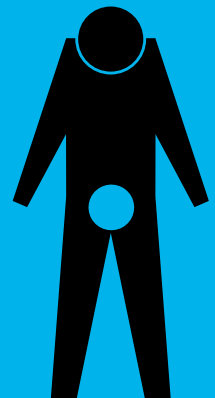


# An introduction to advanced prostate cancer



## Introduction

Being told by the doctor or specialist nurse that you have advanced prostate cancer, or that your cancer has come back, can come as a shock and are words that you and your family didn't want to hear. Although advanced prostate cancer (or metastatic prostate cancer) can't be cured it can be treated and controlled.

So, although this news may be very upsetting, and it may be some time before you take it all in, there are a range of treatments that your doctor may offer; for instance there are different types of hormone therapy, radiotherapy and chemotherapy to help you live as full and active a life as possible with advanced prostate cancer.

If there is a prostate cancer support group in your local area you will meet others who are enjoying life, even with advanced prostate cancer. This lets you know that you and your family are not alone and gives you a sense of what is possible.

You may be reading this for more information because:

- You are having tests and examinations to find out more about your prostate cancer, in other words, you are being investigated to find out the stage of your prostate cancer
- You have already been diagnosed with prostate cancer which has spread outside the prostate to other parts of the body
- You have previously had treatment for prostate cancer, but it appears that your cancer has come back again

The three goals in treating advanced prostate cancer are to:

- Help you feel better generally, lead as full and enjoyable a life as possible and try to improve your quality of life
- Relieve any symptoms that you may be having
- Slow down the rate that your cancer is developing

## How to get the most out of this booklet

The aim is to give you and your family information and help you understand more about prostate cancer, the tests and examinations you may have and what the results might mean. In the series of booklets, treatments, life with advanced prostate cancer, newer therapies and clinical trials are explained.

You may hear this called your cancer journey and there are many people and organisations that can help you and your family along the way. At the back of the booklet you will find details of organisations, which may be able to help you at different stages on your journey.

Some men may choose to read this booklet from cover to cover. Others may only want a little information at first, and prefer to dip in and out of this booklet, then read the other booklet(s) in the advanced prostate cancer series that are important to them at that time.

For ease of use, this booklet has been divided into sections by topic. Each section may give you more information than you need at the present time. So, if this is the case, it may help to look over the guide on page 5 so you can choose which sections are most important for you now. Within the booklet, at the start of each section, there is a brief outline of what it is about, followed by the more detailed explanation.

Although you may not need all the information in the booklet right away, it is there if you or your family want it in the future and it may help you on your cancer journey.

Once you have had time to take things in, it may help you and your family to:

- Find out more about prostate cancer
- Ask your doctor or specialist nurse to talk over anything you are not sure about
- Understand the stage and grade of your cancer
- Know the treatment choices available and suitable for you

- Talk to other men and their families who have had to deal with the same problems
- Ask the specialist nurse if there are any support groups in your area or if there is someone you can speak to
- Ask what may happen in the future

In addition to this booklet, there are more detailed booklets in the advanced prostate cancer series:

**Booklet 2** - Hormone Therapy Explained, Treating Bone Pain and Spinal Cord Compression and Chemotherapy Explained

**Booklet 3** - Life with Advanced Prostate Cancer

**Booklet 4** - Clinical Trials Explained and Newer Therapies Explained

Details of these can be found at the back of this booklet

**Please note:**

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

## Section 1

### About the prostate and prostate cancer - page 8

#### **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 new to the topic and who want some background information

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

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

## Section 2

### How advanced prostate cancer is diagnosed - page 13

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

- The PSA test and Digital Rectal Examination (DRE)
- Trans Rectal Ultrasound (TRUS)
- Prostate biopsy
- Bone scan
- MRI scan (Magnetic Resonance Imaging)
- CT scan (Computerised Tomography)

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

Men who have seen their GP for initial tests but have been referred to the urologist in hospital for further tests. It may help men understand what the tests are for, what happens and what the results might mean

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

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

## Section 3

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

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

- The Gleason Score; information on what it is and what the Gleason Score means
- 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 so they can discuss these with their doctor

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

Men and their families who already understand what the Gleason Score and Staging mean

## Section 4

### The next step following the results of tests and investigations – page 29

#### **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

#### **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 less 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 5

### A brief guide to treatments - page 32

**This section gives an outline of treatments for advanced prostate cancer**

- Hormone therapy
- Treating bone pain and spinal cord compression; this talks through the use of pain-killing drugs, radiotherapy, Strontium 89 and Bisphosphonates
- Chemotherapy

**Who might find this useful:**

Men who want some information on all of the treatments available. They can then decide which of the other booklets in the series might be most useful for them to read if they are starting on, or have just started, a particular treatment

**Who might find this least useful:**

Men who have already started on a particular treatment and have a good understanding of what it is

