

PROSTATE INFORMATION

# 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, clinical nurse specialist (CNS) 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 clinical nurse specialist (CNS), "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 CNS 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:

EARLY PROSTATE CANCER EXPLAINED

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 CNS, then it is important that you follow their instructions and guidance.

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# EARLY PROSTATE CANCER EXPLAINED



# 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
- MRI (mpMRI) scan

# 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 26

#### 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.



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# **Section 5**

# Further investigations which may be done - page 33

#### This section explains:

- Bone scan; what it is, why it's done, what happens and getting the results
- MRI and mpMRI 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
- PET scans; what it is, why it's done, what happens and getting the results
- PSMA scan (Prostate Specific Membrane Antigen scan)

#### 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 41

#### 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 44

#### 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 robotic assisted laparoscopic, 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
   Stereotactic body radiation therapy
   EBRT with brachytherapy seed boost
   Brachytherapy

what these are, who these 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
- **Cryotherapy;** what it is, how to be referred for this treatment, when it might be used, how it is given, side effects and follow-up
- Watchful waiting; what it is, when it might be suggested
- Brief overview of the newer experimental treatments; high intensity focused ultrasound (HIFU), high dose rate brachytherapy (HDR Brachytherapy)



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# 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 107

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 117

#### 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 122

#### 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 and those born biologically male have a prostate. It starts out about the size of a pea then slowly grows to the size of a walnut until the EARLY PROSTATE CANCER EXPLAINED



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 or 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.

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#### 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, than men of other ethnicities.

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;
- Painful to pass urine;



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- Seeing blood in urine or semen;
- 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 checker on our website at 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 for further investigations.

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. In fact, your GP may not rely only on one PSA test but may do a series of PSA tests.

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.

In January 2019, GPs were issued with the updated Urgent Suspicion of Cancer referral guidelines. The guidelines provide a guide to normal PSA levels (ng/ml) by age group.



#### Suggested upper levels of PSA (ng/ml)



For older men, routine or no referral may be appropriate (subject to clinical consideration) for PSA levels of:

80-85 years	>	10 ng/ml
86 years and over		> 20 ng∕ml

Although a PSA test result may be raised this doesn't necessarily mean that treatment or investigation is warranted.

(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-psatest-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/ examine your prostate. Although the DRE might be slightly uncomfortable, it shouldn't be painful and only takes around 15-30 seconds. 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 for further investigation as discussed below.

# **Section 3**

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

A brief summary of information in this section

#### • MRIscan and mpMRI scan

In some hospitals, some men may be referred to have an MRI scan or mpMRI scan prior to having a prostate biopsy.

An MRI scan uses a magnetic field and special computer software to produce detailed pictures of your prostate, surrounding tissues, bones and other organs. An MRI scan can be additionally improved by using different parameters to highlight differences between healthy and unhealthy tissue in the prostate.



# 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.

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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.

#### What is a Magnetic Resonance Imaging (MRI) scan?

Most hospitals are now moving towards MRI scan before biopsy but this may not be available in all areas. Some men may still have a biopsy, possibly followed by MRI scan.

An MRI scan uses high powered magnets and special computer software/ programmes to produce detailed pictures of your prostate, surrounding tissues, bones and other organs. So unlike x-rays it doesn't use radiation.

# What is a Multiparametric Magnetic Resonance Imaging (also shortened to mpMRI)?

Standard MRI scans can be enhanced by using intravenous contrast that allows additional imaging parameters to be collected, which improve the ability of radiologists to identify abnormal areas in the prostate (e.g. diffusion weighted images, dynamic contrast enhancement). Using these different parameters can highlight differences between healthy and unhealthy tissue. It's called multiparametric (mp) when 2 or more of these parameters are used. It may be that 4 different parameters are used to identify prostate cancer.

By using parameters in this way, an mpMRI scan shows the prostate very clearly and if there is anything unusual/suspicious in or around the prostate.

#### What happens?

The machine used to do an MRI scan is like a long tunnel although many of the modern machines nowadays have a slightly shorter tunnel.



As the scan is done in the narrow 'tunnel' you should discuss with the urologist or CNS if you don't like or have a fear of enclosed/confined spaces (claustrophobia) as they may be able to refer you elsewhere for your scan so the machine has a shorter tunnel. Your GP may also be able to prescribe some medication to help before going for the scan.

Before the scan staff will ask about your health and if you have any metal implants like a pacemaker; you will have to take off any metal jewellery/piercings.

The special contrast/dye that improves the quality of the MRI pictures is given through a cannula (a small needle placed into a vein in your arm or hand).

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. The table glides into the tunnel and the images are recorded while you are in the tunnel.

At some points, you might be asked to lie totally still and even hold your breath while the images are being taken; you might find it's quite noisy in the tunnel.

The scan takes around 30 minutes to an hour and you might be asked to wait afterwards to make sure that the images are clear and sharp.

There is more information on MRI scan on page 19

#### 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;
- An MRI scan or subsequent MRI has shown cause for concern;
- Although repeat biopsies are not now recommended routinely if you manage your cancer by AS, there may be circumstances when it may be advised to have another biopsy.

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(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, 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;
- If you have an artificial heart valve, aortic aneurysm, achilles problems/ tendonitis or epilepsy.

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.

You will be given a local anaesthetic to stop you feeling any pain. Once the urologist 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. 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.

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#### **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 (waterpipe). 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.

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# 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 for up to about a week;
- Blood in your semen for around 4-6 weeks;
- 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 transrectal 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.



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- 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 urologist or CNS 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 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 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 3 to 5. A grade of 3 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 urologist or CNS 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.

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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:

Prognostic grade group	Compares with Gleason of
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



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# 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 '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	2-3 There is an increased chance	4-5 There is a greater risk that the cancer will grow
	in the prostate and grow slowly (be less aggressive)	of the cancer breaking out of the prostate	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 a magnetic field rather than x-rays to produce detailed pictures of the prostate, surrounding tissues, bones and other organs. Many hospitals are now moving towards men having an MRI scan before having a biopsy; however as MRI before biopsy is still not available in all areas an MRI may only be available after a prostate 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.



# • PET scan (Positron Emission Tomography)

A PET scan may be done after the man has had main (primary) treatment for prostate cancer but his PSA level has started to rise again, suggesting that the cancer has recurred. A PET scan can detect minute amounts of cancer that have perhaps spread to lymph nodes, soft tissue or bones and can detect these minute amounts of prostate cancer earlier than a CT, MRI or bone scan.

# • Prostate Specific Membrane Antigen (PSMA) PET scan

There is a newer scan called a Prostate Specific Membrane Antigen (PSMA) PET scan which is a special type of PET scan.

(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

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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 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 high powered 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.

# What is Multiparametric Magnetic Resonance Imaging (also shortened to mpMRI)

Standard MRI scans can be enhanced by using intravenous contrast that allows additional imaging parameters to be collected, which improve the ability of radiologists to identify abnormal areas in the prostate (e.g. diffusion weighted images, dynamic contrast enhancement). Using these different parameters can highlight differences between healthy and unhealthy tissue. It's called multiparametric (mp) when 2 or more of these parameters are used. It may be that 4 different parameters are used to identify prostate cancer.

By using parameters in this way, an mpMRI scan shows the prostate very clearly and if there is anything unusual/suspicious in or around the prostate.

#### Why might these be done?

Many hospitals are now moving towards men having an MRI scan before having a biopsy; however as MRI before biopsy is still not available in all areas an MRI may only be available after a prostate 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.

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- 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 minutes to an hour. 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 overleaf.



# 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.

#### PET scan (Positron Emission Tomography)

# What is it?

This type of scan for prostate cancer can be very beneficial as it provides more detailed pictures of the prostate and surrounding areas, including lymph nodes and detects minute changes in other soft tissue and bones. In this way, it can show cancerous cells before tumours or any physical changes have taken place. Knowing where the cancer has spread means that

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clinicians treating the man are able to provide more accurate and precise treatments as well as the right type of treatment.

At the time of writing (July 2019) PET scans are only available in the following hospitals so you may have to travel to have a PET scan; Aberdeen, Dundee, Gartnavel in Glasgow, Royal Infirmary in Edinburgh.

#### Why is a PET scan done?

Following a first line (main or primary treatment) for prostate cancer (such as prostatectomy or radiotherapy) you will be regularly followed up and PSA blood tests done. If the PSA level starts to increase it implies that not all the cancer has been removed and consequently has recurred; in this case it's often difficult to know where the cancer has spread to.

A PET scan can detect prostate cancer earlier than a CT, MRI or bone scan when minute amounts of cancer have perhaps spread to lymph nodes, soft tissue or bones.

