked to sign a consent form agreeing to have the operation.
- You may be referred to a specialist physiotherapist who will advise you on a programme of pelvic floor exercises to start before having your operation or perhaps the CNS will discuss these with you. For more information about pelvic floor exercises, Prostate Scotland has a booklet '*Spotlight on Pelvic Floor exercises for men*'. This is available on our website. For a copy to be sent to you call us or email [info@prostatescotland.org.uk](mailto:info@prostatescotland.org.uk)

- You will be asked about any medication you are taking. Remember to tell staff about aspirin, warfarin, clopidogrel, rivaroxaban, apixaban or any other pills you are taking. You may already have been given advice on these by staff in the clinic.
- At some point, you will be given an enema, which encourages your bowels to move so that your bowel is empty before surgery. Ask the CNS when you will be given an enema.
- You will be given information about eating and drinking before the operation takes place.
- After the operation has been explained to you, you will be asked to sign a consent form agreeing to have the operation.
- You will be seen by an anaesthetist prior to or on the day of your operation.
- During your operation, you will be lying on your back with your head in a slightly down position:
  - i. With laparoscopic radical prostatectomy, you will have five small cuts across your lower tummy. Each of these cuts will be around 1cm long and has a special, small plastic tube placed inside. Each cut serves a different purpose during the operation; one is used for a camera to magnify inside, 3 others are used for the instruments to undertake the operation.

The final cut is made slightly longer, about 3-4 cms to allow the doctor to insert the special instruments needed so that the prostate can be taken out.

The surgeon will directly work inside your body using the instruments to do the operation.

- ii. With robotic assisted laparoscopic radical prostatectomy there will be a trolley/cart which holds the robot 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 to do the surgery.

You will have five small cuts across your lower tummy. Each of these



cuts will be around 1 cm long and has a special, small plastic tube placed inside. Each cut serves a different purpose during the operation; one is used for a camera to magnify inside, 3 others are used for the instruments to undertake the operation.

The final cut is made slightly longer, about 3-4 cms to allow the doctor to insert the special instruments needed so that the prostate can be taken out.

- iii. With an open radical prostatectomy, one larger cut of about 7-10 cms (4 ins) will be made from your tummy button to your pubic bone.
- The prostate, part of the urethra and seminal vesicles will be taken out.
  - If the surgeon thinks that there might also be cancer in the lymph nodes then these will be taken out at the same time (called lymph node dissection). The surgeon may discuss with you about removing lymph nodes if you have intermediate or high-risk cancer or prognostic grade group 3-5 and this will be done at the same time as the prostatectomy. (Lymph nodes are part of the body's normal immune system to fight infection.)
  - 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 will often appear shorter too.
  - You may be given oxygen during and after the operation.
  - You may have an intravenous line (drip) that will stay in place until you are eating and drinking normally.
  - Some men may require a blood transfusion following the surgery.
  - The operation can last anything from about 1½ hours up to about 4 hours.
  - You will be given painkillers, if necessary, on the ward to help with any pain or discomfort.

### **Will I have an anaesthetic?**

Yes, you will have a general anaesthetic, which means you will be asleep during the operation.

### **Will I have a catheter?**

- When you get back to the ward from the theatre, you will have a catheter (a

small flexible drainage tube) in your bladder. This tube drains urine from your bladder into a bag to allow healing. This will usually stay in place for about 1-2 weeks but can vary in different hospitals.

- You may have a tube drain in place for 1-2 days after your operation to drain any excess blood into a bag.
- Most likely you will go home with the catheter in place to drain urine into a bag. You will be given advice on how to care for the catheter.
- If you notice that urine is not draining from the catheter into the catheter bag and you feel uncomfortable with a strong urge to pass urine, you should contact your GP, or NHS 24, or go to an accident and emergency department.

For more information about caring for your catheter, Prostate Scotland has a booklet '*Spotlight on Caring for your indwelling catheter at home*'. This is available on our website. For a copy to be sent to you call us or email [info@prostatescotland.org.uk](mailto:info@prostatescotland.org.uk)

### **Will I have to stay in hospital?**

Yes. If your recovery goes well you may be in hospital for around 2-3 days, but this can vary in different hospitals. If you have had robotic assisted laparoscopic prostatectomy and are recovering well you may even go home within 24 hours. If you have had an open radical prostatectomy, then it may be slightly longer before you get home; between 3-5 days. In all cases, the doctors will see you after your operation and discuss with you when they are happy for you to go home.

### **Are there any potential side-effects?**

There are always some potential risks or side-effects from having any kind of surgery. The doctor or CNS will take you through the possible complications and side-effects before you sign the consent form.

### **Medical complications**

- 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 preventative measures are taken during the operation. During recovery, special stockings help maintain a continuous blood flow in the legs. In the days after surgery (possibly on the day of your surgery) and as soon as you feel able, you will be encouraged to walk to pump blood from the legs to the heart.

- Urine infections

You will be given an antibiotic if necessary.

### **Injury to the back passage (rectum)**

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

### **Potential side-effects of a radical prostatectomy**

- **Urinary incontinence**

This is called stress incontinence. Although a common side-effect, it is usually temporary with the majority of men regaining full continence over time.

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 or dribbling out when you cough, laugh, get up from a sitting position or when walking.

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

There is more information on urinary incontinence and pelvic floor exercises on page 82. You can also speak to the CNS or consultant about this.

For more information about incontinence, Prostate Scotland has a booklet '*Spotlight on Incontinence as a symptom of prostate problems*'. This is available on our website. For a copy to be sent to you call us or email [info@prostatescotland.org.uk](mailto:info@prostatescotland.org.uk)

• **Problems having erections**

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

After a radical prostatectomy, it is usual for men to be unable to have an erection. In many cases the ability to have an erection can return to levels similar to those the man had before his prostatectomy. There is more information on erectile dysfunction and potential recovery of function on page 84. You can also speak to the CNS or consultant about this.

For more information on erectile dysfunction, Prostate Scotland has a booklet *‘Spotlight on Prostate conditions and erectile dysfunction’*. This is available on our website. For a copy to be sent to you call us or email [info@prostatescotland.org.uk](mailto:info@prostatescotland.org.uk)

**Getting home...**

It might be best to have some loose-fitting clothes to dress in to go home. Trousers that have an elasticated waist such as tracksuit bottoms may be the most comfortable.

If you were asked to stop taking some of your usual medication before your operation, ask the doctor 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 your operation 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 down in about a weeks’ time.

To help with any pain and discomfort, it is best to be prepared and have some suitable painkillers at home. Ask the nurse or doctor in hospital if you are unsure about this.

You will most likely be advised to continue with your pelvic floor exercises when you get home to help with continence. Ask your CNS for more information.

At first, discomfort around the area of your wounds will help stop you from doing too much. Avoid vigorous activity in the first few weeks, so start off with some light exercise and then gradually increase. Remember not to pick up anything heavy as this puts a strain on your wound.

If you have had an open prostatectomy, you may have some tenderness/pain when bending from your waist.

After surgery, you should be able to go back to driving in about 2-3 weeks but you should chat this over with your own consultant for more specific advice and let your car insurance company know.

You should be able to return to light work 3-4 weeks after a laparoscopic/robotic assisted minimal access operation or about 6-8 weeks after an open radical prostatectomy. Again, speak to your consultant for more specific advice.

When you are able and it feels comfortable, you can begin to have sexual intercourse (please see more information on page 84). The ability to have a full erection often takes many months to recover fully, and in some cases may never do so.

When you have a catheter, it is best to have a shower rather than a bath, as long as 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 be given some incontinence pads to use at this time. Pads may also help with any leaks after your catheter is taken out. Ask for more advice from staff on the ward.

### **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, normally about 1-2 weeks after your operation, you may be given a special x-ray, called a cystogram to check on how quickly your catheter can be taken out. If there are no leaks, then the catheter can be taken out, but, if there is a leak then the catheter will be left in for slightly longer. A cystogram may not be done in all hospitals so you can ask your consultant if you are likely to have one.

#### • Uteric 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 water-pipe (urethra) under local anaesthetic and as an out-patient. 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.

#### Constipation

Constipation, and your bowels being sluggish, is a temporary but common side-effect after radical prostatectomy and it may take time to get back to what was normal for you. That said, some men find constipation troublesome while others do not. Being constipated can be painful, make you feel very uncomfortable and may affect your wounds and healing if you strain or push too hard to pass a bowel movement. It's best not to let this go on for too long before asking for advice from your consultant, CNS, GP, pharmacy or NHS 24 as there are medicines that can help make constipation better. Before buying any over-the-counter medicines for constipation, check with your CNS, GP, pharmacy or NHS 24 what would be best in this instance.

#### What you can do to help:

- Have enough fluid each day by drinking around 2 litres (about 8 glasses of water); try having a cup of hot water first thing in the morning before having breakfast.
- Include more fibre in your diet by switching to wholemeal bread, bran type cereals and eating more fruit and vegetables.

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

### Going back to the clinic

You will get an appointment to attend the urology outpatient department in about 6-8 weeks (depending on availability). You will most likely be asked to have a PSA test done at your GP practice prior to your clinic appointment so the clinician or CNS has an up-to-date PSA level. At your clinic appointment, you will be asked how you are, hear about your results and have your wound examined.

Perhaps the following chart will help you understand what the results might mean for you when the clinician or CNS is discussing your results.

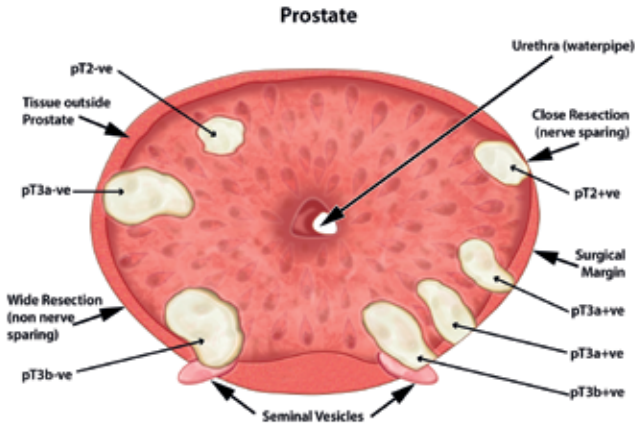
Positive surgical margin(s) means that cancer cells were found close to the edge of the prostate and the consultant or CNS will discuss what this might mean for you.