## Section 6

### A brief guide to making decisions - page 36

**This section will help you make decisions about:**

- Your treatment
- Taking part in a clinical trial

**This section gives an outline of how you can be involved in making decisions:**

- Why being involved can be important for the man and his family
- How you and your family might be involved in making decisions

**Who might find this useful:**

Men and their families who are thinking about how much they want to be involved in making decisions about their treatment or taking part in clinical trials

**Who might find this least useful:**

Men who are already involved in helping make decisions or have already made these decisions

## Section 1

### About 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 and out of normal control causing a growth or tumour. Advanced prostate cancer means that the cancer has broken through the wall of the prostate into surrounding tissue, or spread to bones, lymph glands or to other organs in the body e.g. liver, lungs
- 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 12 men may develop prostate cancer
- Some signs may be problems with passing urine, pain or stiffness in the lower back, hips or upper thighs, feeling more tired than usual, generally feeling unwell, losing weight, not having much of an appetite



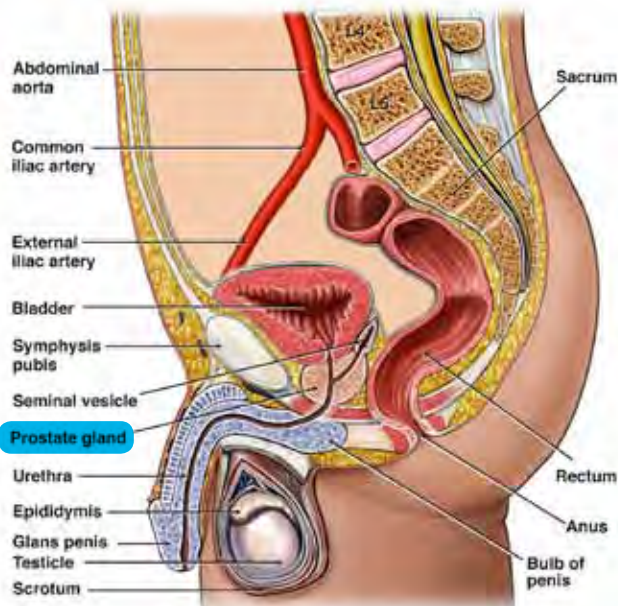
### What is the prostate?

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 sexual intercourse.

Only men have a prostate. It starts out about the size of a pea then slowly grows to the size of a walnut, until the man is in his 20s. Around the age of 40 it starts to grow or enlarge again and this may cause problems for a man when passing urine.

### Where is it?

The prostate is inside the pelvis, just below the bladder and in front of the back passage. It wraps around the tube, called the urethra, through which urine flows out of the bladder and semen passes out through the penis. So, 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 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 develop abnormalities, multiply and grow faster than normal. This causes a growth or a tumour. As the prostate is inside the body this growth can't be seen and often causes no symptoms in the early stages.

### 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 that surrounds the prostate or into the seminal vesicles which 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 then 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 bladder, bowel, lungs or liver. About 20% of men currently have advanced or metastatic prostate cancer at the time of diagnosis (SCAN Urology report 2009). We hope that with greater awareness this proportion will continue to fall.

### What are the symptoms or signs?

Problems with passing urine. You may:

- Need to pass urine more often than before and more often during the night
- Find it difficult to start passing urine
- Need to get to the toilet quickly
- Take longer to empty your bladder
- Stop and start when passing urine

Keeping a diary of visits to the toilet may be helpful for the doctor.

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

### **What causes prostate cancer?**

At the moment, no one really knows what causes prostate cancer or why some cancers are more aggressive than others.

However, the chance of getting prostate cancer increases with:

Age	As a man gets older – it mainly affects men over 65, but it can affect younger men in their 40s
Family history	<p>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</p> <p>This is also important to think about if you have a son(s) in their forties onwards</p> <p>If there is a strong family history of certain kinds of breast cancer</p>
Background	If the man is from an African/Caribbean background then he is 3 times more likely to develop prostate cancer and up to 5 years earlier

If you are concerned about your family history of prostate or breast cancer, you may want to talk this over with your GP.

Other symptoms of advanced cancer will depend on where the other cancer or secondary is in your body.

The symptoms of advanced or metastatic prostate cancer depend on the size and spread of the cancer. If the cancer hasn't spread very much then you may not have many symptoms or possibly no symptoms at all.

How you might be feeling:

- More tired than usual
- Generally feeling unwell
- Losing weight
- Loss of appetite

Advanced prostate cancer when it spreads, tends to spread first of all to the bones. With cancer that has spread to the bones you may have:

- A niggling ache in the affected bone
- Pain in the affected bone may make it difficult to move around or sleep at night and you may have to take pain-killers
- Pain or ache in the affected bone all the time
- Deep pain or stiffness in the lower back, upper thighs or hips
- Weakness in the bone, so it can break more easily

If you have a numb feeling, pins or needles or weakness in your legs, arms or body you should tell your doctor immediately as this may need urgent treatment.