#### What happens?

(Some hospitals may send or give you information about a PET scan so it is important that you follow their guidelines)

You may already have been sent an appointment letter that gives details about how to prepare for the scan. It may be that you are asked not to eat anything for about 6 hours before your scan appointment time and only have water to drink beforehand.

It's probably best to wear comfortable, loose fitting clothing without any metal fasteners or zips or you may be given a hospital gown to wear.

Before a PET scan, a substance called a radiotracer is injected into your arm or hand. This radiotracer or tracer is particularly radioactive. To minimise any exposure to the nurses, you may find that the injection is carried out very quickly and the nurses wear a monitor which will bleep if it detects radiation and they will step out of range of you.

Once the injection is done, it's important to rest without moving about for around an hour to make sure the radiotracer is taken into the cells in your body.



The radiotracers react differently with cancer cells than normal cells; the cancer cells use the radiotracer much more quickly than normal cells. Through carefully checking the areas that the radiotracer collects or doesn't collect, it's possible to identify any irregularities.

You will be asked to lie flat on your back on a narrow table, trying to keep perfectly still as any movement may blur the picture. The table will move into a doughnut shaped machine where the PET scan will be done. The scan takes around 30 minutes to complete. It's a straight forward procedure and won't hurt but it can be a bit uncomfortable having to lie still, in the same position for quite a long time.

The radiographer isn't able to stay in the room with you during the scan but can still see you and remain in touch with you. There may be a buzzer to press in case you are experiencing real difficulties. It's important to alert staff if you suffer from claustrophobia as they may be able to give you something to help you remain calm during the scan.

You should be able to go home after the scan but will probably have to wait a wee while to make sure the images are good quality so the radiologist has sharp images to see what is happening in your body.

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 for them. Writing down the date in your Prostate Log Book may help jog your memory.

#### Prostate Specific Membrane Antigen (PSMA) PET scan

There is a newer scan called a Prostate Specific Membrane Antigen (PSMA) PET scan which is a special type of PET scan. Using a special contrast, the scan captures images of the body to find if and where there might be prostate cancer. Evidence from recent studies is showing that this type of scan may be more accurate than a PET scan.

At the time of writing (July 2019) this is not yet available on the NHS in Scotland but may be available soon. Four centres in Scotland are expected to have this type of scan available from spring 2020 onwards.

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# 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 CNS;
  - 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. Some support groups offer a 'buddy' system where they link men newly diagnosed with prostate cancer, to men



in the group who have a similar diagnosis or who have already had the treatment that the newly diagnosed man is considering.

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 32** to refresh your memory).

They do this by looking at: (1) Your Gleason score/prognostic grade group or grade of your cancer – this is how the cells from your prostate looked under the microscope; (2) Your MRI scan; (3) The stage of your cancer – this points to how big the cancer has grown or if it has spread; (4) Your PSA blood level; (5) How old you are and any symptoms you have that are troubling you; (6) Whether you have any other medical conditions affecting your health; (7) 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 CNS 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 (July 2019) 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'* 

#### 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.)





# **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. There may also be the option of stereotactic body radiation therapy (SBRT) as part of a clinical trial
- Hormone therapy may also be used in combination with radiotherapy or brachytherapy
- Cryotherapy uses freezing to kill the cancer cells
- Watchful Waiting is a way to manage prostate cancer

# • 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 **pages 27-29 and 32** for more information on low and intermediate-risk and also prognostic grade groups.)

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#### 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, intermediate-risk, or for a small number of men with high-risk prostate cancer. (Please see page 32 for 'risk group' information).

The operation removes the whole prostate, part of the urethra and seminal vesicles. Radical prostatectomy is usually done by robotic assisted minimal access surgery or less commonly now by a laparoscopic (keyhole) or 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 1 - 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 three ways:

i. External beam radiotherapy (EBRT)

EBRT is suitable for men with low to high risk prostate cancer. 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 men with low and intermediate prostate cancer risk and occasionally for men with high risk prostate cancer. 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. Brachytherapy can also be used as a seed boost in combination with EBRT to the prostate and pelvis. This is suitable for men with intermediate and higher risk prostate cancer.

# iii. Stereotactic Body Radiation Therapy (SBRT)

SBRT is a minimally- invasive type of external beam radiation treatment that delivers very precise doses of radiation from outside the body. The dose of each fraction of SBRT is larger than with conventional EBRT. As a result the treatment dose is delivered in 5-7 fractions over 1-2 weeks. To deliver such doses safely they need to be delivered very accurately to 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.



# Cryotherapy

Cryotherapy uses freezing to kill the cancer cells. Special probes or needles are inserted into the prostate. A special gas is passed at high pressure into the probes making the probes extremely cold destroying the prostate tissue it touches. The temperature of the probes is closely monitored during the procedure. Cryotherapy is being used in Scotland as a localised treatment for local recurrence of prostate cancer.

#### Watchful Waiting to manage prostate cancer

Watchful waiting (WW) is a way to manage prostate cancer. It means that the man won't have any active treatment for his prostate cancer. The GP, Practice Nurse or sometimes the urology hospital team will look after him by doing a check- up now and again, usually every 6 - 12 months.

#### • 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.
- 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 urologist/oncologist 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 urologist/oncologist or CNS 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 urologist/oncologist or CNS 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 or you decide you no longer want to manage your cancer in this way.

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;
- 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 urologist 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

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a DRE (digital rectal examination). In addition, repeat MRI scans and/or repeat biopsy 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 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 likely to spread.

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;
- Changes on an MRI scan suggesting that the prostate cancer is progressing
- 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.

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 or by calling Prostate Scotland and a copy can be sent to you.



Advantages	Drawbacks
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.	Although AS does not cure your cancer, the urology team carefully monitor your cancer to check if the cancer is progressing.
You avoid any risk of potential side-effects that you might get from other types of treatment.	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.
Your prostate cancer may grow so slowly that other treatments may never be needed.	There is a very small risk that a slow-growing cancer may suddenly grow and spread outside the prostate capsule while you are being monitored by AS 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.
While your cancer is being monitored new and better treatments may become available.	You will need to attend your GP or hospital to have regular check-ups such as PSA tests, DRE, MRI scans and or 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.

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

A list of possible questions is given on page 51. 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.

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- 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 urologist suggests 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

Robotic assisted and keyhole surgery are becoming the most common way of removing the prostate.

# 1. Robotic assisted laparoscopic radical prostatectomy (RARP)

RARP is now available in Aberdeen, Edinburgh and Glasgow.

This has rapidly become the most common minimal access surgical approach to radical prostatectomy (removal of the prostate) for those men who have chosen/been advised to have a prostatectomy.

In the operating theatre a side cart with the robot is placed next to the operating table. Four robotic arms are attached to the robot with the small instruments necessary for the operation attached to the arms.

The surgeon sits at a console within the operating theatre. From the control panel on the console he/she very precisely operates the small instruments attached to the robot arms to undertake the surgery.

You will have 5/6 small cuts (incisions) across your lower tummy. 4/5 of these

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will be around 1cm long with the final cut being slightly longer, about 2-3cms to allow the surgeon to insert the special instruments needed so that the prostate can be taken out.

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;
- 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

2. Laparoscopic radical prostatectomy (LRP – also called keyhole surgery) Until recently, this was probably the most common way of taking the prostate out and is very similar to the operation described above; the difference being is that the surgeon will carry out the surgery using the small instruments, rather than using the robot.

Similarly, you will have 5 small cuts across your lower tummy. 4 of these will be around 1cm long with the final cut being slightly longer about 3-4 cms.

#### **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 robotic assisted 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 medically fit for treatment;
- For men who are otherwise healthy and fit enough for a general anaesthetic;
- If you have had previous treatment for prostate cancer such as radiotherapy or brachytherapy and the cancer has recurred but has not spread out-with the prostate gland.

# What happens?

# **Minimal Access 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 will be asked to sign a consent form agreeing to have the operation.
- In some centres you will be seen by a CNS to discuss continence and erectile function issues with you.
- In some centres you may be offered the opportunity to attend classes called 'surgery school' before your prostatectomy.

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- 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
- 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.
- On the morning of your operation you may be given an enema or suppository depending on how recently you have opened your bowels.
- You will have been 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 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 or six small cuts across your lower tummy. Most 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 2-3 cms to allow the doctor to insert the special instruments needed so that the prostate can be taken out.



- ii. With laparoscopic radical prostatectomy, you will have five or six small cuts across your lower tummy. Most 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 2-3 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.
  - This type of surgery has largely been replaced with RARP
- 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. This type of surgery is not performed very often now.

#### Robotic assisted radical prostatectomy

- 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 he/she may discuss removing the lymph nodes with you, if you have intermediate or high risk cancer (prognostic grade group 3-5). These will be taken out during your prostatectomy, called a lymph node dissection. (lymph nodes are part of the body's normal immune system).
- 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 will be given oxygen during and maybe after your operation and you may also having a warming blanket.
- 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 2 hours up to about 4 hours.
- You will be given painkillers, if necessary, on the ward to help with any pain or discomfort.