If the surgical margin is involved this increases the risk of needing further treatment, but there is still a good chance that no further treatment will be required.

### How do I know if the treatment has worked?

After you have had surgery, the doctor will want to see how you are with regular check-ups. Your PSA level will be measured. After a radical prostatectomy, your PSA should drop quickly and should be practically undetectable\*. If it does not drop this low or starts to rise then this suggests there may be cancer cells elsewhere in your body.

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



Your Gleason Score is: -----

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

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

- a Tumour involving less than 1/2 of 1 lobe of the prostate.
- b Tumour involving more than 1/2 of 1 lobe of the prostate.
- c Tumour involving both lobes of the prostate.

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

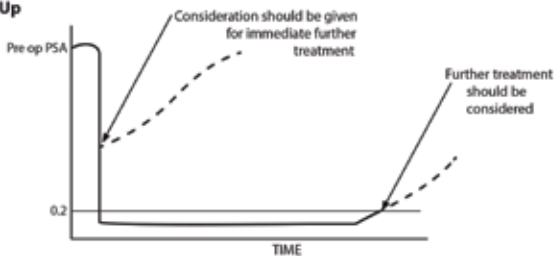
**pT3a+ve** Tumour has gone outside the prostate and involves the surgical margin.

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

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

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

**PSA Follow Up**



Created by Medical Illustration, NHS Highland



**Weighing up the decision? What advantages and drawbacks are there to think about with a radical prostatectomy?**

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

\*See pages 55-56

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

- Is a radical prostatectomy a suitable option for me to think about?
- What do you expect a radical prostatectomy to do to the cancer? Could it cure my cancer?
- Which operation do you think is best for me – laparoscopic radical prostatectomy, robotic assisted laparoscopic radical prostatectomy or open radical prostatectomy? Are all of these available in my area?
- When could this be done?
- How familiar is the surgical team in performing laparoscopic radical prostatectomy, robotic assisted laparoscopic radical prostatectomy and open radical prostatectomy? Are there outcome or results figures available to me?
- Why do you think this might be the best option for me?
- Is nerve sparing surgery an option for me?
- Could having a radical prostatectomy make me feel worse?
- Can you explain what the advantages and drawbacks and side-effects are likely to be? Are they likely to affect me in the short term or are they more likely to be longer term?
- In your unit, after having a radical prostatectomy, roughly how many men do you find have problems with incontinence and erectile dysfunction and for how long?
- How many laparoscopic/open prostatectomies has your team carried out?
- 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 where would I have the radical prostatectomy?
- How long will the operation last?
- When and how will we know whether the radical prostatectomy has been successful?
- What check-ups would I have and how often would I need checkups? What would be done at the check-ups: PSA, scan, etc?
- If the radical prostatectomy is not successful, then what would my options be?

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

### Radiotherapy for prostate cancer

Radiotherapy can be given in two ways and more information will be given on each of these.

- **External beam radiotherapy or EBRT**

High energy x-ray beams from outside the body are used to treat your prostate cancer. These are aimed at the prostate and very accurately target and kill the cancer cells inside the prostate. You will have EBRT at the hospital as an outpatient, so you won't need to stay in hospital.

For more information about EBRT, Prostate Scotland has a booklet '*Spotlight on External Beam Radiotherapy for Prostate Cancer*'. This is available on our website. For a copy to be sent to you call us or email [info@prostatescotland.org.uk](mailto:info@prostatescotland.org.uk).

- **Brachytherapy**

This means that small metal 'seeds', smaller than an uncooked grain of rice, are inserted into the prostate. These emit radiation which kills the cancer cells in the prostate. (Please see pages 68 to 76 for further information on brachytherapy.)

For more information about brachytherapy, Prostate Scotland also has a booklet '*Spotlight on Prostate brachytherapy*'. This is available on our website. For a copy to be sent to you call us or email [info@prostatescotland.org.uk](mailto:info@prostatescotland.org.uk)

(The information that follows about radiotherapy for prostate cancer is meant as general guidance. As procedures may vary from hospital to hospital, ask for more advice from staff at the hospital you are attending. If you have been given specific guidance by the hospital, then it is important that you follow their instructions. Please also be aware that you will have treatments tailored to suit your specific needs; your treatment may be slightly different to that of another patient with a similar diagnosis.)

### What is EBRT?

A special machine called a linear accelerator produces high energy x-ray beams which are then very carefully and accurately aimed at the prostate. The treatment can also cover a small area around the gland, including the seminal vesicles, in case the cancer has spread to these areas. The beam is shaped by the use of multi-leaf collimators within the head of the linear accelerator to shape the beam to conform to the target shape. The x-ray beam is shaped to conform to the shape of your anatomy and surrounding area (prostate, bladder, back passage, hips) so the prostate can be accurately targeted and reduce the dose to the healthy surrounding normal tissues of the bladder and bowel. These beams kill the cancer cells inside the prostate.

### When might this be suggested?

- As a primary/main treatment when the cancer is contained in the prostate and has not spread (metastasised) to other parts of their body;
- As a treatment, after a period of active surveillance if there are signs of the cancer growing;
- For men with low, intermediate and high-risk prostate cancer or prognostic grade groups 1-5;
- For men who are expected to live for at least 10 years;
- External beam radiotherapy can sometimes be used together with hormone therapy. In this case, radiotherapy usually starts anywhere between 3-8 months after hormone therapy. For men with high risk prostate cancer, prognostic grade group 4/5, hormone therapy may be continued after radiotherapy.

### What happens?

Some men may be given hormone treatment for several months before radiotherapy treatment with the aim of shrinking the cancer so that radiotherapy has a higher/better chance of working. For men having EBRT who have high-risk prostate cancer, prognostic grade group 4/5, hormone therapy is continued after

radiotherapy for up to 2-3 years as it has been shown to reduce recurrence rates and improve survival.

Ask your oncologist for more information as to whether you might have hormone therapy.

Before starting radiotherapy, your treatments need to be planned carefully and this may take a few weeks. This is to find out the exact position of your prostate and to make sure that the same area is treated each time.

In some centres, gold marker (fiducial) seeds/markers may be inserted into the prostate gland any time prior to or just before the planning scan (this is done in similar way to having a TRUS biopsy). These seeds/markers are not radioactive but are used to ensure that the radiotherapy beams are very accurately targeted at the prostate gland and minimise the dose to the bowel and bladder.

Prior to radiotherapy starting, you will have an appointment for a special CT planning scan. The CT scanner is a special type of x-ray machine that takes many detailed pictures of different views inside your body.

- In some hospitals, you may have an enema to clear your bowel before your CT planning scan;
- You will lie on your back on the scanner bed and the radiographers will get you into the correct position. This is also the position you will lie in to have your future radiotherapy treatments;
- To make sure the same area is treated every time, the radiographer will make a number of pinpoint dots on your skin. So these tiny marks don't wash off, they will be 'tattooed' onto your skin;
- The bed will move through the scanner taking special pictures of your pelvic area;
- The CT scan is downloaded into a special computer and the oncologist (doctor treating the cancer) will identify the area to be treated;
- The oncologist will plan your treatment timetable and how much radiation to use – that is the dose of radiation you will have. The exact dose will depend on the size and type of your cancer and your general health.

**Please also be aware that as your treatments will be tailored to suit your specific needs, your treatment may be slightly different to that of another patient with a similar diagnosis.**

### Radiotherapy simulator

You might need to visit a radiotherapy simulator which takes more x-rays. This is to check that the oncologist is happy with your position and that the treatment plan is correct.

The treatment is different for everyone.

- You will usually have radiotherapy treatment every day, Monday to Friday, for between 4-8 weeks as an outpatient;
- 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, but the cancer cells don't recover so easily. As each dose of radiation causes a little more damage to the cancer cells, it is important to attend all your appointments;
- In some hospitals, you may have an enema before your first 7-10 treatments;
- Radiographers give the radiotherapy treatments. You will lie down on the bed and the radiographer will make sure that you are in the correct position, perhaps using rests and supports;
- Once everything is ready, the radiographer will go into another room and turn on the machine. Although you will be on your own, the radiographer will still be able to see you and talk to you;
- You will hear a ticking noise as the machine moves around, perhaps into three or four different positions;
- You can breathe normally, but it is important to lie very still;
- While you may be in hospital for up to an hour, the treatment only lasts about 10-15 minutes. The machine is only on for about 5 minutes. The rest of the time is taken in making sure that you are in the correct position;
- This treatment doesn't make you radioactive, so it's safe to go home and be with other people.

### Will I have an anaesthetic?

No. The treatment is like having an x-ray. You can't see the radiation and it doesn't feel hot or cold. You shouldn't feel any soreness from the radiation treatment.

### Are there any potential side effects?

While the treatment itself doesn't hurt, it may have some troublesome side-effects. However, people react differently to the treatment. The type and how

severe your side-effects are has nothing to do with whether your treatment is working or not.

**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 medications, if necessary, and usually settle by 6 weeks after your treatment has finished.

**Potential short-term side effects**

• **Feeling tired and having little energy.**

During radiotherapy your body uses a lot of energy dealing with the effects of radiation on normal cells. Most people will be able to carry on with their usual daily activities and some people carry on working. Feelings of tiredness can build up over the course of treatments but should go away gradually when the treatment finishes.

• **Symptoms when passing urine**

Because the bladder lies close to the prostate it may become irritated or inflamed because of the treatment you may notice that:

- You need to pass urine more often;
- You need to pass urine in more of a hurry;
- You need to pass urine more often during the night;
- You have a burning feeling when passing urine.

• **Bowel symptoms**

Because the bowel lies close to the prostate and may become irritated or inflamed because of the treatment you may notice that:

- You need to open your bowels more often and motions may be looser;
- You have a feeling of urgency to open your bowels;
- You might have cramps in your lower tummy and pass a lot of wind;
- You have blood in your motions. If this happens you need to let the doctor know.