You should also let your doctor know if you have had problems with constipation or not being able to control your bladder or bowel as the doctor will probably want to find out what is causing this.

If you are worried by or have any other symptoms which last for more than a few weeks then you should let your doctor know, but remember these may not be anything to do with your cancer.

## Section 2

### How advanced prostate cancer is diagnosed

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

- Tests and examinations such as PSA level and Digital Rectal Examination are explained. Tests and scans which you may have done, or have already had, are explained following referral to a urologist
- A Trans Rectal Ultrasound (TRUS) uses sound waves to give a clear picture of the shape and size of the prostate on a screen. This may show areas in the prostate where the urologist or specialist nurse may want to take samples
- Prostate biopsy. During a biopsy a small probe is passed into the back passage and a special needle is used to take tiny samples of prostate tissue from different areas in the prostate, usually with a local anaesthetic. These samples are sent to a lab to be examined for any signs of prostate cancer. The results are usually sent to the hospital consultant within 2 - 3 weeks who will then arrange to discuss the results and possible treatment with you
- Bone scan. A bone scan may be done to find out if the cancer has spread to the bones, as, if prostate cancer spreads, it 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 indicate that a secondary tumour might be present. The scan is examined by a specialist doctor in radiology who will send a report to your urologist or oncologist
- X-ray. An x-ray may be done to check out normal wear and tear on bones and joints

- MRI scan (Magnetic Resonance Imaging). An MRI scan uses magnets rather than x-rays to produce detailed pictures of the prostate, surrounding tissues, bones and other organs. It is usually done after a prostate biopsy has found cancer in the prostate, although in some centres, certain patients may have an MRI scan before having a biopsy. It shows whether the cancer remains within the prostate or has spread to other organs or tissues. This 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

This section deals with the tests and examinations done to help the doctor understand more about your cancer, where it has spread to and so decide the most suitable treatment choices for you.

### Tests and examinations

You may choose to read all the information in the following section or only the tests and examinations that you may not be so familiar with. The list opposite gives a guide of where to find the information that you want to read.

Please remember that this information is a general guide. As there is more than one approach, there may be slight differences in the way tests are carried out by your GP or in the hospital you are attending. If you are at all unsure, ask your doctor or specialist nurse for more advice.

Test or examination	Page
Prostate Specific Antigen (PSA) blood test	15
Digital Rectal Examination (DRE)	16
Trans Rectal Ultrasound (TRUS)	17
Prostate biopsy	17
Bone scan	20
X-ray	21
Magnetic Resonance Imaging (MRI scan)	21
Computerised Tomography (CT scan)	22

### Prostate Specific Antigen or PSA blood test

PSA is a protein that 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, which will usually be higher if there is disease in the prostate and is a useful test for monitoring diseases of the prostate such as prostate cancer.

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. If not, you can also get a log book as a download from [www.prostatescotland.org.uk](http://www.prostatescotland.org.uk) or by contacting us at [info@prostatescotland.org.uk](mailto:info@prostatescotland.org.uk) or by calling 0131 226 8157 for a copy.

### What is the normal level for PSA?

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

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

In general though, if your PSA level is very high then the chance of having prostate cancer or your cancer recurring is greater. The PSA test is also used to check whether your prostate cancer may be growing and if any treatment you are having is working.

### **What does it mean if my PSA level is rising?**

If your PSA level is rising, it could mean that the cancer may be growing larger within your prostate, in the area around the prostate or somewhere else in your body.

If your PSA level is rising very quickly, this suggests that the cancer is, or has become, more aggressive. A PSA level over 20ng/ml tends to mean that the cancer is more likely to have broken through the wall of the prostate and started to grow (or metastasise) in other parts of your body.

Your doctor or specialist nurse may mention PSA doubling time. This is a measure of how quickly your PSA level is rising and is used to keep a check on your prostate cancer. So, the longer it takes your PSA level to double the better.

A rising PSA level may be particularly important if you have already had surgery to remove the prostate (radical prostatectomy). After a radical prostatectomy, PSA levels fall very quickly and become almost undetectable, so a rising PSA level could indicate that there is recurrent disease or that some cancer cells had already spread outside the prostate.

### **Digital Rectal Examination or DRE**

A DRE gives doctors an idea of the shape, size and condition of your prostate. The doctor checks for any hardened area, odd shape, or unusual lump(s).

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



### What next?

If your GP has concerns, you will be referred to the hospital to see a doctor who specialises in this type of disease, or, you may already be attending a urologist. The urologist will probably want you to have more tests before making a diagnosis.

### Trans Rectal Ultrasound or TRUS

This test takes about 15 minutes and is usually done to guide a needle to take small samples from the prostate using a local anaesthetic to reduce any discomfort.

You will be asked to lie on your left side with your knees bent up towards your chest.