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# 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.
- Some men find their catheter might leak (urine by-passes the catheter) and for a few this leakage can happen quite frequently. If you experience strong tightenings or spasms in your bladder, then get in touch with your CNS or nurses on the ward. They may want to check the catheter and may be able to prescribe a medicine to help.

It is very important that you, nor anyone else (including District Nurses), does not try to take the catheter out or change it. Always get in touch with the CNS for more help and advice.

- 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. You will most likely be given a catheter and incontinence **Take home pack**' that may include: night drainage bags, long or short leg drainage bags, a catheter stand, net pants, packs of incontinence pads. It may also include a 'Urinary Catheter Passport'
- If you notice that urine is not draining from the catheter into the catheter bag and you feel uncomfortable with a strong urge to pass urine, you should contact your GP, or NHS 24, or go to an accident and emergency department.

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



# Will I have to stay in hospital?

Yes, you will have to stay in hospital. How long will depend on a few factors; you are able to move around as well as you did before your operation, you have had a bowel movement, you know how to care for your catheter and your pain medication is controlling any pain.

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

**LRP.** If your recovery goes well you may be in hospital for around 1-3 days, but this can vary in different hospitals.

**Open prostatectomy.** With this surgery you may be in hospital slightly longer between 3-5days.

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 urologist 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. While you're in hospital you may be prescribed Clexane or Dalteparin to help prevent and treat unwanted blood clots. A few men may continue with one of these for a short period when they get home.
- Urine infections. You will be given an antibiotic if necessary.

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# 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 from pages 109-111. 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

#### • 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. This is because the nerve bundles and blood vessels that are needed for a man to have a normal, natural erection lie close to the prostate and may be stretched/damaged during the operation. For some men, it is possible to save these nerves called nerve sparing surgery. You can ask the urologist if nerve sparing surgery is a possibility for you. For others, to make sure that all the cancer is removed during their operation, it isn't possible to save these nerves and blood vessels. In this case, it is no longer possible to have a natural erection but there are treatments available to help. For more information on erectile dysfunction and potential recovery of function see pages 111-116. You can also speak to the CNS or urologist 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

#### 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 urologist or CNS about restarting these when you get home.

It's usual for you to pass some blood or small clots for up to 10-14 days after the operation. Increasing your fluid intake just after 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.

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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 robotic assisted/ laparoscopic 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 from pages 111-116). The ability to have normal spontaneous erections cannot be guaranteed and may take 2-3 years to gradually recover and for some men 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.

#### • Ureteric stents

In some cases it may be necessary to place small plastic tubes into the drainage pipes from the kidneys during the operation. This is usually if the pipes enter the bladder very close to where the stitching will take place. These plastic tubes are called stents. They will need to be removed 4-6 weeks after your operation. This is done via a small, flexible camera passed into the 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 sideeffect 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.

# EARLY PROSTATE CANCER EXPLAINED



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.





#### EARLY PROSTATE CANCER EXPLAINED



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

Advantages	Drawbacks
Can offer a cure for cancer still within the prostate.	This operation is suitable for the majority, but not all patients.
You may be reassured to know that your prostate and so the cancer within it has been removed.	For a small number of cases there may be a positive surgical margin* that increases the risk of requiring additional treatment in the form of radiotherapy or hormone therapy at a later date.
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. Long-term cure rates are well proven and are comparable with other treatments such as radiotherapy.	It is still a major operation and you need to be in hospital for a day or two. 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. As with all the other treatments, there is no complete guarantee of cure. There is a very small risk of severe bleeding and rectal injury linked with the operation.
Although there may be unwanted side- effects such as stress incontinence and erectile problems, treatments for these are available and well-defined.	In some cases incontinence and/or erectile dysfunction may be long-term issues.
After the prostate is removed, your PSA level should be undetectable. So, it is a simple way of checking whether your cancer has come back again	
After the operation, you may still be considered for radiotherapy if this is necessary.	Radiotherapy can have side-effects and these may be more troublesome if you have had previous surgery.
If you previously had problems passing urine then a radical prostatectomy can solve these.	
	*See pages 63-64



Before choosing a radical prostatectomy, you may have some questions to ask your urologist /oncologist 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 robotic assisted laparoscopic radical prostatectomy, 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 robotic assisted laparoscopic radical prostatectomy, 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 and what is the impact on my erections if I cannot have nerve sparing?
- 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 robotic assisted/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?

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- 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**

There are a few ways that radiotherapy can be given and more information will be given on each.

#### • External beam radiotherapy or EBRT

High energy x-ray beams from outside the body are used to treat your prostate cancer. These are focused on 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

# • 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 77-85 for further information on brachytherapy.)

Brachytherapy can also be used as a seed boost in combination with EBRT to the prostate and pelvis. This is suitable for men with intermediate or high risk prostate cancer.

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



#### • Stereotactic Body Radiation Therapy or SBRT

This is a minimally invasive type of radiation that very accurately delivers larger doses of radiation in a shorter period of time, over 1-2 weeks. A tumour tracking system is used that allows for any movement so the radiation beams can be precisely adjusted and corrected to where the tumour is located. See pages 86-95

(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 External Beam Radiotherapy or EBRT?

A special machine called a linear accelerator produces high energy x-ray beams which are then very carefully and accurately focused on 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;
- Men who are medically fit for treatment;
- 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,

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prognostic grade group 4/5 or high PSA, hormone therapy may be continued after radiotherapy. In some patients the option of EBRT followed by a seed insertion will be discussed in combination with hormone treatment.

#### 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.

If you don't have fiducial markers inserted you may have a special scan performed daily before radiation treatment begins. This is called a Cone Beam CT or CBCT for short. This can be used to ensure the radiation beam is directed as planned at each daily treatment.

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. For radical radiotherapy to the prostate, it is becoming more common for men with low or intermediate risk to be given higher doses over a shorter period often 20 days unless it is felt necessary to treat the pelvic lymph nodes; in this case treatment would be 8 weeks;
- Before radiotherapy appointments you may be given suppositories /enema to get rid of gas in your bowel. The giving of suppositories may vary in different hospitals; these might be given at the initial CT scan and the first 10 treatments;
- To help minimise the side-effects on the bladder, you need to have a comfortably full bladder during treatment. You may be asked to empty your bladder then drink a specific amount of water;
- 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, it is important to attend all your appointments;

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- 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 sideeffects. 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

The bladder lies close to the prostate and 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

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. Some patients will benefit from medications for this such as Immodium or Fybogel;
- 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.

#### Constipation

Alternatively, some men find it difficult to open their bowels. You may be prescribed Fybogel granules to help. Speak with the CNS, oncologist or pharmacist before using any over-the-counter constipation relief medications.

#### • 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.

# EARLY PROSTATE CANCER EXPLAINED



## • Skin problems

You may find that the skin between your legs will briefly become red and sore, a bit like sunburn. Ask the CNS or oncologist 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.

#### Potential 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 oncologist 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 oncologist 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 109.

## • 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. There are medications and treatment to help with erectile dysfunction. You can find more information on page 111.



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

#### • Urethral stricture

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

#### 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 CNS or oncologist.

#### 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 oncologist may want to do some more tests.

#### EARLY PROSTATE CANCER EXPLAINED



#### What advantages and drawbacks are there to think about with EBRT? **Drawbacks Advantages** EBRT is non-invasive. It does not require a If there is local recurrence in the prostate despite radiotherapy then salvage surgical treatment carries more general anaesthetic. potential side-effects such as incontinence and impotence Offers cure rates (if cancer is low-risk) and requires an experienced surgeon. comparable to the results with surgery and brachytherapy, taking into account Salvage focal re-irradiation with either EBRT or the relative aggressiveness of cancers. brachytherapy seeds may be an option for some men. Cryotherapy and HIFU are other options that may be For higher risk prostate cancer, i.e. T3 cancers, considered. this is the most established treatment and is usually combined with hormone treatment For some men observation and delayed hormone therapy for between 3 months to 3 years. may be more appropriate. It is less invasive than surgery or brachytherapy. Difficulties with getting and keeping It can have a delayed, but long-term, effect on getting and keeping erections. erections are not as common as with surgery. It can cause urinary symptoms such as frequency and urgency. Less likely to have long-term urinary It can cause inflammation of the rectum called proctitis incontinence. leading to diarrhoea and urgency of bowel motion. Treatment is painless and can be done as an A small number of men have persistent symptoms outpatient. It is suitable for men of any age. including rectal bleeding after treatment that may need further treatment. Minimal or no time off work is possible and normal activities can usually be continued. It usually needs to be done 5 days a week for between For some men with low or intermediate risk. 4-8 weeks although often appointments can be given a higher dose of treatment will be given over to suit your other commitments. over a shorter time, often 20 days. It may also be suitable for men whose The PSA level should continue to fall but can take some general health and fitness would rule time to reach its lowest 'nadir' level. It is not possible to out surgery. know how successful the treatment has been until after a period of follow up. There is a very small increased risk of a radiation induced cancer 5-10 years after treatment in the pelvic area. Most are early tumours of the bladder, bowel or skin and easily treated. EBRT is not recommended for men with inflammatory howel disease

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.