• **Proctitis**

Proctitis is an inflammation of the lining of the rectum and may be troublesome towards the end of and for 4-6 weeks after your treatment has finished. You may notice:

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

• **Skin problems**

You may find that the skin between your legs will briefly become red and sore, a bit like sunburn. Ask the doctor what can be done for this.

• **Hair loss**

You will lose hair in the area of treatment and this may not grow back, but it will not cause you to lose the hair on your head.

**Long-term side-effects**

Most side-effects will settle down after your treatment has finished. For some men the side-effects can be more lasting. You can ask the doctors or CNS how these might affect you.

• **Bowel habit**

Some men find that their bowel habits will change permanently. It might be small changes like opening your bowels more often during the day, having a slightly looser bowel motion or passing more wind.

If you find that changes in your bowel habits are having a big effect on your life then speak to the doctors or CNS, especially if you have bleeding from your back passage.

• **Symptoms when passing urine**

You may find that you are passing urine more often or have difficulty in passing urine but you are less likely to have long-term urinary incontinence with EBRT compared with having your prostate removed with surgery. There are often ways to help with this and your oncologist or CNS will be able to give you more advice. You can find more information about urinary incontinence on page 82.



● **Difficulties with erections**

Difficulties in getting and keeping erections may occur in approximately 60% of men after radiotherapy. This is because the blood vessels and nerves needed to get an erection can be damaged during the treatment. You may not notice this at first, as it happens gradually and can take up to 2 years before it becomes fully apparent. You can find more information on page 84.

For more information on erectile dysfunction, Prostate Scotland has a booklet '*Spotlight on Prostate conditions and erectile dysfunction*'. This is available on our website. For a copy to be sent to you call us or email [info@prostatescotland.org.uk](mailto:info@prostatescotland.org.uk)

**At home**

It may help if you:

- Save your energy by resting a bit more;
- 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 have some time off, work for fewer hours, 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 if you are not too tired;
- Have a healthy, well-balanced diet.

For more information, ask the doctors or CNS.

**How do I know if the treatment has worked?**

After you have had radiotherapy, the doctor will want to see how you are with regular check-ups. Your PSA level will be measured. After radiotherapy, your PSA will drop slowly and reach its lowest level about 1-2 years afterwards. This is because there are still some normal prostate cells making PSA. If the PSA level rises again, the doctor may want to do some more tests.

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

Advantages	Drawbacks
<p>EBRT is non-invasive. It does not require a general anaesthetic.</p> <p>Offers cure rates (if cancer is low-risk) comparable to the results with surgery and brachytherapy, taking into account the relative aggressiveness of cancers.</p> <p>For higher risk prostate cancer, i.e. T3 cancers, this is the most established treatment and is usually combined with hormone treatment for between 3 months to 3 years.</p> <p>It is less invasive than surgery or brachytherapy.</p>	<p>If there is local recurrence in the prostate despite radiotherapy then salvage surgical treatment carries more potential side-effects such as incontinence and impotence and requires an experienced surgeon.</p> <p>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.</p> <p>For some men observation and delayed hormone therapy may be more appropriate.</p>
<p>Difficulties with getting and keeping erections are not as common as with surgery.</p> <p>Less likely to have long-term urinary incontinence.</p>	<p>It can have a delayed, but long-term, effect on getting and keeping erections.</p> <p>It can cause urinary symptoms such as frequency and urgency.</p> <p>It can cause inflammation of the rectum called proctitis leading to diarrhoea and urgency of bowel motion.</p>
<p>Treatment is painless and can be done as an outpatient. It is suitable for men of any age.</p> <p>Minimal or no time off work is possible and normal activities can usually be continued.</p>	<p>A small number of men have persistent symptoms including rectal bleeding after treatment that may need further treatment.</p> <p>It usually needs to be done 5 days a week for between 4-8 weeks although often appointments can be given to suit your other commitments.</p>
<p>It may also be suitable for men whose general health and fitness would rule out surgery.</p>	<p>The PSA level should continue to fall but can take some time to reach its lowest 'nadir' level. It is not possible to know how successful the treatment has been until after a period of follow up.</p> <p>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, bowel or skin and easily treated.</p> <p>EBRT is not recommended for men with inflammatory bowel disease.</p>

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

- Is radiotherapy a suitable option for me for me to think about?
- Is it available in my area?
- What do you expect the radiotherapy to do to the cancer?
- Could it cure my cancer?
- Would I need to have hormone therapy before the radiotherapy?
- Why do I need to take hormones?
- If I do, how long will this be for and what are the possible side-effects of the hormone treatment?
- Why do you think this might be the best option for me?
- Could having radiotherapy make me feel worse?
- Can you explain what the risks and side-effects are likely to be? Are these likely to affect me in the short-term or are they more likely to be longer term?
- In your unit, after having radiotherapy, 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 radiotherapy start?
- How often will I have the treatment and for how long?
- Where would I have the treatment?
- Is it ok for me to drive to and from having my treatment?
- When and how will we know whether the radiotherapy treatment has been successful?
- What check-ups would I have and how often would I need follow-up appointments?
- What would be done at the check-ups: PSA check, scan, etc?
- If radiotherapy is not successful then what would be my options? E.g. surgery, more radiotherapy, hormone treatment?
- Are there other suitable treatment choices that I could think about?
- Why would EBRT be better for me than a radical prostatectomy or brachytherapy?
- What is the outlook for me?
- Is there someone that I can talk to who has had the radiotherapy treatment that I am thinking about?

## What is prostate brachytherapy?

This is sometimes called LDR brachytherapy or low-dose rate brachytherapy or sometimes seed implants.

At the present time prostate brachytherapy is only undertaken in 2 centres in Scotland - Edinburgh and Glasgow. Patients elsewhere in Scotland deciding to have this treatment may have to travel to Edinburgh or Glasgow.

Brachytherapy is a method of delivering a kind of 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.

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 where the cancer cells are.

The seeds stay in the prostate, slowly giving out radiation for around 9 months, until they are no longer active. Because the seeds send out low level radiation, very little escapes from the prostate, so don't worry you won't be radioactive.

## When might this be suggested?

- When the cancer is small, contained within the prostate, and thought to be low or intermediate-risk or prognostic grade group 1, 2 or 3;
- When your Gleason score is below 8 or prognostic grade group 1, 2 or 3;
- When the prostate is measured and it is less than 50 cc. Sometimes, hormone treatment is used to shrink prostate glands that are between 50 and 70 cc, so brachytherapy can be used;
- For men who are expected to live for at least 10 years.
- When the PSA level is below 20 ng/ml;
- For men who have not had external beam radiotherapy (EBRT);
- For men who don't have severe problems when passing urine; in other words have a strong flow of urine;
- If you have previously had a transurethral resection of the prostate (TURP) then brachytherapy is a less suitable treatment option for you.

(The information that follows about prostate brachytherapy is meant as general guidance. As procedures may vary slightly from hospital to hospital, ask for more advice from staff at the hospital you are attending. If you have been given any specific guidance by the hospital then it is important that you follow their instructions.)

### What happens?

The amount of radiation, and the effect it has on the cancer cells, is decided by the number of seeds implanted (put into) into the prostate and by getting them into exactly the right place. This will vary from patient to patient. This is usually done in two stages. The two stages can be done separately, or may be done at the same time depending on which hospital you are attending.

In Edinburgh, the 2 stages are done on the same day using a single anaesthetic.

In Glasgow the 2 stages are done separately on different days.

#### • Stage 1

The planning stage. This measures the size and shape of the prostate. This information helps the specialist team work out and plan how many radiation seeds to use and where to put them. Each man will have an individual plan.

#### • Stage 2

An ultrasound probe will be put into your back passage to help the doctor see exactly where each needle is going.

Seed implants are inserted. About 20-35 very fine, hollow needles containing the radioactive seeds are pushed through the skin (perineum) behind your scrotum and in front of the back passage.

Between 60-120 seeds are used, 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 radioactive.

After the operation, if you have a lot of swelling you may be given an ice pack to place between your legs.

You will most likely find that a catheter has been put into your bladder while you were in theatre for your operation but it's usually removed once you are settled in the ward.

It is beneficial to drink lots of water, as this helps to flush out the bladder and reduce the risk of any blood clots.

You will be given antibiotics to help prevent any infection and it is essential to finish the full course.

You will most likely be given a medicine to help you pass urine.

### **Will I have an anaesthetic?**

Yes. 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.

### **Will I have to have hormone treatment before brachytherapy treatment?**

Some men may need hormone therapy. 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. Ask your oncologist if this might be a possibility for you.

### **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 doctor or CNS what usually happens in the hospital you are attending.

### Are there any side-effects?

#### • Discomfort

This is usually for a short time and it is caused by the needles going through the perineum into the prostate. Pain-killers will help with this. A warm bath may also help ease the discomfort.

#### • Problems passing urine

You may find passing urine causes some pain, have a slow stream when passing urine and you may need to pass small amounts of urine but much more often. These symptoms should settle after about 10-12 weeks. If you're concerned, contact your CNS. It's also quite common to see traces of blood in your urine for several days after your operation.

#### • Difficulties with erections

You may find that you have difficulty in getting and keeping erections. If this is the case then speak with your consultant 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. There is more information about erectile dysfunction on page 84.

### Getting home

You may not have any side-effects for the first few days. However, if you feel any discomfort you can take simple painkillers, such as paracetamol or ibuprofen, to help with this.

Remember to finish your full course of antibiotic tablets to prevent an infection after the implant.

You may be given a tablet (tamsulosin) to help make it easier for you to pass urine. This might continue for between 3-6 months.

### How you might feel:

In the first 2 or 3 days after the implant you may find:

- Tenderness over your bottom when you sit down;
- A small amount of blood in your urine which will possibly last a few days;
- Bruising underneath your scrotum and possibly going down your thighs, but this should disappear within a week or two.