The doctor or specialist nurse gently passes a small, lubricated ultrasound instrument into your back passage. 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 shows areas where the doctor or specialist nurse might need to take small samples from your prostate. This is called a prostate biopsy.

### Prostate biopsies

Biopsies are done in hospital by a doctor or specialist nurse during a TRUS (Trans Rectal Ultrasound). A biopsy means that tiny samples are taken from the prostate using a special needle, the number taken may vary but is usually 10 or more. In some centres, certain patients may be asked to have an MRI scan before a biopsy. However, if your PSA level was very high and your prostate feels cancerous on DRE and the doctor has seen signs that the cancer has already spread to the bones, then you may not need a biopsy.

### Why is it done?

- If your PSA level is high
- If the DRE found an unusual lump or hardened area in your prostate
- If your prostate was not a normal shape or size

### **Before the biopsy tell the doctor or specialist nurse:**

- If you have any problems with bleeding
- If you have an allergy to any medicines like antibiotics
- About all the medicines or herbal pills you are taking
- If you take any drugs to thin your blood such as warfarin, clopidogrel, aspirin or non-steroidal anti-inflammatory drugs

Most likely you will need to sign a consent form agreeing to have the biopsy done. Before signing, you can talk over any concerns or worries you may have about the biopsy with the doctor or specialist nurse and what the results may mean for you.

### **What happens?**

The urologist or specialist nurse might ask you to take antibiotics immediately before and a few days after the biopsy. This is to help stop you getting an infection.

You may also be given a local anaesthetic to reduce any discomfort during the biopsy.

You will be asked to lie on your left hand side with your knees bent up to your chest. A small probe is gently passed into your back passage up to your prostate. The doctor guides a small needle to take tiny samples from your prostate. The number taken may vary but is usually 10 or more. 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, although usually the local anaesthetic stops you feeling any pain. A biopsy usually takes about 10 – 15 minutes. After the biopsy you will be asked to pass urine before you go home. You may also be given a date to come back to see the doctor or specialist nurse.

### **Then what happens?**

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

### **Are there any 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.

You may find:

- Blood in your urine
- Blood in your semen
- Blood when you pass a motion
- A dull ache in the area between your scrotum and back passage
- It may be best to avoid sexual intercourse for a few 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 or shivering then you should contact your doctor straight away.

### **Going Home**

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.

If you are given antibiotics to take at home, it is important that you read the instructions carefully and make sure that you finish the full course of tablets.

If you are in a lot of pain then you may be able to take over-the-counter pain-killers such as paracetamol or ibuprofen. Ask the doctor, specialist nurse or pharmacist if you are unsure what to take.

Take it easy for the rest of the day.

Try to drink plenty of fluids to help flush out any possible infection.

### **How long before I get the results?**

The results will go to your consultant in about 2 - 3 weeks time. This may vary from area to area so ask the doctor or nurse who did the biopsy when you are likely to get your results. If you don't hear, there's no harm phoning the hospital to ask when you are likely to hear about your results.

### **Bone scan**

Your doctor may suggest that you have a bone scan to check if the cancer has spread outside the prostate, especially if you are feeling pain or an ache in a bone. This is because prostate cancer tends to spread to bones first of all.

Some hospitals may send or give you information about the bone scan so it's 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 needs time to circulate around your body and is slowly taken into your bones.

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

When you go back, you will most likely be taken to a scanning room. In some places you may be asked to put on a hospital gown, but in other hospitals you won't 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 scanned by a special camera looking for any 'hot spots'. Hot spots are areas that take up a lot of the radioactive material and this may point to an area of tumour or secondary cancer being present. However, old fractures or arthritic changes can also show up as hot spots, so it is worth telling your doctor or radiographer about these. 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 an 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. Maybe make a note of this date in your Prostate Log Book to remind you to ring if you haven't had the results through.

### **X-ray**

Your GP or urologist may ask you to have an x-ray done of your chest and bones. For some men an x-ray may be one of the first signs of having cancer. The x-ray is to check for any wear and tear in the bones and joints and may also find out if the cancer has spread to the bones or any other parts of your body.

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

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

An MRI scan uses magnets rather than X-rays to produce detailed pictures of your prostate, surrounding tissues, bones and other organs that can then be viewed. The machine is like a long tunnel that 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, there is some information on MRI scans overleaf.

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

Usually it's done after a prostate biopsy has found cancer in your prostate

but in some centres and for some patients it may be done before the 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 treatments most suitable for you.

### **What happens?**

- It's 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. This is to make sure that the MRI scan doesn't affect the metal implants
- If you don't like being in or have a fear of closed spaces tell the staff about this
- You will need to take off any jewellery or other metal objects as these can interfere with the pictures being taken
- 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

The scan usually takes between 30 - 40 minutes. When it's 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 may be done instead of an MRI scan but is done less often now, usually only if you suffer from claustrophobia (fear of closed spaces).