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- 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?

# External radiotherapy (EBRT) combined with Brachytherapy seed boost

This section deals with combining 2 different types of radiotherapy treatment; EBRT combined with a brachytherapy seed boost. (More information on brachytherapy is given in the next chapter).

Combination treatment involves:

- A 4 ½ week course (23 fractions) of external beam radiotherapy given for 5 days a week;
- A boost with brachytherapy seeds around 2 weeks after the course of radiotherapy has finished.

# Why might combination treatment be suggested for me?

- The aim of combining the 2 treatments is to treat more aggressive and more widespread cancers with a higher dose of radiation;
- It can be used very effectively to treat intermediate and high-risk prostate cancers;
- As the radiation emitted from the seeds only travels a couple of millimetres to kill the cancer cells, a higher dose of radiation can be given than having EBRT on its own.

For more information on the procedures for EBRT and brachytherapy please see overleaf.

Other helpful sources from Prostate Scotland include: Spotlight on External beam radiotherapy for prostate cancer Spotlight on brachytherapy for prostate cancer



# 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. Brachytherapy is available to all men, throughout Scotland, with prostate cancer who are suitable for (and select this treatment option). Eligible patients will be referred to the brachytherapy consultant in Edinburgh or Glasgow by their local hospital urology or oncology team. Patients opting for this treatment should be prepared to travel to Edinburgh or Glasgow.

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

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 medically fit for treatment.
- When the PSA level is below 20 ng/ml;
- For some men with intermediate or high risk, bracyhtherapy can be given as a seed boost in combination with external beam radiotherapy;

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- 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.

In both Edinburgh and Glasgow the planning stage (Stage 1) and implant stage (Stage 2) are done on the same day using a single anaesthetic.

#### • Stage 1

The planning stage. This measures the size and shape of the prostate. You may hear this called your prostate volume. 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

Because you need to have your bowel empty for the operation, you may be given an enema prior to brachytherapy. An ultrasound probe will be put into your back passage to help the doctor see exactly where each needle is going.

Using a special metal grid or template in front of the perineum the 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 active.

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 and you may be asked to pass urine into a bottle rather than the toilet just in case you pass a seed, but this is nothing to worry about. You will be given advice on what to do should this happen.

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

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## 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. Simple 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. After your treatment you might notice a reduction in the amount (or absence of) fluid when you ejaculate. This is quite normal. There is more information about erectile dysfunction on page 111.

#### Constipation

After brachytherapy, your prostate may be swollen. To help prevent discomfort caused by constipation, try to keep your bowel movements regular and try to avoid straining when opening your bowels. Fybogel is often suggested to keep your bowel movements regular and help with diarrhoea.

#### **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.

Drinking 8-10 glasses of water each day helps to flush out the bladder and helps reduce the risk of blood clots.

#### 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 may have feelings of tiredness which can last until the energy in the seeds has decreased;
- You should not drive until 24 hours after the operation and some men wait for a few days before driving. Perhaps check with your insurance company;
- 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.

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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 or email for a copy info@prostatescotland.org.uk or call us and a copy will 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?

Offers cure rates for low and intermediate-risk disease equivalent to surgery and external beam radiation (EBRT).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.Short procedure under general anaesthetic with short hospital stay and catheter removed on the ward when the man wakes up.Some discomfort when the implant is done and for a short period afterwards.Very low risk of incontinence and reasonable chance of maintaining erections.Not suitable for all men who have poor urinary function or a markedly enlarged prostate.User risk of bowel problems than with external beam radiation (EBRT).From the evidence there appears to be a very low risk of secondary cancers from brachytherapy treatment.Lower risk of bowel problems than with external beam radiation (EBRT).From the evidence there appears to be a very low risk of secondary cancers from brachytherapy on its own and indeed it is very low risk of secondary cancers from brachytherapy treatment.	Advantages	Drawbacks
Short procedure under general anaesthetic with short hospital stay and catheter removed on the ward when the man wakes up.Some discomfort when the implant is done and for a short period afterwards.Minimal time off work and can continue normal activities.Not suitable for all men who have poor urinary function or a markedly enlarged prostate.Very low risk of incontinence and reasonable chance of maintaining erections.Not suitable for all men who have poor urinary function or a markedly enlarged prostate.Discomfort, frequency and urgency in passing urine until the radiation has died down. Rarely retention of urine requiring a catheter.Some difficulties with erections but treatments are available as with surgery. Infertility – although it has been known for pregnancies to occur following brachytherapy treatment.Lower risk of bowel problems than with external beam radiation (EBRT).From the evidence there appears to be a very uncommon.	Offers cure rates for low and intermediate-risk disease equivalent to surgery and external beam radiation (EBRT). For suitable patients and if there is local recurrence of prostate cancer, it may be possible for focal re-implantation of more seeds.	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. 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.
Very low risk of incontinence and reasonable chance of maintaining erections.Not suitable for all men who have poor urinary function or a markedly enlarged prostate. Discomfort, frequency and urgency in passing urine until the radiation has died down. Rarely retention of urine requiring a catheter. Some difficulties with erections but treatments are available as with surgery. Infertility – although it has been known for pregnancies to occur following brachytherapy treatment.Lower risk of bowel problems than with external beam radiation (EBRT).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.	Short procedure under general anaesthetic with short hospital stay and catheter removed on the ward when the man wakes up. Minimal time off work and can continue normal activities.	Some discomfort when the implant is done and for a short period afterwards.
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	Lower risk of bowel problems than with external beam radiation (EBRT).	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.

## EARLY PROSTATE CANCER EXPLAINED



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?
- If it is not in my area would you consider referring me for brachytherapy to Edinburgh or Glasgow?
- 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?

# What is Stereotactic Body Radiation Therapy (SBRT)?

SBRT is a minimally- invasive type of external beam radiation treatment that delivers very precise doses of radiation from outside the body. This works in the same way as other radiotherapy treatments to damage the cancer cells.

The very sophisticated equipment (Linac) is used to pinpoint the exact position of the tumour within the prostate and then delivers SBRT. To deliver SBRT, changes are made in the way that the LINAC machine is used; the dose rate is increased, and the beam is delivered without a flattening filter. In this way the direction of the radiation beams can be very precisely adjusted and corrected to the tumour site, supported by the use of a tumour tracking system. This allows for any movements or slight changes of position made by the patient.

The dose of each fraction of radiotherapy is larger than with traditional EBRT. As a result the treatment dose is delivered in 5-7 fractions over 1-2 weeks. To deliver such doses safely, they need to be delivered very accurately to the prostate. Because the beams are so precisely targeted there is less radiation reaching other healthy tissues around the tumour site. Additional hormone therapy is not required.

## When might this be suggested?

• As a primary/main treatment to potentially cure the cancer when it is contained in the prostate and has not spread (metastasised) to other parts of their body;

# EARLY PROSTATE CANCER EXPLAINED



- As a treatment, after a period of active surveillance if there are signs of the cancer growing;
- For men with low or intermediate risk prostate cancer;
- For men who are medically fit for treatment.
- For men with a prostate volume of 70cc but possibly up to 90cc if their urinary flow rate is acceptable

Currently, (July 2019) this is only available as a clinical trial.

## What happens?

(The information that follows 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.)

There are 4 steps for SBRT.

- 1. You will have your consultation with the oncologist to discuss your treatment.
- 2. Before your MRI scan you will be given a suppository (medication into your back passage) to expel gas then asked to drink 3 cups of water to maintain a constant volume in your bladder. You will be put into the position that you will be treated in. This scan is fused (overlaid) with the planning CT scan to help determine the best radiotherapy plan.
- 3. **Placing the tumour tracking system.** There are 2 systems currently used; RayPilot® or Calypso®. Whether the Raypilot® or Calypso® system is used they work in the same way. That is, if the prostate moves (possibly as the bladder fills or if gas/wind builds up) then the beam is switched off automatically to prevent treating normal tissue or missing the target.

## The Raypilot® tracking system

## What happens

With RayPilot<sup>®</sup>, the planning CT scan is performed on the same day as the MRI and putting the RayPilot<sup>®</sup> device in place. If this cannot be performed on the same day then the planning CT scan would be performed no more than 7 days later.