**After 3 or 4 weeks you may find:**

- It is painful when you ejaculate;
- That you pass small amounts of urine, but much more often;
- Difficulties with getting and keeping an erection;
- That for the first few days, you should not do any heavy lifting or strenuous exercise;
- You can probably go back to your normal day-to-day activities in a few days.
- You can probably go back to work a few days afterwards as you usually recover quickly. If your job involves a lot of physical activity it might take slightly longer;
- You should not drive until 24 hours after the operation and some men wait for a few days before driving;
- For the first 2-3 months (or for 6 ejaculations) you should use a condom during intercourse in case you pass a seed;
- After 4-6 weeks you will most likely go back to the hospital to have a CT scan to check that the dose and position of the seeds were correct;
- To make sure that the treatment has worked, you will have a PSA blood test in about 3 months and then 3-6 monthly afterwards. The PSA level often gradually decreases over many years;
- Occasionally, at around 2 years, some men may experience 'bounce' or 'spike' in the PSA level. This doesn't necessarily mean that your treatment isn't working and your oncologist or CNS will most likely want to chat over why this might happen.

You may be asked to check your urine for a few weeks afterwards to look for any seeds in the toilet bowl which may have passed into your urine.

Please check with the CNS in your hospital to find out what to do with any seeds that you pass in your urine.

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.



Although this doesn't happen very often, if you have any of the following signs then you should get in touch with your GP or NHS 24:

- Your temperature goes up, you feel chills and are shivering;
- You can't pass urine;
- Your urine is very bloody or there are blood clots in your urine;
- You have difficulty in passing urine.

For more information, there is a booklet entitled '*Spotlight on Prostate Brachytherapy*'. This can be downloaded from our website [www.prostatescotland.org.uk](http://www.prostatescotland.org.uk) or email for a copy [info@prostatescotland.org.uk](mailto:info@prostatescotland.org.uk) or call us and a copy will be sent to you.

### **Your brachytherapy information card (BIC card)**

After your implant you will be given or sent an information card to carry and you should carry this card with you at all times. The card gives other doctors and nurses who may be treating you essential information that they need to know to keep them safe. You, the CNS or oncologist should fill in any blanks on the card with the information about your treatment. If you're not given a card, it may be 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 which gives details about your seed implants so you can confirm your treatment with security people.

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

Advantages	Drawbacks
<p>Offers cure rates for low and intermediate-risk disease equivalent to surgery and external beam radiation (EBRT).</p>	<p>If there is local recurrence in the prostate despite brachytherapy then salvage (potentially curative) treatment carries more potential side-effects such as incontinence and impotence. Salvage prostatectomy, which is not often performed, requires an experienced surgeon.</p> <p>Cryotherapy and HIFU are other options that can be considered. For some men observation and delayed hormone therapy may be more appropriate. There may be the possibility of a re-implant.</p>
<p>Short procedure under general anaesthetic with short hospital stay and catheter removed on the ward when the man wakes up.</p> <p>Minimal time off work and can continue normal activities.</p>	<p>Some discomfort when the implant is done and for a short period afterwards.</p>
<p>Very low risk of incontinence and reasonable chance of maintaining erections.</p>	<p>Not suitable for all men who have poor urinary function or a markedly enlarged prostate.</p> <p>Discomfort, frequency and urgency in passing urine until the radiation has died down. Rarely retention of urine requiring a catheter.</p> <p>Some difficulties with erections but treatments are available as with surgery. Infertility – although it has been known for pregnancies to occur following brachytherapy treatment.</p>
<p>Lower risk of bowel problems than with external beam radiation (EBRT).</p>	<p>From the evidence there appears to be a very low risk of secondary cancers from brachytherapy on its own and indeed it is very uncommon.</p>

Before choosing brachytherapy you may have some questions to ask your oncologist or CNS. A full list of possible questions is given below.

Think about what you would like to know, so perhaps you would need only to ask a few of these, or you may have questions of your own.

- Is brachytherapy a suitable option for me to think about? Is it available in my area?
- What do you expect the brachytherapy to do to the cancer? Could it cure my cancer?
- Would I need to have hormone therapy before the brachytherapy? If I do, how long will this be for and what are the side-effects of hormone therapy?
- Would I also need to have EBRT?
- Why do you think brachytherapy or brachytherapy and hormone therapy, might be the best option for me?
- Could having brachytherapy make me feel worse?
- Can you explain what the risks and side-effects are likely to be? Are these likely to affect me in the short term or are they more likely to be longer term?
- Because of the radiation, will it be safe for me to be around pregnant women and children?
- In your unit, after having 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?
- Why do you think this might be the best option for me?
- How does this treatment work?
- How do I have the treatment?
- Are the seeds put into the prostate only where the cancer is or do the seeds cover the whole prostate?
- When would I have the brachytherapy?
- Where would I have the treatment?
- How many times would I be in hospital and for how long?
- When and how will we know whether the brachytherapy treatment has been successful?

- What check-ups would I have and how often would I need check-ups?  
What would be done at the check-ups: PSA , scan, etc?
- If brachytherapy is not successful then what would my options be?
- Are there other suitable treatment choices that I could think about?
- Why would brachytherapy be better for me than a radical prostatectomy or EBRT?
- What is the outlook for me?
- Is there someone that I can talk to who has had the brachytherapy that I am thinking about?
- What happens if I go through airport security with these seeds in my prostate?

### **Hormone treatment**

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

Hormone treatment works by reducing the amount of testosterone in the body and as a result slows down the growth of the cancer or shrinks it.

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, and in some cases many years.

If you are considering having external beam radiotherapy or brachytherapy, you may be given hormone treatment 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 (particularly in higher-risk cancers such as a Gleason score of more than 8 or prognostic grade group 4 or 5) as it has been shown to reduce recurrence rates and improve survival.

(The information that follows about hormone therapy is meant as general guidance. As procedures may vary slightly from hospital to hospital, ask for more advice from staff at the hospital you are attending. If you have been given any specific guidance by the hospital then it is important that you follow their instructions.)

### What is it?

Hormone treatment can be given in two ways, by an injection or taking tablets. At the beginning, you will often have both.

#### • By injection

Testosterone production is switched off by having an injection. Depending on the injection used it may be administered just under the skin, usually in the tummy area, or into the buttock. The injection may be given once a month, once every 3 months or once every 6 months. You will most likely be given the injection by your GP or nurse at your local clinic.

#### • Tablets

By taking a tablet, testosterone can be blocked from going into the cancer cells. This may be given for a week or two before starting injections and may be continued for a week or so after your injections have started. A small number of men may be on tablets alone (monotherapy).

### What are the side-effects of hormone treatment?

Side-effects vary from person to person and can be similar to those experienced by women going through the menopause. Although you might not have all of these, the most common side-effects are:

#### • Loss of libido (lack of interest in having sexual intercourse)

Unfortunately this is a common side-effect for which there is no treatment.

#### • Erectile dysfunction (ED, sometimes called impotence)

Because hormone treatment works by switching off or blocking testosterone, not being able to get and keep an erection firm enough to have intercourse is a common side-effect. Speak to your oncologist or CNS for more help with ED as there are treatments that can help. There is more information on ED on page 84 of this booklet or our spotlight guide '*Prostate conditions and erectile dysfunction*'.

#### • Hot flushes of your face and neck and sweating

These are often one of the first and perhaps most common complaints from men on hormone therapy. 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. Let your oncologist or CNS know if these are troublesome as there are treatments to help.

- **Changes to your body shape**

Some men find that they gain weight especially around their middle. At the same time they may notice that they lose some muscle tissue.

To help with both of these difficulties, have a healthy well-balanced diet combined with some regular, resistance exercise such as going for a brisk walk, going swimming or using some light weights to exercise.

Some men may notice that their penis and testes become smaller.

- **Feeling sluggish, having no energy, fatigue or tiredness**

Taking some regular exercise can help with any feelings of tiredness. Perhaps when you have a bit more energy is the time to do any tasks or plan your day to take advantage of those times when you are perhaps feeling less tired.

- **Bone thinning**

Because bones need testosterone to keep them healthy and strong, over time hormone therapy can cause bones to thin or become weak so they may break more easily. Again taking some regular, resistance exercises may help. However, if this does not help there may be the option of medication.

- **Swelling and tenderness around the breast area (also called gynaecomastia)**

Hormone therapy can cause one or both breasts to swell, become tender and can cause nipple(s) to become sensitive. The amount of swelling can vary considerably and can vary as to how much it affects the man. There are treatments which can include a one off small dose of radiation, medications or surgery. Speak to the oncologist or CNS if this is a difficulty for you.

- **Mood swings – feeling upset or depressed**

Hormone therapy can make you much more emotional and you may get upset more easily and feel quite tearful. Again speak to your oncologist or CNS as it may

be possible to change your treatment. It may be helpful to go along to a support group to chat with other men and their families who have been in similar circumstances.

● **Hair loss**

You may notice that you lose hair on your arms, legs, underarms and genital area and you may not need to shave as often if you are on hormone therapy for a longer period of time.

● **Heart problems**

Some evidence suggests that if you are having hormone therapy for more than 6 months you may be more at risk of developing heart problems. Your doctors may want to keep a regular check on this.

If any of the side-effects listed above have an impact on your quality of life, let the oncologist or CNS know as there may be some treatments that they can give to help.

**Is there anything you can do to help yourself?**

Men on hormone therapy for prostate cancer are encouraged to be physically active and walk or exercise in order to help manage the side-effects, improve quality of life and their ability to cope with daily living activities. If you exercise regularly and continue to be physically active this might also provide you with long-term health benefits.

**Further information**

If you would like further information Prostate Scotland has a spotlight guide '*Hormone therapy for prostate cancer*' available to download or you can contact us and a copy will be sent to you.

**Questions that you may want to ask the oncologist or CNS**

Before starting on hormone therapy, you may have some questions to ask your oncologist or CNS. A full list of possible questions is given overleaf. Think about what you would like to know, so perhaps you would need only to ask a few of these, or you may have questions of your own.

- 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 had my other chosen treatment?
- Am I likely to have all or only some of the side-effects?
- What happens when the hormone treatment stops – would I continue to have the side-effects?
- What are the advantages of combining hormone therapy with radiotherapy or brachytherapy?
- Who would give me the hormone injections?

### Other treatments

There are some newer treatments for prostate cancer but these are still considered to be experimental. These treatments are not generally available in Scotland. If you would like to know more about them, ask the doctor in the team looking after your care.