### **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.

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

### **Why is it done?**

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

### **What happens?**

- A special dye is injected into a vein usually in your arm to help make the pictures clearer. This might make you feel hot for a few minutes. Sometimes you might be asked to drink an aniseed tasting liquid that helps to make the pictures clearer
- 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
- 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 scan 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 for these. Writing the date down may help jog your memory or use the Prostate Log Book that may be included with this booklet.

## Section 3

### Test results and what they mean

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

- Doctors use the results of your tests and scans to check if and where the cancer has spread and help them decide how best to treat you. It can be really helpful for you to remember the results so you can talk about what these mean with your doctor.
- Gleason Score. This number gives an idea 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 looks for the types of cells which are most common and second most common. These are given a score between 1 and 5. Added together this gives your Gleason Score, usually between 6 and 10. This score indicates whether the cancer is likely to be low, intermediate or high-risk cancer.
- 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 contained inside 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?

The urologist or specialist nurse will talk to you about the stage and spread of your cancer and also about the treatment choices you may have.

- **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.
- **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, examines the samples taken from your prostate 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 quickly outside of the prostate.

The doctor looking at the cells decides which type of cell is most common and which is the most aggressive within your cancer. Each of these two cell types is then given a score from 1 to 5. These numbers are added together to give a final score out of 10. This is your Gleason Score. The lowest number is now usually 3+3 or 6. For instance if there was predominately Gleason 3 but a small amount of 4 and a tiny amount of 5 it would be scored as 3+5.

Your Gleason 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 with this booklet. (You can ask your doctor or specialist nurse for a copy, download from the Prostate Scotland website [www.prostatescotland.org.uk](http://www.prostatescotland.org.uk) or contact us at [info@prostatescotland.org.uk](mailto:info@prostatescotland.org.uk) or by calling 0131 226 8157 and a copy can be sent out to you).

Here's a guide to what the Gleason Score means:

Result	Low Risk	Medium Risk	High Risk
Gleason Score	6  The cancer is likely to remain in the prostate and grow slowly (be less aggressive).	7  There is an increased chance of the cancer breaking out of the prostate and spreading to other parts of the body.	8 - 10  There is a greater risk that the cancer will grow quickly (more aggressive) and may have already spread outside the prostate to the bones or other parts of the body.
PSA level ng/ml	10 or lower	10 - 20	More than 20

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

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

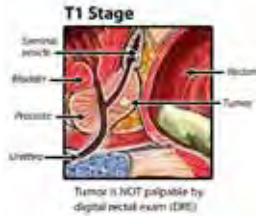
### Staging

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 the stage of the tumour (whether it is confined within the prostate capsule or has grown through it)
- the letter 'N' for lymph nodes
- the letter 'M' for metastasis or metastases

What does T stage mean?

**T1**



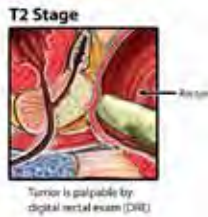
The tumour is too small to be seen during a scan and the doctor will not have been able to feel it when he/she examined the prostate.

This type of tumour shows up when the samples of tissue taken during the biopsy are looked at under the microscope.

This is called early or localised prostate cancer.

**T2**

The tumour is still inside the prostate



The tumour will be seen during a scan and the doctor will have been able to feel a lump or hard area when he/she examined the prostate.

This type of tumour is still inside the prostate.

This is also called early or localised prostate cancer.

**T3**

The tumour has broken through the capsule (cover) of the prostate

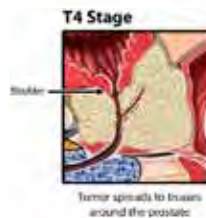


The tumour will be seen during a scan and the doctor can feel it breaking out through the wall of the prostate.

This type of tumour has spread outside the prostate to areas around the prostate, but not any other areas in the body.

This is called locally-advanced prostate cancer.

**T4**



The tumour has spread into the bones or other organs in the body such as the back passage, bladder, lymph nodes or less commonly the liver or lungs.

This is called advanced prostate cancer. Where the cancer has spread to other areas in the body the new site is called a secondary (secondaries) site or metastasis.

What does the 'N' stage mean?

The 'N' stands for lymph nodes.

Lymph nodes are part of the immune system and help fight infection or disease. 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, bone or other organs

## Section 4

### 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 the specialist nurse or your GP
  - to get in touch with a support group in your area
  - if someone attends your appointment with you
  - to write down any questions so that you can ask these at your next appointment
- Following test results, the type of treatment offered will be based on several things; the Gleason Score, stage of the cancer, PSA level, the man's age, other medical conditions and whether the potential side-effects of treatment would have a greater impact on the man's quality of life than the effect of the cancer
- A multi-disciplinary team (MDT) which includes urology surgeons, oncologists, radiologists, pathologists, and specialist nurses in urology or oncology will be involved in care and treatment. The decision made will also take into account the views of the man and his family

### Waiting for the results.....

For many men, being told that they have advanced prostate cancer and then having a range of tests and examinations can be very stressful. This can also be a very worrying time for wives, partners and the rest of the family. It may help if your wife, partner or close family member goes along with you to the doctor 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 support group as members have been diagnosed with prostate cancer, have undergone the same tests, gone through the anxiety of waiting for results and so understand how you and your family might be feeling.