You will be given an enema to clear the back passage before the device is put into the prostate. Local anaesthetic will be given to the skin of the perineum and around the prostate.



You will be asked to lie on your back and the ultrasound probe (TRUS – similar to having a biopsy) will be slid gently in to the back-passage to visualise the prostate and guide the insertion of the Raypilot<sup>®</sup> system. The Raypilot<sup>®</sup> is placed into the prostate through the perineum (the patch of skin between the back passage and scrotum). The whole procedure takes about 20 - 30 minutes in total from start to finish.

At present, 2 additional fiducial markers (1-5mm) gold seeds are inserted into the prostate at the same time using the same procedure as when you had a biopsy (ie through the bowel wall).

You will be given antibiotics to take for a few days after the insertion of the RayPilot  $\ensuremath{^{\circledast}}$ 

As the Raypilot<sup>®</sup> has a thin tube that comes out of the perineum, you will be given instructions as to how to look after it; but you can shower, bath, exercise etc. as normal without any discomfort.

This tube is connected to the Linac bed to power the system which acts like a GPS to tell the Radiographers the exact position of the prostate at all times during treatment.

Afterwards, there may be some discomfort and you may notice a small amount of blood from your back passage or the skin of the perineum. Before you go home staff will most likely want to check that you are passing urine and it is not too heavily stained with blood.

Although it's not common, some men may develop an infection. If you pass a large number of blood clots, have a high temperature, feel hot, cold and shivery and have difficulty passing urine you may have an infection that needs to be treated. Contact your GP or the number you have been given by the hospital.

## EARLY PROSTATE CANCER EXPLAINED



# The Calypso® system

## What happens

You will be given an enema to clear the back passage before the Calypso<sup>®</sup> system device is put into the prostate and you will be given a local anaesthetic to the wall of the bowel.

You will be asked to lie on your side. The ultrasound probe will be slid gently in to the back-passage to visualise the prostate and guide the insertion of the system. Three Calypso beacons are inserted into the prostate in the same way as the fiducial markers.

Getting the system in place will take about 20-30 minutes in total from start to finish.

These beacons act as radio transponders to track the position of the prostate; these will remain in the prostate after the radiotherapy is completed much in the same way as traditional fiducial markers are.

With the Calypso® system the planning CT scan is usually performed 7-10 days later to let the beacons settle in the prostate.

You will be given antibiotics to take for a few days after these have been inserted to help stop any spread of infection from the bowel to the prostate.

Afterwards, there may be some discomfort and you may notice a small amount of blood from your back passage.

Before you go home staff will most likely want to check that you are passing urine and it is not too heavily stained with blood.

Although it's not common, some men may develop an infection. If you pass a large number of blood clots, have a high temperature, feel hot, cold and shivery and have difficulty passing urine you may have an infection that needs to be treated. Contact your GP or the number you have been given by the hospital.



## 4. Individual treatment plan

Once the team treating you have all the results of the initial planning, an individual treatment plan will be devised for you. This is to ensure that the dose is correct and will be precisely targeted to the exact position(s) in your prostate. You will be told about the number of appointments that you will need and when you will need to attend.

Generally, this is likely to be 5-7 fractions of treatment over 1-2 weeks. However your oncologist will most likely discuss this with you in greater detail.

Before your appointment you will be given a suppository to ensure your bowel is free of gas and will be asked to drink a set amount of water to fill up the bladder. This is to keep your bladder and bowel in a similar condition to your planning scan and limit any radiation to healthy tissue or organs near the tumour.

Your appointment will last around 30 – 40 minutes. Some of this time will be taken up by checking your details and ensuring you are positioned correctly. You will most likely be asked to take off your jacket and possibly anything with metal such as zips or jewellery and you may asked to put on a gown.

Once called in to the treatment room, the radiographers will help you onto the treatment couch then adjust the couch and the machine to the correct position. They will also ensure that you are lying in the correct position for your treatment to begin. It's very important that you lie in the same position that the radiographers put you in and lie as still as possible even though the machine can make adjustments for slight movements.

You will find that there will be a detector plate above your pelvis; this is about the size of a small tray.

After the radiographers have finished all the checks, they will leave you on your own in the treatment room but will still be able to see and hear you in case you need to contact them. If you think it might help you to relax, check with the radiographer if you can take in a CD to be played during your treatment. You may hear a buzzing as part of the machine moves around into different positions and angles so the various beams meet and accurately deliver treatment to the tumour, although you won't feel anything and the machine won't touch you.

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When your treatment is completed the radiographer will come back to the treatment room and help you off the couch. Unless told otherwise, you should be able to go home. Make sure you know the date for your next appointment.

The treatment doesn't make you radioactive so it's quite safe to go home and be with other people.

On the last day of your treatment, and before you go home, you will be given simple anti-inflammatory pain killers 30 minutes before the radiographer removes your RayPilot<sup>®</sup>. The system is removed by a single firm pull on the tube to dislodge it from the prostate. After the RayPilot<sup>®</sup> (if using the RayPilot<sup>®</sup> system) is taken out, a simple dry dressing will be placed over the perineum to protect your under wear from any spots of blood. The dressing can be taken off once you get home.

#### Will I have an anaesthetic?

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

#### What about potential side-effects?

While the treatment itself doesn't hurt, it may have some troublesome sideeffects. However, not all men react the same to the treatment and the sideeffects you may have could be different from someone else having SBRT. You may notice side-effects just after your treatment has started and these may go on for a few weeks after your treatment finishes. The type of side-effects, how troublesome these might be or indeed the absence of side-effects doesn't mean that your treatment is not working. Please let the radiographer, oncologist or CNS know about any troubling side-effects as some side-effects can be helped with medications if necessary and usually settle down.



## Feeling tired and having little energy.

Most people find that they are able to carry on with their usual daily activities and some people carry on working.

However, feelings of tiredness may build up because your body uses a lot of energy dealing with the effects of radiation on normal cells. How tired you might be and for how long varies from man to man.

#### Symptoms when passing urine

Because the bladder lies just above the prostate it may become irritated or inflamed due to 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;

These side-effects are often temporary and settle within 4 weeks of treatment.

However, if you are in a lot of pain and stop passing urine, you should contact your GP, NHS 24 or go to your nearest A&E department.

#### Bowel symptoms

As the bowel lies close to the prostate it may become irritated or inflamed because of the treatment.

You may notice that:

- You need to open your bowels more often, have a feeling of urgency and motions may be much looser;
- You might have cramps in your lower tummy, pain around your back passage and pass a lot of wind;
- Alternatively some men find difficulty in opening their bowels (constipation);

These side-effects are often temporary and settle within 4 weeks of treatment.

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As with all other treatments for prostate cancer, there is a small risk of longerterm urinary and bowel symptoms.

#### Difficulties with erections

Over time you may notice difficulties in getting and keeping an erection (erectile dysfunction or ED) although this is much less likely than with EBRT or prostatectomy. This is because the blood vessels and nerves needed to get an erection can be damaged during the treatment.

One recent study has suggested that 25% of men experienced a decrease in erectile function after SBRT.

There are several types of treatment available for ED, and, if this becomes a difficulty you should speak with your oncologist or CNS. Options might include medication taken as a tablet, medication as a pellet using an applicator, cream applied to the tip of the penis, medication which is injected or through the use of a vacuum pump.

For more information see Page 111 or 'Spotlight on Prostate conditions and erectile dysfunction'

#### At home...

It may help if you:

- Try to get a good night's sleep and perhaps 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;
- Taking light exercise every day (such as going for a walk) and keeping active should actually help with any feeling of tiredness;
- Have a healthy, well-balanced diet.

For more information, ask the oncologist or CNS.



## EARLY PROSTATE CANCER EXPLAINED



# How do I know if the treatment has worked?

After you have had SBRT, the oncologist or CNS will want to see how you are with regular check-ups and your PSA level will be measured. It's been noticed that the PSA level often falls most in the first month after treatment then steadily reduces over time for about 2 years after treatment.

Following SBRT, there may be occasions where the PSA may 'bounce or spike'. This doesn't necessarily mean that your treatment isn't working and your oncologist or CNS will most likely want to chat over why this might happen. However, if your PSA level keeps on rising, this *may* be due to the cancer recurring and your doctor or CNS will talk this over with you and may want to do further tests.