These include:

- **High intensity focused ultrasound or HIFU**

This is a relatively new method which uses highly-focused ultrasound waves to kill the prostate cancer cells. It targets the whole of the prostate, not just the area of cancer. The focused ultrasound waves raise the temperature to about 100°C to kill the prostate cancer cells.

- **Cryotherapy**

This method uses freezing to kill the prostate cancer cells. A computer is used to carefully control the temperature, which will get as low as -140°C, to make sure that the urethra and back passage are not damaged by getting too cold.



At the present time, cryotherapy is only available if the cancer has not spread outside the prostate and if external beam radiotherapy or brachytherapy has not been successful and there is local tumour re-growth only. At the time of writing cryotherapy is only available in Scotland from the National Health Service at the Beatson Hospital in Glasgow.

- **High dose rate brachytherapy implant or HDR brachytherapy**

This means that very thin hollow tubes/needles are inserted into the prostate then carefully controlled amounts of radiation treatments are given. The tubes are easily withdrawn and no seeds are left in the prostate.

It is given in combination with 3-4 weeks of EBRT with 1-2 fractions of HDR to boost the radiation dose to the tumour. It is generally considered for men with high-risk prostate cancer.

The HDR needles are inserted into the prostate using the same technique as for LDR seeds under a general anaesthetic. The planning computer will then determine the time and position that the implant source spends within each needle to deliver the required dose. The needles are then connected to a machine that contains the brachytherapy source Iridium 125. The Iridium source travels from the machine into each needle in turn to deliver the required dose.

At the end of the treatment the source returns to its machine and no seeds remain in the body. The needles may remain in position within the prostate overnight if a second fraction of treatment is required and the process is repeated the next day. This treatment is currently not available in Scotland but it is hoped may be available in the future.

## Section 8

### Managing some of the potential side effects of the treatments

#### A brief summary of information in this section

- **Urinary incontinence**

This means that there may be difficulty in being able to hold urine inside the

bladder and some urine may leak or dribble out. It can be caused as a result of some of the treatments for prostate cancer and can last for different lengths of time. Doing pelvic floor exercises before and after treatment can help regain control over the bladder. A specialist physiotherapist or nurse who specialises in urology can give advice on pelvic floor exercises.

- **Erectile dysfunction (ED)**

When a man has trouble getting or keeping an erection firm enough to have intercourse it is called erectile dysfunction or sometimes impotence. This can often be one of the side-effects of some of the treatments for prostate cancer. ED depends on many factors and the effect will vary from man to man. There are various treatments available to help overcome this; through medications taken as a tablet, by injection, applicator, cream or vacuum pumps.

## 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 or dribbling out when you cough, laugh, get up from a sitting position or when walking. This is called stress incontinence.

Although some men feel embarrassed by this, it is usually managed by using incontinence pads and should start to get better as the wounds begin to heal.

In fact, after prostate cancer surgery most men will have some incontinence for varying amounts of time, but the majority will have recovered within a year. Some men are able to control their bladder within a few days or weeks, whilst others take some months after their operation to recover. However, there is no way to forecast how long this will take for you, as it varies from person to person. Generally, recovery is faster the younger, slimmer and fitter you are. Doing pelvic floor exercises before and after treatments can also help greatly with incontinence.

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

### Until you are able to control your bladder

To help with leakage or dribbling, you can wear an absorbent pad inside your underwear and there are many different kinds of pads available. These are designed to lock away urine so they can stop any leaks onto your clothes, help prevent any smell and to keep you dry. Knowing that these can prevent any embarrassing accidents may make you feel better and give you more confidence to carry on with your day-to-day activities. Ask the CNS or nurse in the ward for more information and about how you obtain these.

- Limit alcohol and caffeine intake (caffeine is found in tea, green tea, coffee, cola type drinks and energy drinks);
- It's best to drink about 6-8 glasses or mugs or 8-10 cups 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 it worse not better;
- Empty your bladder before bedtime or before any vigorous activity;
- Losing weight may help improve bladder control.

### 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 get up from sitting down, or when you cough, sneeze or laugh. It may take you some time to reach step 3, as this is the final part of being in full control of your bladder.

### Pelvic floor muscles and pelvic floor 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.

After a radical prostatectomy and assuming minimal nerve damage, muscles need to be trained to: contract, relax, have endurance and strength. 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 customised programme of pelvic floor exercises can be provided by an experienced specialist physiotherapist 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.

Some words of advice:

- It may take up to 3-6 months for you to be able to control your bladder and you may find it goes on improving for up to a year.
- Some people think that they can speed up the process by doing more exercises, more often during the day. However, over-exercising the muscles can lead to the muscles becoming fatigued and can slow the recovery process. Please contact your local physiotherapy department or POGP (Pelvic, Obstetric and Gynaecological Physiotherapy), [www.pogp.csp.org.uk](http://www.pogp.csp.org.uk), for details of specialist physiotherapists in your area.

For more information on pelvic floor exercises there is a booklet entitled *'Spotlight on Pelvic Floor Exercises for men'* available to download from our website [www.prostatescotland.org.uk](http://www.prostatescotland.org.uk) or email [info@prostatescotland.org.uk](mailto:info@prostatescotland.org.uk) or call us and a copy will be sent to you.

For more information on incontinence, there is a booklet entitled *'Spotlight on Incontinence as a symptom of prostate problems'* available to download from our website [www.prostatescotland.org.uk](http://www.prostatescotland.org.uk) or email [info@prostatescotland.org.uk](mailto:info@prostatescotland.org.uk) or call us and a copy will be sent to you.

### **Erectile dysfunction (ED)**

When a man has trouble getting or keeping an erection firm enough to have intercourse, it is called erectile dysfunction or sometimes impotence. Not being able to have an erection can affect men at different ages and stages in their life and for different reasons.

Whilst you (and your partner) may be upset and worried about this, there are now many things that can be done to help.

A few things which may affect your erection:

- After surgery to remove your prostate, your body needs time to heal, with a gradual recovery of erections, which may in fact take a few years. Indeed, it is common not to have an erection in the first six or nine months after surgery and it may take up to 18-24 months before you can have a natural erection;
- If you have external beam radiotherapy, 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 with brachytherapy;
- Your age. Men under 60 tend to have better quality erections before surgery and, therefore, are more likely to recover erections after surgery;
- It can also depend on:
  - How good or firm your erection was before your operation;
  - How sexually active you were before your operation;
  - Whether the surgeon was able to save the nerves (called nerve sparing surgery) that lie very close to the prostate and which are responsible for erections.

### What does nerve sparing mean?

You don't need your prostate to have an erection. However, it lies close to nerve bundles and blood vessels that are needed for a man to have a normal, natural erection.

For some men, to make sure that all the cancer is removed during their radical prostatectomy, 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 you can get an erection by injections into the penis or by using a vacuum pump.

For other men, it is possible to save the nerves, and around 50-80 men out of 100 will get back the normal erection function they had before surgery – but it may take up to 2 years to fully recover.

### What can be done to help with this?

If you experience difficulties with erections, tell your doctor who may be

able to suggest something to help you with this.

Many doctors now think that after surgery, the sooner you start having stimulation or trying to have intercourse may actually improve the chances of having the same kind of erection as you did before your operation. Touching, caressing, holding and massage can help. So, there is no need to wait to have a 'full' erection before trying to have intercourse. A lot of evidence now shows that introducing treatment for ED early after the operation may improve your chance of regaining erections.

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

### **Medication to be taken by mouth**

Pills that can help include sildenafil, vardenafil, tadalafil. These work by increasing the blood flow to the penis to help you have an erection and work best if the nerves are still intact.

Possible side-effects are 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.

### **Medication which is injected**

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

It usually takes about 5-10 minutes to get an erection and it lasts for between half an hour to an hour and will go on even after orgasm.

Possible side-effects are a painful, long-lasting erection, bruising, mild pain in the penis, scar tissue on the area where you have the injection.

### **MUSE - medication by an applicator**

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

a small pellet of medicine, which is the same as that used in the injection discussed above. The tube is gently put into the urethra inside the penis. By pressing a button on the applicator, the small pellet is released and taken into the tissues which give erections. An erection develops in about 10 minutes and lasts for at least 30 minutes.

Some side-effects may include a painful, long-lasting erection, some pain, mild injury to the urethra. It may cause some irritation for a small number of women.

With all medications, if your erection lasts for more than 3 hours then you should contact your GP. This could damage tissues inside your penis.

### **Vitaros cream**

The clinician or CNS may prescribe Vitaros Cream® and will give instructions on the amount to use, how to use the cream and how often this cream can be used. An erection should develop within about 5-30 minutes of applying the cream.

After washing your hands, you can open the sachet which has a single use syringe-like device inside. The cap should be removed and the tip of the device is placed on the tip/opening of the penis. You can then press the plunger so the cream is squeezed out into the opening of the penis and the area around the tip of your penis. You must not insert the tip of the container into the opening of your penis. Hold the penis upright for about 30 seconds to allow the cream to run into the opening of the penis. Any extra cream can be gently rubbed into the skin around the top of the penis. Replace the cap on the container, put into the sachet and these can be thrown out. Wash your hands carefully as Vitaros can sting the eyes.

Some of the possible side-effects include dizziness or mild to moderate local aching, burning or pain and redness of the penis, rash or itching. To prevent your wife/partner experiencing any side-effects such as mild vaginal burning or itching, you should wear a condom.

### **Vacuum pumps**

If injections, cream or tablets haven't helped, or if you prefer another option, then you can try a vacuum pump. This works by suction drawing blood into the penis. A rigid tube is placed over the penis and sealed. A pump helps make a vacuum which forces blood to flow 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.

There is now a newer treatment called shock wave therapy for ED but it is not available through the NHS in Scotland.

### **What might be best for me?**

As treatments will vary from man to man, ED is treated according to what suits the man best. So once you've been diagnosed with ED, the urologist looking after you will advise on the most suitable treatment, taking into account your wishes.

### **After radical prostatectomy**

#### **• Infertility**

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

#### **• Dry ejaculation or orgasm**

Because your prostate, vas deferens and seminal vesicles will have been removed, you will not produce any semen. So, although you will feel the same spasms and pleasure that accompany an orgasm, you will not ejaculate. Some men worry about the effect this will have on their partner, but for most partners this is not a problem. Many men find that the sensation of orgasm may be changed or different.