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

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

Once the doctor has all your test results he/she will take a number of issues into account before deciding which treatment(s) may be most suitable for you.

The doctor does this by looking at:

- i Your Gleason Score or grade of your cancer – this is how the cells from your prostate looked under the microscope
- ii The stage of your cancer (or TMN) - this summarises how extensive your cancer is and whether it has spread
- iii Your PSA blood level
- iv How old you are
- v How much your symptoms are troubling you
- vi If you have any bone pain
- vii If you have or had any problems with your bowel or passing urine
- viii Any treatment you have already had for your prostate cancer
- ix Whether you have any other medical conditions affecting your health
- x If the side-effects of the treatment would have greater impact on your quality of life than the effect of the cancer.

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

They will:

- Have thought about these points and talk these through with you
- Suggest which treatment(s) may be most suitable and offered to you
- Talk to you about all your treatment choices, the benefits 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

## Section 5

### A brief guide to treatments

**This section gives an outline of the treatments for advanced prostate cancer**

- Hormone therapy; what it is and when it might be used
- Treating bone pain and spinal cord compression; this talks through treating pain using pain-killing drugs, radiotherapy, Strontium 89, Bisphosphonates, how to recognise signs of spinal cord compression and how this is treated
- Chemotherapy; what it is and when it might be used

The three goals in treating advanced prostate cancer are to:

- Help you feel better generally, lead as full and enjoyable a life as possible
- Relieve any symptoms that you may be having and possibly make your quality of life better
- Slow down the rate of your cancer growth

So, treatments for advanced prostate cancer are aimed at doing all of these things.

#### Hormone therapy

Hormone therapy or treatment is the standard treatment for men with advanced prostate cancer and works well for most men often keeping their cancer in check for several, and in some cases, many years.

Once prostate cancer has broken through the prostate wall and has spread to other parts of the body, a treatment is needed that tackles the cancer cells wherever they are in the body. The most successful way to do this is by giving hormone therapy that 'switches off' or removes the male hormone testosterone. This is sometimes also called **androgen deprivation therapy (ADT)**.



There are a few ways that hormone treatment can be given; by injection, taking tablets, or, very occasionally nowadays, by an operation. Sometimes the doctor may suggest switching from one kind of hormone treatment to another or having an injection and tablets together.

To check that hormone treatment is working, the doctor will see you regularly and will ask how you are feeling, about any side-effects from your treatment, examine you and check your PSA level.

If you want to find out more about hormone therapy, there is a booklet available called “Hormone Therapy, Treating Bone Pain and Chemotherapy Explained”. Your doctor or specialist nurse may give this to you or it is available by downloading from the Prostate Scotland website [www.prostatescotland.org.uk](http://www.prostatescotland.org.uk) or by contacting us at [info@prostatescotland.org.uk](mailto:info@prostatescotland.org.uk) on 0131 226 8157 and a copy can be sent to you.

### **Treating bone pain**

Once prostate cancer has broken through the prostate wall it most commonly spreads to the bones first of all (called secondaries or metastases), making the bones weak, and for some men causing pain. Bones nearest to the prostate such as pelvic bones, hips and lower spine, may be the first to be affected. You may feel this pain as a dull ache or sharp pain that can get worse when you move around. If you have any pain in your bones, let your doctor know about this as there are several ways to help with this pain.

#### Treating bone pain

- This talks about any potential pain from cancer, which drugs may be prescribed and the 3 steps of pain relief from these pain-killing drugs
- Radiotherapy (or palliative radiotherapy) is given as a small dose or doses to help with pain in the bones. This is very carefully planned to make sure it targets the cancer cells in the bones. You are encouraged to carry on with your daily routine as far as possible but resting when you need to. Doctors may give some medicines to help with other minor side-effects of the treatment
- Strontium 89 is taken up into bones and settles where there are metastases. There, it gives out very small amounts of radiation that kill the cancer cells

within bones, although you won't be 'radioactive'. It's given by an injection and can take up to 2 weeks to work. For the first 2 weeks there are some safeguards to follow when passing urine. You may be given a card to carry for the first few months, to give to others who may be treating you, to let them know that you have had this treatment.

- Bisphosphonates (you may hear this called zoledronic acid) work by strengthening bones and helping relieve pain. They are given through a drip in your arm every few weeks. There are some minor side-effects but, generally, most men cope with these really well. As a safeguard, men considering this treatment should have a dental check up and any dental treatment done before starting zoledronic acid.