Advantages	Drawbacks
SBRT is minimally-invasive, does not require a general anaesthetic and no hospital stay. Offers cure rates for cancer with low and intermediate risk prostate cancer comparable to the results with surgery brachytherapy and EBRT	Follow up of patients treated is still relatively recent so long term side effects are not well known Salvage therapy for local recurrence would require surgery, cryotherapy or HIFU with some increased risk of toxicity. There may also be the option of focal salvage seed brachytherapy.
Difficulties with getting and keeping erections are not as common as with surgery or External beam if additional hormone therapy is used	Risks increase over time
Number of treatment visits is much less than with conventional external beam	Mainly suitable for prostate volumes of less than 70cc but a prostate volume of up to 90cc might be considered if their urinary flow is good. Not suitable for men with significant urinary bother or those who have had a TURP.
SBRT very accurately and precisely targets the tumour with less chance of healthy tissue and organs near the tumour being affected. At the time of writing (July 2019) Stereotactic body radiation (SBRT) is available as part of a clinical trial. This involves receiving curative radiotherapy in only 5 large doses over 1 week.	Any movement of the prostate during treatment could increase the dose to the normal tissue or decrease the dose to the tumour, however this risk is significantly reduced by monitoring the prostate position with specialist systems such as RayPilot® and Calypso®. There is a very small increased risk of a radiation induced cancer in the pelvic area 5-10 years after treatment. Most are early tumours of the bladder, bowel or skin and easily treated. (3 cases per 1000 patients treated)



## 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, and some are only an issue in the longer term, the most common side-effects are:

#### • 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.

## • 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 111 of this booklet or our spotlight guide *'Prostate conditions and erectile dysfunction'*.

#### • 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.

#### • 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.

#### • 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.

#### • 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.

#### • 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.

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## • 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?

#### Additional treatments

## What is cryotherapy?

Cryotherapy (also called cryoablation or cryosurgery) freezes tissue within the prostate. When the prostate tissue is frozen cancer cells die; but freezing can also affect nearby healthy tissue. The freezing process uses argon gas with a computer being used to carefully control the temperature, which may get as low as -40°c.

At present, cryotherapy is only undertaken at Gartnavel/ Queen Elizabeth University Hospital in Glasgow but is a national service for Scotland. Men from other areas who are interested in cryotherapy treatment, and who meet the criteria (conditions you must meet to be suitable for this type of treatment), should ask their urologist or oncologist for more information and if they can be referred for assessment. Patients opting for this treatment should be prepared to travel to Glasgow.

#### When might cryotherapy be used?

Cryotherapy might be suggested as a treatment option for different reasons and at different times to treat prostate cancer. It can be used:

- If there is local recurrence of the prostate cancer after other cancer treatment, such as radiation therapy. This is known as salvage treatment;
- More recently, it has been used as a primary (main) treatment for patients with localised or locally advanced prostate. (not in Scotland as yet)

To confirm whether prostate cancer has returned you will most likely have:

- A prostate biopsy;
- Scan of your pelvis;
- Bone scan.

# EARLY PROSTATE CANCER EXPLAINED



## What happens?

- You may already have been taught how to do pelvic floor exercises to help with incontinence following cryotherapy;
- You will most likely be admitted to the ward the day before your cryotherapy procedure;
- The day before your operation, you will be given 2 enemas to empty your bowel so the oncologist has a clear picture of your prostate from the ultrasound. You may also be given an antibiotic during the procedure to prevent infection;
- An ultrasound probe is put into your back passage to show your prostate on a screen;
- A catheter is put into the urethra inside your penis (urethra is the tube that takes urine from your bladder). The catheter is filled with a warming solution so the urethra isn't affected or damaged by the cold during the procedure;
- The oncologist or surgeon views the prostate on a screen so he/she can accurately place the special needles or probes (called cryoprobes) through the perineum into the prostate to target the areas of prostate cancer. (The perineum is the skin between the scrotum and back passage);
- A special gas (argon gas) is passed at high pressure into the probes making the probes extremely cold destroying the prostate tissue it touches;
- The oncologist monitors and controls the temperature of the probes and so the amount of freezing in the prostate. In this way it helps lower the risk of damaging healthy tissue;
- As the probes have been inserted through the perineum you will have some small pinhole wounds. A dry dressing will cover these while you are in the ward but will normally be taken off before you go home.

#### Will I have an anaesthetic?

Yes you will have an anaesthetic. This will most likely be a general anaesthetic where you will be asleep throughout the operation. In some centres a spinal anaesthetic (where you will be numb from the waist down) is used.

## How long will the operation last?

Usually the operation lasts around 2 hours.



## How long might I have to stay in hospital?

Normally this will be the night before your operation and the night of your operation, then discharged the following day.

#### Will I have a catheter?

During your operation you will have a catheter in place, and will almost certainly go home with the catheter in place and for about 1 week afterwards. This will most likely be a catheter in your urethra (called urethral catheter). Depending on individual circumstances, some men may have a supra-pubic catheter. This means that the catheter will come out through a small cut on the lower part of your tummy just above the pubic bone.

For more information on having a catheter please see pages 107 or our booklet Spotlight on caring for your indwelling catheter.

#### **Potential side-effects**

#### Pain

After cryotherapy, it's quite normal to have some pain or discomfort in the perineal area (where the needles/probes were inserted) as well as some pain and swelling in the scrotum or penis. Simple pain-killers should be all that is needed to help and you may be discharged home with a small supply of pain-killers. If the pain isn't relieved by simple pain-killers, then ask your GP or pharmacist for more advice.

#### **Blood in urine**

You may find you pass small amounts of blood in urine for a few days after your treatment.

#### **Bruising and swelling**

It's quite normal to have some bruising and swelling of the area around the scrotum but this should gradually settle.

#### Bleeding

You may have some slight bleeding from the area where the probes were inserted. If this happens, then cover with a dry dressing. If you have concerns and you consider the bleeding to be heavier than before, then get in touch with your GP. EARLY PROSTATE CANCER EXPLAINED



## Incontinence (not being able to control urine)

Some men will experience leakage of urine after cryotherapy which may improve with time. If this is a difficulty then some men may need to wear pads. There is more information on incontinence on pages 109-111 or see our booklet 'Spotlight on incontinence'.

#### Difficulty passing urine

If this is a persistent difficulty, some men may need a TURP (trans urethral resection of the prostate) to trim the prostate so urine flows more easily.

#### **Urine infection**

It is possible to develop a urine infection. If you have a fever, chills, pain when passing urine, pain in your lower tummy or back or if you have a strong, unpleasant smell from your urine then it is best to make an appointment to see your GP.

#### Constipation

Constipation can become a difficulty, possibly caused by the pain-killers you are taking, not moving around as much or because you are not drinking enough fluid. It's important to try to avoid this happening so you are not straining to pass a motion. You will be discharged with a mild laxative.

To help avoid constipation becoming a problem:

- It's best to drink about 2 litres of fluid each day;
- Eating plenty of fresh fruit and vegetables;
- Eating high fibre foods such as wholemeal bread and wholegrain cereals.

#### **Erectile dysfunction**

Erectile dysfunction means that you are not able to achieve and maintain an erection. As the nerves responsible to have an erection lie very close to the prostate there is a high risk that these nerves will be damaged by freezing, resulting in erectile dysfunction.

Although there are treatments available to help with this difficulty they may not work for all men. If this is an issue for you, you should chat it over with your urologist, oncologist or CNS when you attend your cryotherapy assessment appointment.



## Fistula

Although this doesn't happen very often a fistula (an unusual connection or opening) can occur between the back passage and urethra. This is caused by the freezing process reaching the back passage. It is a serious condition and the opening will have to be repaired. In some cases it will require having a stoma and colostomy bag. This means that a small part of the bowel is brought out of the body to the surface and waste from the bowel is collected in a colostomy bag outside the body.

## When should I expect follow-up appointments?

As the cryotherapy service is a national service for Scotland, to save some patients travelling long distances, follow-up may be done by a telephone consultation. Other patients will have follow up appointments at the hospital.

As PSA results are essential for follow-up appointments, please remember to have a PSA test done just prior to your appointment so results of the test are available.

1 week after treatment	The catheter is removed. For those patients who do not live locally to Glasgow, removal of their catheter may be organised in their local area.
6 weeks after treatment	An out- patient appointment with a PSA test
3 months after treatment	An out- patient appointment with a PSA test
6 months after treatment	An out- patient appointment with a PSA test
9 months after treatment	An out- patient appointment with a PSA test
12 months after treatment	An out- patient appointment with a PSA test

After 12 months you will go back to seeing the urologist/oncologist who referred you to the cryotherapy service in the first place and he/she will continue to check on you.

Prostate Scotland acknowledges help and support on this section from the cryotherapy service at Queen Elizabeth University Hospital Glasgow.

## EARLY PROSTATE CANCER EXPLAINED



# Watchful Waiting

Watchful waiting (WW) is a way to manage prostate cancer. WW may be suggested as appropriate when the urologist or GP believes that:

- The prostate cancer is the type that grows very slowly and is unlikely to spread;
- The man may have another health condition which means that he wouldn't be well enough to have another type of treatment or that the side-effects of treatment would be more bothersome;
- He is of an age where there is no clear evidence that treating the prostate cancer would bring life expectancy benefits.