It is, however, common to leak a little urine instead as the muscles relax at the point of orgasm.

For more information on erectile dysfunction, there is a booklet entitled '*Spotlight on Prostate conditions and erectile dysfunction*' available to download from our website [www.prostatescotland.org.uk](http://www.prostatescotland.org.uk) or email [info@prostatescotland.org.uk](mailto:info@prostatescotland.org.uk) or call us and a copy will be sent to you.



### Post treatment recovery clinics

There are usually some side-effects from the treatments for prostate cancer, whether this is for a short time or over a longer period of time. For some men, these side-effects can affect their quality of life. As a way to help men and their families, some clinicians in certain hospitals have set up after treatment recovery clinics. The services and the way these clinics work will most likely vary depending on which hospital that you attend. Please ask your consultant or CNS if this is perhaps a service available in your area.

## Section 9

### Deciding on treatment: a step on your journey

#### A brief summary of information in this section

- It is important to take time to make the decision that is right for you. Make sure that you have accurate and relevant information to help you make this decision.
- In making this decision it is important to include members of your family, the multi-disciplinary team who are involved with your care and, if you are comfortable with it, talking over your situation with men (and their families) from a prostate cancer support group who have been in a similar situation.
- There are some tips included on how to get the most out of your consultation with the doctors and specialist nurses and some questions you might want to ask.

It is recommended that you spend some time thinking about what is right for you when deciding on treatment for your prostate cancer. Prostate cancer is generally slow-growing, giving men and their families plenty of time to make the decision. It's easy to understand why some men want to know what will cure their cancer fastest and then to 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 making such an important decision too quickly. Try looking at the videos and information about treatment options on the Prostate Scotland website too.

### Who can I talk to?

- Members of the multi-disciplinary team (MDT) from the hospital who are looking after you – consultant urologist, consultant oncologist and specialist nurses in cancer or urology;
- Your GP;
- Your partner;
- Your family and friends;
- A prostate cancer support group whose members have experienced prostate cancer.

Deciding on the best treatment for you isn't always easy or clear-cut. The multi-disciplinary team will think about the 'risk' to you from your prostate cancer and will recommend or offer you the treatments they think may be best for you.

They reach their decision by taking into account:

- Your general health;
- The grade of your prostate cancer;
- The size and position of the cancer within the prostate;
- Whether the cancer has spread outside, or is likely to spread outside, the prostate;
- Your PSA level;
- The possible side effects of the treatment and how they will affect you;
- Your views on how much the side effects will affect your life and relationships and if you could live with the side-effects;
- How old you are.

### What do you need to think about to make the decision?

1. You need to know how much your cancer is a threat to your health now and how it might affect your health and wellbeing in the future.
2. Your doctor or multi-disciplinary team will explain to you which treatment

choices are available and suitable for you. Make a list of these choices. Then write down what you like and what you don't like about each one. Then think about how important each of these points is to you and how important they might be to your family. There is a leaflet included with this booklet which may help you to reach a decision. It is called, '*Deciding on treatment: a step on your journey*'. While you are working this out, it may be worthwhile to ask someone else to help you e.g. the specialist nurse or speaking to someone on a telephone helpline or someone from a prostate cancer support group.

3. Many men and their partners find it helpful to meet the urology surgeon and oncologist to talk over the treatment choices.
4. Look over the advantages and drawbacks for each treatment again. They are given at the end of the section on active surveillance page 43, radical prostatectomy page 57, radiotherapy page 66 and brachytherapy page 74.
5. Look over the list of questions, too, that are given at the end of each section. You might want to ask your doctor some of these.
6. If you are recommended only one choice, you can ask why other treatment choices are not suitable for you.
7. Make sure you know and fully understand what the side effects of each treatment are likely to be and think about how this will affect all aspects 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.
8. Find out more about the treatment choices yourself by speaking to others who have had the treatments. This will give you an idea of what actually happened in practice and how they felt. However, it is important to consider that different men will put different values on the possible outcomes of treatment. So, some things are more important to some men than others. It's important that you feel that you have made the best choice for you.

At the end of these steps you will probably have a better idea about:

- The type and amount of treatment you are advised to have;
- The advantages and drawbacks of each of the treatments;
- Any other treatments which may be available;
- The possible side effects and how these will affect your life.

## **Take your time to think carefully about the choices, then make the decision that you feel is right for you**

### **Tips on talking with the doctors, specialist nurses or multi-disciplinary team**

1. Being diagnosed with prostate cancer can stir up lots of strong feelings – fear, worry and anger. In all likelihood, it's not only you who will feel like this, it will affect your partner and family too. If you are struggling with this, speak to the staff in hospital or your GP about it.
2. Make a list of questions that you want to ask when you see the doctor, and take this with you to your appointment, as it is very easy to forget what you wanted to ask when you are sitting in with the doctor. This also ensures that you have asked everything you wanted to. You can jot down answers to your questions so that you can look back over them after your consultation. You could ask the doctor to write down any test results for you, as these will be important later on when he/she talks about your PSA level, Gleason score, prognostic grade group or staging of your cancer.
3. As there is often a lot of information to take in, it is usually very helpful if your partner, family member or friend sits in while you see the doctor, as they can also ask questions, take notes or just listen. Then you can talk this over with them after your consultation. Tell the clinic staff, specialist nurse or doctor that you would like someone to sit in with you.
4. If you don't understand what you've been told, let the nurse or doctor know right away so they can explain it again. Your diagnosis, tests, test results, treatment choices and side effects are not always easy to understand, so lots of people need another explanation and more time to take it all in.
5. You might feel that the doctors and nurses are too busy to answer your

questions, but it's important that you are clued up on what will happen now and when treatment has started. You can ask for more time to think about your decision and don't feel you need to make your decision in too much of a hurry.

6. If you think it will help, ask if you can audio-record the consultation so that you can listen to the conversation as many times as you want in the comfort of your own home, where you may be feeling less stressed. You can buy a digital audio-recorder or dictaphone from most electronic stores. This might also help you to write down any questions that you want to ask the doctor or specialist nurse next time. In some hospitals the doctor or CNS may offer you an audio-recording of your consultation.
7. You can tell the doctor or nurse from the start how much you would like to take part in making the decision about your treatment.

For example:

- If you would like to take control of the decision;
  - If you would like the doctor/nurse to make a recommendation/make a decision for you;
  - If you would feel comfortable making a decision together with your doctors.
8. Keep in mind what worries you and what is important to you.

**Reaching a decision on how you want to treat your prostate cancer is very personal. It's a mixture of what is important to you, what you value the most, which treatment choices are available for you, what the side effects are, what the benefits are and how it will affect your quality of life. You will most likely feel more satisfied and more confident with the treatment if you have had a say in reaching a decision that is consistent with your own personal preferences and values.**

## Section 10

### Understanding locally-advanced prostate cancer

Some men will have been told from the outset by the consultant or CNS that they have been diagnosed with 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 they may be offered by their urologist or oncologist.

There is more information in the earlier sections of this booklet about the prostate, prostate cancer, tests, investigations and treatments. At the back of this section, there is a handy chart of where you will find the information you may want or need in 'Early Prostate Cancer Explained'. At the end of each section there is a list of additional Prostate Scotland booklets that may be helpful in understanding the treatment that you have been offered.

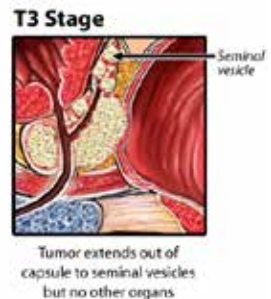
#### What is locally-advanced prostate cancer?

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

#### How has this been diagnosed?

You will have had some, or perhaps all, of the following tests and investigations to help the doctors decide what type of prostate cancer you have:

- PSA test;
- Digital rectal examination (DRE);
- Prostate biopsy;
- MRI or CT scans;
- Bone scans;
- X-ray (an x-ray may be done to check out normal wear and tear on bone and joints).



### **What might the results of the tests mean for me?**

Once the urologist, oncologist and multi-disciplinary team have all your test results, a number of issues will be taken into account before deciding which treatment(s) may be most suitable for you. They do this by looking at:

- i. Your prognostic grade group or Gleason score. This looks at how fast the cells are dividing and what they look like under the microscope;
- ii. The stage of your cancer;
- iii. Your PSA blood level;
- iv. How old you are and how much your symptoms are troubling you;
- v. Whether you have any other medical conditions affecting your health;
- vi. If the side effects of the treatment would have greater impact on your quality of life than the effect of the cancer.

### **How is locally advanced cancer treated?**

#### **• Hormone therapy or treatment**

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 ‘switches off’ or 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.

Hormone therapy can be used as:

- A treatment on its own;
- Before having radiotherapy (called neo-adjuvant therapy);
- After radiotherapy (called adjuvant therapy).

Hormone therapy can be given in two ways; by injection or taking tablets. At the beginning you will often have both.

### By injection

Testosterone production is switched off by having an injection. Depending on the injection used it may be administered just under the skin, usually in the tummy area, or into the buttock. The injection may be given once a month, once every 3 months or once every 6 months. You will most likely be given the injection by your GP or nurse at your local clinic.

### Tablets

By taking a tablet, testosterone can be blocked from going into the cancer cells. This may be given for a week or two before starting injections and may be continued for a week or so after your injections have started. A small number of men may be on tablets alone (monotherapy).

Because hormone therapy blocks testosterone, there will be some side-effects including: not being able to get and keep an erection, lack of sexual desire, hot flushes, heart problems, changes in your mood, thinning of the bones and breast swelling or tenderness.

If any of these side-effects have an impact on your quality of life, let the oncologist or CNS know as there may be some treatments that they can give to help.

More information on hormone therapy can be found earlier in this booklet on page 76 or in:

- *Spotlight on Hormone therapy for prostate cancer*
- *Spotlight on Prostate conditions and erectile dysfunction*

### External beam radiotherapy (EBRT)

EBRT can be used to treat locally advanced prostate cancer using high energy x-ray beams from a special machine called a linear accelerator. The beams are accurately shaped to your body frame and pelvis. The beams are then very carefully and accurately aimed at 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.