### Spinal Cord Compression (SCC)

Spinal Cord Compression is pressure on the spinal cord and its nerves. Although this isn't very common, it's something that you should report to your doctors immediately. Signs to look out for include; pain in your back, a numb feeling or pins and needles in your fingers and toes, feeling a bit wobbly on your feet, problems passing urine or not being able to control your bowel.

To make sure of what is going on your doctor may send you for an MRI scan, CT scan or bone scan. If it's proved that you have SCC, then treatment is started straight away with the aim of shrinking the tumour and so easing pain. Treatment may include radiotherapy, steroids and resting in bed. Very occasionally, an operation may be required to relieve the pressure on the spinal cord.

If you want to find out more about bone pain and spinal cord compression, there is a booklet available called "Hormone Therapy, Treating Bone Pain and Chemotherapy Explained". Your doctor or specialist nurse may give this to you or it is available by downloading from the Prostate Scotland website [www.prostatescotland.org.uk](http://www.prostatescotland.org.uk) or by contacting us at [info@prostatescotland.org.uk](mailto:info@prostatescotland.org.uk) or by calling 0131 226 8157 and a copy can be sent to you.

## Chemotherapy

Chemotherapy actually means giving strong drugs to kill or stop the growth of cancer cells wherever they are in the body. The most common drug used is docetaxel or you may hear it called Taxotere®. This is called a 1<sup>st</sup> line treatment and there are 2<sup>nd</sup> line treatments available. The dose and how chemotherapy affects you will vary from man to man.

Chemotherapy is given by a drip going into a vein in your arm and the drug is slowly run through. In general, 1<sup>st</sup> line treatment is usually given as 6 - 10 cycles or treatments every 21 days and it's important to attend all your appointments. Chemotherapy affects each man differently, some men experience only minor side-effects, whilst for others, side-effects can be more pronounced.

If you want to find out more about chemotherapy, there is a booklet available called "Hormone Therapy, Treating Bone Pain and Chemotherapy Explained". Your doctor or specialist nurse may give this to you or it is available by downloading from the Prostate Scotland website [www.prostatescotland.org.uk](http://www.prostatescotland.org.uk) or by contacting us at [info@prostatescotland.org.uk](mailto:info@prostatescotland.org.uk) or by calling 0131 226 8157 and a copy can be sent to you.

## Section 6

### A brief guide to making decisions about:

- Your treatment
- Taking part in a clinical trial

**This section gives an outline of how you can be involved in making decisions:**

- Why being involved can be important for the man and his family
- How you might be involved in making decisions

Your doctor may give you information on a treatment or treatments for advanced prostate cancer, and for some men, offer them the chance to take part in a clinical trial. Some men are keen to have a say on their treatment, other men prefer to be guided by their doctors while for others the best treatment is a very clear cut decision. Let the doctor or specialist nurse know how you feel about helping make these decisions and how much you want to take part.

You may be asked:

- If you feel one treatment may be more suitable for you than another, so you can take part in helping decide on how your cancer may be treated
- Whether or not you want to take part in a clinical trial

Whilst helping make decisions 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 or taking part in a trial, the more satisfied and confident you are likely to be with your choices. You will not need to make any decisions on your own; doctors, nurse specialists and other men who have been in this same position are available to give you information, help and support along the way.

Taking part in making decisions can be as simple as:

- Knowing what your results are and what they mean
- Asking the doctor or nurse to explain anything you aren't sure about
- Asking your doctor questions about the treatment or trial
- Asking if you can make an audio-recording of your consultation with the doctor
- Talking over treatments with your family

If you want to find out more about helping make decisions, there is a booklet available called "Deciding on treatment; a step on your journey". Your doctor or specialist nurse may give this to you or it is available by downloading from the Prostate Scotland website [www.prostatescotland.org.uk](http://www.prostatescotland.org.uk) or by contacting us at [info@prostatescotland.org.uk](mailto:info@prostatescotland.org.uk) or on 0131 226 8157 and a copy can be sent to you.