It means that the man won't have any active treatment for his prostate cancer. The GP, Practice Nurse or sometimes the urology hospital team will look after him by doing a check- up usually around every 6-12 months. They will most likely ask about symptoms, any new symptoms and consider his PSA level. Usually there won't be any further/other tests unless the GP, urologist or CNS (Clinical Nurse Specialist) thinks the cancer may be starting to grow or change. Check-up appointments may be every 6-12 months.

If any new symptoms are noticed, it's important to chat this over with the GP in particular informing the GP about:

- Pain or stiffness in the lower back, hips or upper thighs;
- An unexplained weight loss;
- Seeing blood in urine.

Watchful waiting is a different way to manage prostate cancer from Active Surveillance.

For more information on Watchful Waiting see our booklet 'Spotlight on Watchful Waiting to manage prostate cancer'

For more information on Active Surveillance see our booklet 'Spotlight on Active Surveillance to manage prostate cancer'.



## 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. This treatment is not generally available in Scotland.

## 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.

## EARLY PROSTATE CANCER EXPLAINED



# **Section 8**

# Managing some of the potential side effects of the treatments

## A brief summary of information in this section

#### • Having a catheter

A catheter is a long, thin, flexible, soft hollow tube that is used to drain urine out of your bladder into a drainage bag outside your body. After a prostatectomy you will most likely go home with a catheter to allow the prostate area to heal. You will probably be given a catheter and incontinence 'Take home pack' and may also be given a 'urinary catheter care passport'.

## • 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.

## **Catheter care**

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



During your operation a catheter tube can be passed via your penis into your urethra (waterpipe) then into your bladder. Once inside the bladder a small balloon near the tip of the catheter is inflated with sterile water to keep the tube in place. Urine drains from the catheter into a catheter bag. When you get home it is a good idea to check the tube every day to make sure that it doesn't have any kinks in it, make sure the bag is emptied and the bag is held in a comfortable position.

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

If you have a catheter because you have had a prostatectomy, then you, (nor anyone else including District Nurses), should not try to take the catheter out or change it. Instead, contact the CNS or ward staff for more help and advice.

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

#### A word about infection

Because your catheter can provide a direct path for bacteria (germs) to get into your bladder, you may develop a urinary tract infection (UTI). If your urine looks cloudy, has a strong smell, you feel feverish and generally feel unwell it's important to get in touch with your GP or CNS for more advice.

#### **Urinary Catheter Care Passport**

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

# EARLY PROSTATE CANCER EXPLAINED



The passport is for you to keep while you have your catheter and very importantly **take with you to all your healthcare appointments**. (Eg. whether GP, CNS, Urologist or District Nurse).

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

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

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

## 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 (if you are overweight) 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.

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#### 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, 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 or email 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 or email 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.

**prostate** 



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 take 2-3 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 2-3 years before you can have a spontaneous natural erection. For some men spontaneous natural erections may never return;
- If you have external beam 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;
- 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 to have a prostate to achieve an erection. However, the nerve bundles and blood vessels that are needed to have a normal, natural erection lie next to the prostate and may be stretched or damaged during the surgery.

For other 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 2-3 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, avanafil. 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.

Your urologist/GP may prescribe these medications to be taken routinely even though you're not planning to be intimate; there is evidence to suggest that earlier treatment results in a better response to treatment.

Possible side-effects 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 by injection

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. When having these injections you should not use any other medication for ED.

There are 2 medications that are available and the urologist, CNS or GP will decide which one to try for you:

- Invicorp<sup>®</sup>
- Caverject<sup>®</sup>

# scotland

If this treatment is recommended, you will be taught how to do the injection. It involves injecting the drug into the side of penis using a very fine needle. 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 bruising, mild pain/discomfort when you do the injection, scar tissue on the area where you have the injection. Some men experience headaches or dizziness.

A painful, long-lasting erection that lasts for 3-4 hours (called priapism) is very uncommon but should it happen it needs urgent medical attention.

#### 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<sup>®</sup> 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.

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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. In fact, sometimes using a vacuum pump is introduced much earlier into your treatment plan to 'exercise' the penis. These pumps are available on prescription from the CNS, urologist or GP and it is recommended that you use this pump rather than buying a pump over-the-counter or through the internet.

The pump 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 draws blood into the penis so it becomes erect. A band can be placed around the base of the penis to keep the erection firm for up to 30 minutes.

Don't be disappointed if a vacuum pump doesn't work for you straight away- it may take a few times to be able to use the pump correctly. If you are finding it difficult, speak to your CNS, urologist or GP for more advice.

#### Shockwave therapy

Shockwave therapy is a method of treating ED but it is not available through



the NHS. It uses low-intensity shockwaves, similar to ultrasound waves. These shockwaves encourage new micro blood vessels to grow and appear to boost the blood flow into the penis resulting in a better quality erection.

#### 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

Dry ejaculation will happen after a prostatectomy or possibly after brachytherapy (seed implants). 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 ejacualte. 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 or email 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 recovery

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clinics after treatment. 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 there 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 urologist, oncologist or CNS 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. https://www.prostatescotland.org.uk/ disease-tests-and-treatments/early-prostate-cancer



## 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 CNS in cancer or urology;
- Your GP;
- Your partner;
- Your family and friends;
- A prostate cancer support group whose members have experienced prostate cancer. Some groups also offer a 'buddy service.'

Deciding on the best treatment for you isn't always easy or clear-cut. The multidisciplinary 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 CNS or speaking to someone on a telephone helpline or someone from a prostate cancer support group.

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- 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 50, radical prostatectomy page 65, radiotherapy page 75 and brachytherapy page 84, stereotactic radiotherapy page 95.
- 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. You can check out videos by patients who have chosen each of the treatments by going onto our website; then select prostate cancer, early prostate cancer and scroll down the page to active surveillance, surgery, and radiotherapy.



- 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 urologist, oncologist or CNS, 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 urologist, oncologist or CNS 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 on your appointment with you, 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, urologist, oncologist or CNS that you would like someone to sit in with you.
- 4. If you don't understand what you've been told, let the urologist, oncologist or CNS know right away so they can explain it again. 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.

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- 5. You might feel that the urologist, oncologist or CNS 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 or you may want to use the recording system on your smart phone. This might also help you to write down any questions that you want to ask the urologist, oncologist or CNS next time. In some hospitals the urologist, oncologist or CNS may offer you an audiorecording of your consultation.
- 7. You can tell the urologist, oncologist or CNS 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 urologist, oncologist or CNS 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);
- MRI or CT scans;
- Prostate biopsy;
- Bone scans;
- X-ray (an x-ray may be done to check out normal wear and tear on bone and joints).



capsule to seminal vesicles but no other organs





## 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: hot flushes and sweating, loss of libido, erectile dysfunction, feeling sluggish & fatigue, changes to your body shape, gynaecomastia (breast swelling and tenderness), mood swings, bone thinning, hair loss, heart problems.

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 from pages 96-99 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 focused on 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.

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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 to lie very still and stay in the same position.

Because EBRT can affect healthy cells too, there will most likely be some sideeffects; 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 68. 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

# scotland

## EARLY PROSTATE CANCER EXPLAINED

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.

For more information on Watchful waiting please see our booklet 'Spotlight on Watchful Waiting to manage prostate cancer'.

## 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 robotically assisted laparoscopic procedure or a laparoscopic procedure (keyhole surgery) or less commonly now by open operation.

More information about radical prostatectomy can be found earlier in this booklet on page 51. 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 sideeffects 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).

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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.

Торіс	Page
PSA blood test	15
Digital rectal examination DRE	17
Prostate biopsy	20
Prognostic grade group∕ Gleason score	26
Staging	30
MRI scan (Magnetic Resonance Imaging)	19 and 35
CT scan or CAT scan (Computerised Tomography)	37
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Erectile dysfunction ED	111
Making decisions about treatment	117



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What the medical wor	rds in our booklets mean
Α	
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.

В	
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.
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.
C	
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.