Some men may be given hormone treatment for several months before radiotherapy treatment with the aim of shrinking the cancer so that



radiotherapy has a higher/better chance of working and this may continue after radiotherapy treatment.

Before starting EBRT, the oncologist will plan what the best treatment is in your circumstances; this is to damage the cancer cells while healthy cells remain as healthy as possible. Treatment will not start right away and your treatment may be completely different from somebody else with the same or similar diagnosis.

Once all the planning has been done to show the position of your prostate and the position of the tumour(s), your treatment can begin. Treatment is usually given over 5 days a week for around 4-8 weeks. You may hear treatments called fractions. Although each treatment won't take very long, you will need lie very still and stay in the same position.

Because EBRT can affect healthy cells too, there will most likely be some side-effects; feelings of tiredness, problems when passing urine, bowel symptoms, redness of the skin around the treatment area, difficulties with erections.

If any of these side-effects have an impact on your quality of life, let the oncologist or CNS know as there may be some treatments that they can give to help.

More information about EBRT can be found earlier in this booklet on page 60. Other booklets that you may find useful include:

- *Spotlight on External beam radiotherapy for prostate cancer*
- *Spotlight on Incontinence as a symptom of prostate problems*
- *Spotlight on Prostate conditions and erectile dysfunction*

#### ● **Watchful waiting**

If the man is not fit enough or has other health problems then radical treatment is not an option and your urologist may suggest 'watchful waiting' for some men with locally advanced prostate cancer. It's a way of keeping a careful check on the cancer through monitoring or watching what is happening with it. Watching and waiting might be suitable if your cancer is not causing any symptoms or problems right now or if other treatments aren't suitable for you because of additional health problems. Usually it will

mean checking your PSA level and possibly having a digital rectal examination from time to time. This might be done by your GP, CNS or urologist.

If they notice any changes or if you start having other symptoms, then the urologist or CNS will chat with you about starting hormone therapy.

### **Surgery to remove the prostate**

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. A radical prostatectomy is usually done as a laparoscopic procedure (keyhole surgery) or a robotically assisted laparoscopic procedure or less commonly now by open operation.

More information about radical prostatectomy can be found earlier in this booklet on page 45. Other booklets that you may find useful include:

- *Spotlight on Surgery for prostate cancer: Minimal access radical prostatectomy*

### **Trans-urethral resection of the prostate (TURP)**

A TURP is completely different from the radical prostatectomy mentioned above. The purpose of a TURP is not to remove the prostate and is not a cure for prostate cancer. It is surgery to help ease one of the potential side-effects of locally advanced prostate cancer.

A Trans-urethral resection of the prostate (TURP) is done when part of the tumour in your prostate is blocking or squeezing on the urethra making it narrower, and this can cause difficulties passing urine. (The urethra is the tube that runs through the prostate taking urine from the bladder outside the body).

To help deal with this blockage or narrowing the doctor may suggest that you have a TURP. Although this operation doesn't take the prostate or the tumour(s) out (and it can't get rid of all the cancer cells), it 'trims off' the part of the tumour pressing on the urethra which may make it easier for you to pass urine. It is also a fairly common operation for men who have an enlarged prostate.

If this is an option there is more information about TURP in our booklet:

- *Spotlight on treatment for an enlarged prostate*

The following topics are mentioned in this section. To refresh your memory, more details can be found earlier in this booklet and the page number is given below.

<b>Topic</b>	<b>Page</b>
PSA blood test	15
Digital rectal examination DRE	16
Prostate biopsy	17
Prognostic grade group/ Gleason score	25
Staging	27
MRI scan (Magnetic Resonance Imaging)	32
CT scan or CAT scan (Computerised Tomography)	33
Radical prostatectomy	45
External Beam Radiotherapy (EBRT)	60
Brachytherapy	68
Hormone therapy	76
Incontinence	82
Erectile dysfunction ED	84
Making decisions about treatment	89

**Additional Prostate Scotland booklets that you might find helpful:**

- Spotlight on Hormone therapy for prostate cancer*
- Spotlight on External beam radiotherapy for prostate cancer*
- Spotlight on Surgery for prostate cancer; Minimal access radical prostatectomy*
- Spotlight on Treatment for an enlarged prostate*
- Spotlight on Incontinence as a symptom of prostate problems*
- Spotlight on Prostate conditions and erectile dysfunction*
- Spotlight on Prostate brachytherapy*

## What the medical words in our booklets mean

### A

Abiraterone or Abiraterone acetate	Since October 2015, Abiraterone is now available via the NHS in Scotland for men with advanced prostate cancer where the cancer has spread and become resistant to hormone therapy.  This means that Abiraterone can now be prescribed, depending on clinical need, <b>before</b> the man starts chemotherapy or <b>after</b> a course of chemotherapy.
Active Surveillance	This means actively monitoring the cancer through regular check-ups, PSA tests, DRE and possible biopsies.
Adrenal glands	There are two adrenal glands just above the kidneys; they produce a variety of different hormones.
Advanced prostate cancer	When cancer cells have broken through the prostate capsule and have spread away from the prostate and start to grow at other sites.
Aggressive	A greater chance of the cancer growing quickly and spreading out of the prostate.
Anaesthetic	A general anaesthetic means being put to sleep during an operation.
Anaemia	The haemoglobin level in the blood falls below the normal level. Symptoms may include fatigue, weakness and difficulty in breathing.
Analgesic	A drug that helps with pain.
Androgens	Male hormones responsible for male characteristics, e.g. testosterone.
Androgen deprivation therapy	A prostate cancer treatment that stops or blocks androgens to the prostate cancer cells.
Anti-androgens	Medications that block the testosterone receptor.

Anti-emetics	A medicine that prevents sickness or helps with being sick.
<b>B</b>	
Biopsy	Taking tiny pieces of tissue from the prostate to look at them under a microscope.
Bisphosphonates	Drugs that can help protect bones against some of the effects of prostate cancer. At the time of writing (April 2016) these were only available only as part of a clinical trial.
Bladder	The organ sitting just above the prostate which holds urine.
Bone scan	A very small amount of radioactive material is injected then a special scan is done to find out if the cancer has spread to the bones.
Brachytherapy	A type of radiotherapy where tiny metal seeds which emit radiation are placed in the prostate to kill cancer cells.
<b>C</b>	
Cancer	Cells grow faster than normal and cause a growth called a tumour.
Cancer cells	Cells that grow and multiply abnormally and can spread to other parts of the body.
Cancer journey	The time from when your cancer is diagnosed through to treatment and check-ups.
Cannula	A small tube which has a needle on the end. The needle is inserted into a vein in your arm or the back of your hand, which can be connected up to a drip.
Catheter	A thin flexible tube which drains urine from the bladder into a bag.
Chemotherapy	Treatment with drugs intended to kill cancer cells.

Combination therapy	When a doctor suggests combining treatments for maximum effect, such as radiation therapy combined with hormonal therapy or LHRH agonist combined with an antiandrogen.
Complete androgen blockade	Therapy used to eliminate male sex hormones (androgens) in the body. This may be done with surgery, hormonal therapy, or a combination.
Consent form	A form you will be asked to sign to confirm that you are willing to go ahead with treatment, tests or examinations.
Constipation	Unable to open the bowels.
Continuous hormone therapy	Hormone therapy which continues with no breaks.
CT simulator	A special type of x-ray machine.
Cryotherapy	Freezing to kill the cancer cells.
Cystogram	An x-ray of the bladder.
Computerised tomography (CT or CAT scan)	Special x-ray equipment combined with advanced computers to take many pictures of lots of different views inside the body.

## D

Diagnose	Identify a disease by its signs and symptoms and then confirm with tests.
Digital rectal examination (DRE)	The doctor inserts a gloved finger into the back passage to examine the prostate gland for signs of disease.
Dry orgasm	During orgasm ejaculate does not come out of the penis.

## E

Early or localised prostate cancer	The cancer has stayed inside the prostate and has not spread to other parts of the body.
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Ejaculate	The fluid that is released at orgasm.
Enema	A capsule or fluid that is put into the bowel to clear the bowel out before a procedure.
Enzalutamide	Enzalutamide is now available via the NHS in Scotland for men with advanced prostate cancer where the cancer has spread and become resistant to hormone therapy. This means that Enzalutamide can now be prescribed, depending on clinical need, <b>before</b> the man starts chemotherapy or <b>after</b> a course of chemotherapy.
Epidural anaesthetic	A local anaesthetic injected into the spine which causes numbness from the waist down.
Erectile dysfunction (ED) or impotence	When a man has trouble getting or keeping an erection.
External beam radiotherapy (EBRT)	High energy x-ray beams from outside the body to kill cancer cells.
<b>F</b>	
Fatigue	Extreme tiredness.
First (1st) line treatment	The treatment or drug given as the first or main treatment.
Fistula	An abnormal opening or passageway between two organs in the body.
Flare reaction	The short-lived increase in testosterone for the first few weeks after starting an LHRH agonist.
Fraction	A small daily dose of radiation to kill the cancer cells.
Frequency	Needing to pass urine often.
<b>G</b>	
Gleason score	This is a number between 6 and 10 and gives an idea of how quickly the cancer is likely to grow and spread.

Gonadotrophin releasing hormone antagonists	Stop the testes making testosterone.
Gynaecomastia	Swelling or enlargement of the breast tissue.
<b>H</b>	
HDR brachytherapy	HDR (high dose radiation) given by a radioactive Iridium wire being placed into the prostate through flexible needles.
High intensity focused ultrasound (HIFU)	Highly focused ultrasound waves raise the focused temperature to about 100°C to kill the cancer cells.
High-risk prostate cancer	There is a greater risk of the cancer growing quickly and spreading outside the prostate.
Hormone therapy	The male hormone testosterone is switched off or stopped from going into the cancer cells.
Hot flushes	A rush of warmth in the face, neck, upper chest, and back, lasting from a few seconds up to an hour. This may be accompanied by increased sweating.
Hot spots	These may show up during a bone scan and are areas that take up a lot of radioactive material indicating there may be a tumour.
Hypercalcaemia	Abnormally high levels of calcium in the blood.
<b>I</b>	
Incision	Making a cut during surgery.
Incontinence	Unable to hold urine in the bladder.
Infertility	Not being able to produce sperm.
Infusion	Running a fluid containing medication into the body through a vein as treatment.
Intermediate-risk prostate cancer	There is an increased chance of the cancer prostate breaking out of the prostate and spreading to other parts of the body.