## For more information.....

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

Organisation	Website	Contact number	Helpline available
Prostate Scotland	<a href="http://www.prostatescotland.org.uk">www.prostatescotland.org.uk</a>	0131 226 8157	
NHS 24	<a href="http://www.nhs24.com">www.nhs24.com</a>	0845 24 24 24	✓
Prostate Link UK	<a href="http://www.prostate-link.org.uk">www.prostate-link.org.uk</a>		
Prostate Action	<a href="http://www.prostateaction.org.uk">www.prostateaction.org.uk</a>	020 8788 7720	
The Prostate Cancer Charity (Includes some support group contact details)	<a href="http://www.prostate-cancer.org.uk">www.prostate-cancer.org.uk</a>	0800 074 8383	✓
Macmillan Cancer Support Nurses	<a href="http://www.macmillan.org.uk">www.macmillan.org.uk</a>	020 7840 7840 0808 808 0000	✓
Cancer Research UK Cancer Information Nurses	<a href="http://www.cancerresearchuk.org">www.cancerresearchuk.org</a>	020 7242 0200 0808 800 4040	✓
Edinburgh and Lothian Prostate Cancer Support Group	<a href="http://www.elprostatecancersupport.co.uk">www.elprostatecancersupport.co.uk</a>	0131 208 3067	✓
Prostate Cancer Group, Maggie's Inverness	email: <a href="mailto:highlands@maggiescentres.org">highlands@maggiescentres.org</a>	01463 706306	
Prostate Cancer Support Group, Maggie's Dundee	email: <a href="mailto:Lynn.Downie@maggiescentres.org">Lynn.Downie@maggiescentres.org</a>	01382 632999	
Webmd	<a href="http://www.webmd.com">www.webmd.com</a>		
Patient UK	<a href="http://www.patient.co.uk">www.patient.co.uk</a>		
Medicine net	<a href="http://www.medicinenet.com">www.medicinenet.com</a>		

## Other booklets in the Prostate Scotland series on advanced prostate cancer that you may find helpful

<p>Prostate Log Book</p>	<p>This is a useful little booklet that may help you keep track of your appointment dates, test results and any treatment changes. It gives space for you to fill in contact details of your doctors, specialist nurses as well as other organisations that you may want to contact for help or support</p>
<p>Booklet 2 Hormone Therapy, Treating Bone Pain and Chemotherapy Explained</p>	<p>This booklet focuses on the different ways of treating advanced prostate cancer with hormone therapy, how bone pain is treated and explains more on chemotherapy.</p> <p>It explains:</p> <ul style="list-style-type: none"> <li>• What hormone therapy is, when it's used, which drugs are used and some of the potential side-effects</li> <li>• How bone pain is treated with pain-killing drugs, radiotherapy, using Strontium 89 and bisphosphonates</li> <li>• What chemotherapy is, when it's used, which drugs are used and some of the potential side-effects</li> <li>• Questions you may want to ask your doctor</li> <li>• Contact details of useful organisations</li> <li>• Other booklets in the Prostate Scotland series on advanced prostate cancer</li> </ul>
<p>Booklet 3 Life with advanced prostate cancer</p>	<p>This booklet may be beneficial at any stage on your cancer journey. It is in 3 parts:</p> <p><b>Part 1</b> focuses on helping you think about treatment decisions and taking part in clinical trials. It gives:</p> <ul style="list-style-type: none"> <li>- Useful tips to help you make decisions about</li> </ul>

treatment or taking part in a clinical trial or study

- Some hints on how to get the most out of your appointment with doctors, specialist nurses or the research team

**Part 2** touches on some of the possible difficulties you may come across such as:

- Difficulties in passing urine
- Erectile dysfunction (ED or difficulties in getting or keeping an erection) and how these can be helped

**Part 3** Living with prostate cancer introduces you to what is meant by palliative care and the palliative care team

Contact details of an organisation who provide information on financial issues for families who may be concerned about the financial cost of cancer

- Contact details of useful organisations
- Other booklets in the Prostate Scotland series on advanced prostate cancer

Booklet 4  
Clinical Trials and  
Newer Therapies  
Explained

This booklet has two sections.

**Section 1** gives information for those men who are considering taking part in a clinical trial or have been referred to a trial by their consultant. It includes:

- What clinical trials are and who is likely to be on the research team
- Qualifying for a trial and informed consent
- Potential advantages and drawbacks of taking part in a clinical trial
- Some questions you may like to ask before taking part



**Section 2** focuses on two of the newer treatments. At the time of writing these newer therapies were only available in one centre or as part of a clinical trial or not available in Scotland. This booklet gives a brief explanation about:

Cryotherapy

- What it is, what happens, possible side-effects and possible advantages and drawbacks. It puts forward questions you may like to ask your doctor

High Intensity Focused Ultrasound (HIFU)

- What it is, what happens, possible side-effects and possible advantages and drawbacks. It puts forward questions you may like to ask your doctor
- Contact details of useful organisations
- Other booklets in the Prostate Scotland series on advanced prostate cancer

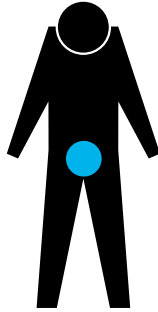
Booklet 5  
Glossary and what  
the medical words  
mean

You may like to ask your consultant, specialist nurse or GP if they have copies of these booklets that they could give you.

Alternatively, all of these booklets are available from Prostate Scotland. They can be downloaded from our website [www.prostatescotland.org.uk](http://www.prostatescotland.org.uk) or by contacting us on [info@prostatescotland.org.uk](mailto:info@prostatescotland.org.uk) or 0131 226 8157 and copies can be sent to you.

**Notes:**





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Prostate Scotland acknowledges the help and support from the members of the group:

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

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