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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.	Enzalutamide	Enzalutamide is now available via the NHS in Scotland for men with advanced prostate cancer where the cancer has spread and become resistant
Consent form	A form you will be asked to sign to confirm that you are willing to go ahead with treatment, tests or examinations.		can now be prescribed, depending on clinical need, <b>before</b> the man starts chemotherapy or
Constipation	Unable to open the bowels.		arter a course of chemotherapy.
Continuous hormone therapy	Hormone therapy which continues with no breaks.	Epidural anaesthetic	A local anaesthetic injected into the spine which causes numbness from the waist down.
CT simulator	A special type of x-ray machine.	Erectile dysfunction (FD) or impotence	When a man has trouble getting or keeping an erection
Cryotherapy	Freezing to kill the cancer cells.	External beam	High energy y-ray beams from outside the body
Cystogram	An x-ray of the bladder.	radiotherapy (EBRT)	to kill cancer cells.
Computerised	Special x-ray equipment combined with advanced	F	
tomography (CT or CAT scan)	computers to take many pictures of lots of different views inside the body	Fatigue	Extreme tiredness.
D		First (1st) line treatment	The treatment or drug given as the first or main treatment.
Diagnose	Identify a disease by its signs and symptoms and then confirm with tests.	Fistula	An abnormal opening or passageway between two organs in the body.
Digital rectal examination (DRE)	The doctor inserts a gloved finger into the back passage to examine the prostate gland for signs of disease	Flare reaction	The short-lived increase in testosterone for the first few weeks after starting an LHRH agonist.
Dry orgasm	During orgasm elaculate does not come out of the	Fraction	A small daily dose of radiation to kill the cancer cells.
	penis.	Frequency	Needing to pass urine often.
E		G	
Early or localised prostate cancer	The cancer has stayed inside the prostate and has not spread to other parts of the body.	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
Ejaculate	The fluid that is released at orgasm.	Gonadotrophin	Stop the testes making testosterone
Enema	A capsule or fluid that is put into the bowel to clear the bowel out before a procedure.	releasing hormone antagonists	

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Gynaecomastia	Swelling or enlargement of the breast tissue.
н	
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.
1 Contraction of the second se	
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 prostate cancer 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. н Laparoscopic radical Keyhole surgery to take out the prostate. prostatectomy A medicine given to help you open your bowels or Laxative make it easier to open your bowels. Desire to have sexual intercourse. Libido Linear accelerator A special machine that produces high-energy x-ray beams. Locally advanced The cancer has spread just outside the prostate through the capsule or into seminal vesicles. prostate cancer The cancer is likely to remain inside the prostate Low-risk prostate cancer and grow slowly. Luteinising hormone -Drugs that stop the testes producing testosterone. releasing hormone agonists (LHRH) Small glands that release cells to defend the body Lymph nodes against harmful foreign particles. Μ Two types of hormone treatment are given Maximum androgen together to prevent the effect of testosterone on blockade the cancer cells. The spread of cancer cells to other areas or sites in Metastases the body where the cancer cells begin to grow and cause another tumour. Prostate cancer cells have spread from the Metastatic prostate prostate to another area or site in the body and cancer these cells have started to grow causing another growth or tumour. To watch carefully or keep a check on through Monitor or monitored regular tests, checks and appointments. or monitoring

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Magnetic resonance imaging (MRI scan)	A scan which uses a magnetic field 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.	
Ν		
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.	
0		
Oncology	Specialising in the study and treatment of cancer.	
Outlook	The prediction of how the disease may affect the life of the person.	
Ρ		
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.	
Positron Emission Tomography (PET) scan	This scan provides more detailed pictures of the prostate and surrounding areas and detects small changes in other soft tissues and bones.	
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.	

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PSA blood test level	the blood and the level can be measured.
PSA doubling time	The amount of time it takes for the PSA level to double.
Prostate Specific Membrane Antigen (PSMA) PET scan	This is a special scan to clearly determine if prostate cancer has spread. At the present time (July 2019) it is not yet available in Scotland but potentially available from late spring 2020.
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.
Robotic assisted radical prostatectomy	Surgery to remove the entire prostate by minimally invasive surgery using computer assisted technology.
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.

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Staging	The size of the cancer and whether it has spread outside the prostate – the term is used when recommending treatment.
Stereotactic body radiation	A type of external beam radiation that uses a tracking system to monitor movements or slight changes of position of the prostate
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.
т	
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 to 'trim off' part of the prostate.
u	
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.

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V	
Vomiting	Being sick.
W	
Watchful waiting	No active treatment is given but the cancer will be monitored and check-ups given.
White blood cell count	The amount of white blood cells. White blood cells are important to fight infection.
Abbreviations you mig	ht hear used in prostate cancer care
CT or CAT scan	Computerised tomography
DRE	Digital rectal examination
EBRT	External beam radiotheraphy
ED	Erectile dysfunction
GnRH agonists	Gonadotrophin-releasing hormone agonists
or analogues	
HIFU	High intensity focused ultrasound
MDT	Multi-disciplinary team
MRI scan	Magnetic resonance imaging
MUSE	Medicated urethral system for erections
PET	Positron emission tomography
PSA	Prostate specific antigen
PSMA	Prostate specific membrane antigen
TNM	Tumour lymph nodes metastases
TRUS	Trans rectal ultrasound
TURP	Trans urethral resection of the prostate

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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.		

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	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			
	Spotlight on Watchful waiting to manage prostate cancer			
	Spotlight on Treatment for an enlarged prostate			
	Some of the medical illustrations used are from Nucleus Medical Media and where these are used are subject to copyright.			



## EARLY PROSTATE CANCER EXPLAINED



## 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	www.prostatescotland.org.uk Please see our website for additional support group details	0300 666 0236 0131 603 8660	information service
NHS 24	www.nhs24.com	111	1
Prostate Link UK	www.prostate-link.org.uk		
Prostate Cancer UK	www.prostatecanceruk.org	0800 074 8383	1
Macmillan Cancer Support Support Nurses	www.macmillan.org.uk	020 7840 7840 0808 808 0000	1
Cancer Research UK Cancer Infomation Nurses	www.cancerresearchuk.org	0300 123 1022 0808 800 4040	1
Edinburgh and Lothian Prostate Cancer Support Group	www.elprostatecancersupport.co.uk Livingston group: email: charliehogg@blueyonder.co.uk	07933 260 066 01506 845 981	√
Webmd	www.webmd.com		
Patient UK	www.patient.co.uk		
Medicine net	www.medicinenet.com		
UCAN Care Centre Ward 209, Aberdeen Royal Infirmary	www.ucanhelp.org.uk	01224 55033 (voicemail)	
Prostate Cancer Support Group Fife	Maggie's Centre Victoria Infirmary, Kirkaldy	01592 647 997	
Scottish Borders Prostate Cancer support group	Macmillan Centre Borders General Hospital	01721 722 655	
Prostate Buddies D&G	www.prostatebuddiesdandg.org.uk		

# Maggies centres often host Prostate Cancer Support Groups.

<b>Maggie's Aberdeen</b> , Aberdeen Royal Infirmary, Elizabeth Montgomerie Building, Westburn Road, Foresterhill, Aberdeen, AB25 2UZ,	telephone 01224 645928,	email aberdeen@maggiescentres.org
<b>Maggie's Dundee</b> , Ninewells Hospital, Tom McDonald Avenue, Dundee, DD2 1NH,	telephone 01382 632999,	email dundee@maggiescentres.org
<b>Maggie's Edinburgh</b> , The Stables, Western General Hospital, Crewe Road, Edinburgh, EH4 2XU,	telephone 0131 537 3131,	email edinburgh@maggiescentres.org
<b>Maggie's Fife</b> , Victoria Hospital, Hayfield Road, Kirkcaldy, KY2 5AH,	telephone 01592 647997,	email fife@maggiescentres.org
<b>Maggie's Forth Valley</b> , Forth Valley Royal Hospital, Stirling Road, Larbert, Stirlingshire, FK5 4WR,	telephone 01324 868 069,	email forthvalley@maggiescentres.org
<b>Maggie's Glasgow</b> , Gartnavel General, 1053 Great Western Road, Glasgow, G12 0YN,	telephone 0141 357 2269,	email glasgow@maggiescentres.org
<b>Maggie's Highlands</b> , Raigmore Hospital, Old Perth Road, Inverness, IV2 3FL,	telephone 01463 706306,	email highlands@maggiescentres.org
<b>Maggie's Lanarkshire</b> , Monklands Hospital, Monkscourt Avenue, Airdrie, ML6 0JS,	telephone 01236 771199,	email lanarkshire@maggiescentres.org

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

For more information on support groups please see our website www.prostatescotland.org.uk/help-and-support-for-you/support-groups



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This booklet has been compiled by Prostate Scotland with advice from PAGES (Prostate Advisory Group Prostate Scotland). Prostate Scotland acknowledges the help and support from the members of the group: Professor Alan McNeill, Consultant Urologist, Western General Hospital, Edinburgh. (Chair of PAGES) Mr Brian Corr, Urology Clinical Nurse Specialist, Raigmore Hospital, Inverness Dr Andrew Dunlop, General Practitioner Principal, East Calder Medical Practice, West Lothian Mr Graham Hollins, Consultant Urologist, University Hospital, Ayr Dr Rob Lester

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