Intermittent hormone therapy	Hormone treatment that is given on a stop/start basis while checking on the PSA level.
Intravenous line (IV)	A drip, normally in your arm, to put fluids or drugs into the body.
Investigations	Tests and examinations done to find out what is wrong or to diagnose the disease.
<b>L</b>	
Laparoscopic radical prostatectomy	Keyhole surgery to take out the prostate.
Laxative	A medicine given to help you open your bowels or make it easier to open your bowels.
Libido	Desire to have sexual intercourse.
Linear accelerator	A special machine that produces high-energy x-ray beams.
Locally advanced prostate cancer	The cancer has spread just outside the prostate through the capsule or into seminal vesicles.
Low-risk prostate cancer	The cancer is likely to remain inside the prostate and grow slowly.
Luteinising hormone - releasing hormone agonists (LHRH)	Drugs that stop the testes producing testosterone.
Lymph nodes	Small glands that release cells to defend the body against harmful foreign particles.
<b>M</b>	
Maximum androgen blockade	Two types of hormone treatment are given together to prevent the effect of testosterone on the cancer cells.
Metastases	The spread of cancer cells to other areas or sites in the body where the cancer cells begin to grow and cause another tumour.

Metastatic prostate cancer	Prostate cancer cells have spread from the prostate to another area or site in the body and these cells have started to grow causing another growth or tumour.
Monitor or monitored or monitoring	To watch carefully or keep a check on through regular tests, checks and appointments.
Magnetic resonance imaging (MRI scan)	A scan which uses magnets to produce detailed pictures of the prostate, bones and other organs.
Multi-disciplinary team (MDT)	This is the team of doctors and specialist nurses and other health care professionals who are involved in your care.
<b>N</b>	
Nausea	Feeling sick.
Nerve sparing	If the surgeon was able to save the nerves which lie very close to the prostate during a radical prostatectomy. These are essential for a man to have an erection.
<b>O</b>	
Oncology	Specialising in the study and treatment of cancer.
Outlook	The prediction of how the disease may affect the life of the person.
<b>P</b>	
Prostate	A small gland just below the bladder and in front of the back passage. It wraps around the urethra (water pipe that allows urine to flow out of the body from the bladder).
Pelvic floor exercises	Muscles in the pelvic floor are trained to contract, relax and strengthen to help with continence.
Prognosis	The prediction of how the disease may affect the life of the person.
Prognostic grade group	A grading system for determining how quickly the cancer is likely to grow and spread.

Prostate specific antigen (PSA)	A protein made in the prostate.
PSA blood test level	Small amounts of PSA leak out of the prostate into the blood and the level can be measured.
PSA doubling time	The amount of time it takes for the PSA level to double.

**R**

Radical prostatectomy	Surgery to remove the entire prostate gland along with the nearby tissue such as the seminal vesicles.
Radiotherapy	The use of high energy x-ray beams to kill cancer cells.
Rectum	The last section of the bowel often called the back passage.
Retrograde ejaculation	During orgasm nothing comes out of the penis as the ejaculate travels back up into the bladder.

**S**

Secondary cancers (secondaries)	The cancer has spread from the original site to other areas in the body and has started to grow into another tumour.
Second (2nd) line treatment	Treatment given after the first line treatment has not worked, or is no longer effective.
Semen	The thick, whitish fluid released through the penis during orgasm. The prostate makes substances that are in semen.
Seminal vesicles	A pair of glands, near the prostate, that add substances to semen.
Side effects	The unwanted effect when a disease is being treated.
Staging	The size of the cancer and whether it has spread outside the prostate - the term is used when recommending treatment.

Steroids	A group of drugs similar to hormones produced by the adrenal glands, which are used to relieve inflammation.
Stress incontinence	Urine leaks out of the bladder when laughing, sneezing, coughing, walking or getting up from a sitting position.
<b>T</b>	
Testes	Male sex organs that produce sperm and androgen/testosterone.
Testosterone	The male hormone which stimulates the man's sex drive.
Trans rectal ultrasound (TRUS)	The use of sound waves to give a clear picture of the shape and size of the prostate.
Tumour	Abnormal cells that grow faster than normal and cause a growth.
Trans urethral resection of the prostate (TURP)	A fairly common operation for men to 'trim off' part of the prostate.
<b>U</b>	
Urethra	The tube that carries urine from the bladder and for semen to pass out through the penis.
Urgency	Needing to pass urine suddenly and without being able to control it.
Urology	The study of disease affecting the waterworks.
Urologist	A doctor who specialises in disease affecting the waterworks.
<b>V</b>	
Vomiting	Being sick.
<b>W</b>	
White blood cell count	The amount of white blood cells. White blood cells are important to fight infection.

### Abbreviations you might hear used in prostate cancer care

CT or CAT scan	Computerised tomography
DRE	Digital rectal examination
EBRT	External beam radiotherapy
ED	Erectile dysfunction
GnRH agonists or analogues	Gonadotrophin-releasing hormone agonists
HIFU	High intensity focused ultrasound
MDT	Multi-disciplinary team
MRI scan	Magnetic resonance imaging
MUSE	Medicated urethral system for erections
PSA	Prostate specific antigen
TNM	Tumour lymph nodes metastases
TRUS	Trans rectal ultrasound
TURP	Trans urethral resection of the prostate

### Who's who on your cancer journey

Dietitian	A person who specialises in the therapeutic use of diet in the treatment of disease.
Multi-disciplinary team (MDT)	The team of specialist doctors and nurses and other health care professionals who are involved in your care.
Occupational therapist (OT)	OTs work with people to help them develop, recover, or maintain activities necessary for daily living.
Oncologist	A doctor who specialises in the treatment of various types of cancer.
Oncology nurse	A nurse who specialises in the treatment of various types of cancer.

Pathologist	A doctor who specialises in the examination of tissues and blood samples to help decide what diseases are present and therefore how they could be treated.
Pharmacist	A health professional trained in preparing and dispensing drugs.
Physiotherapist (physio)	A therapist who treats injury or dysfunction with exercises and other physical treatments. This can be both before and after treatment.
Radiologist	A medical specialist who uses radioactive substances and x-rays in the treatment of disease.
Radiographer	A technician trained to position patients and take x-rays or perform other radio-diagnostic procedures.
Social worker	A person who helps people or families deal with social, emotional, and environmental problems associated with an illness or disability.
Support group	A group made up of men and their families with a common problem, usually meeting to express feelings, share experiences and explore effective coping strategies.
Urologist	A doctor in hospital who specialises in treating problems with the waterworks.
Urology nurse	A nurse who specialises in treating problems with the waterworks.

### Spotlight on guides

Additional Prostate Scotland guides available which may be helpful:

*Spotlight on Caring for you indwelling catheter*

*Spotlight on External Beam Radiotherapy for prostate cancer*

*Spotlight on prostate conditions and erectile dysfunction*

*Spotlight on prostate biopsy*

*Spotlight on pelvic floor exercises for men*

*Spotlight on prostate brachytherapy*

*Spotlight on incontinence as a symptom of prostate problems*

*Spotlight on removing the prostate by minimal access surgery*

*Spotlight on Active surveillance*

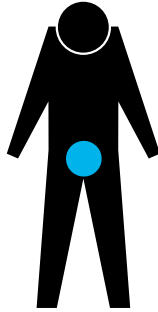
*Spotlight on Hormone therapy*

## For more information

If you have any questions, then you can speak to your hospital consultant, specialist nurse or GP. It may also help to look at the following websites or contact the organisation by phone or email. These organisations also have information leaflets available and some offer telephone helplines which you can contact for support or to answer your questions.

Organisation	Website	Contact number	Helpline available
Prostate Scotland	<a href="http://www.prostatescotland.org.uk">www.prostatescotland.org.uk</a>	0300 666 0236 0131 603 8660	information service
NHS 24	<a href="http://www.nhs24.com">www.nhs24.com</a>	111	✓
Prostate Link UK	<a href="http://www.prostate-link.org.uk">www.prostate-link.org.uk</a>		
Prostate Cancer UK (Includes some support group contact details)	<a href="http://www.prostatecanceruk.org">www.prostatecanceruk.org</a>	0800 074 8383	✓
Macmillan Cancer Support Support Nurses	<a href="http://www.macmillan.org.uk">www.macmillan.org.uk</a>	020 7840 7840 0808 808 0000	✓
Cancer Research UK Cancer Information Nurses	<a href="http://www.cancerresearchuk.org">www.cancerresearchuk.org</a>	020 7242 0200 0808 800 4040	✓
Edinburgh and Lothian Prostate Cancer Support Group	<a href="http://www.elprostatecancersupport.co.uk">www.elprostatecancersupport.co.uk</a> Livingston group: email: <a href="mailto:charliehogg@blueyonder.co.uk">charliehogg@blueyonder.co.uk</a>	07933 260 066 01506 845 981	✓
Prostate Cancer Support Group, Maggie's Dundee	email: <a href="mailto:Lynn.Downie@maggiescentres.org">Lynn.Downie@maggiescentres.org</a>	01382 632999	
Webmd	<a href="http://www.webmd.com">www.webmd.com</a>		
Patient UK	<a href="http://www.patient.co.uk">www.patient.co.uk</a>		
Medicine net	<a href="http://www.medicinenet.com">www.medicinenet.com</a>		
UCAN Care Centre Ward 209, Aberdeen Royal Infirmary	<a href="http://www.ucanhelp.org.uk">www.ucanhelp.org.uk</a>	01224 55033 (voicemail)	
Maggie's Gartnavel General Hospital, 1053 Great Western Road Glasgow G12 0YN	<a href="http://www.glasgow@maggiescentres.org">www.glasgow@maggiescentres.org</a>	0141 357 2269	
Prostate Cancer Support Group Fife	Maggie's Centre Victoria Infirmary, Kirkcaldy	01592 647 997	
Scottish Borders Prostate Cancer Support Group	Macmillan Centre Borders General Hospital	01721 722 655	





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