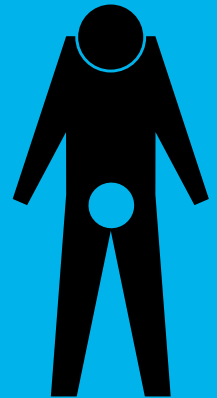


# Life with advanced prostate cancer



## Introduction

The three goals in treating advanced prostate cancer are to:

- Help you feel better generally, and 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 that your cancer is developing

Living with advanced prostate cancer may not be easy but there are things that can be done to help, and people who can support you and your family with any difficulties or worries you may have. Tell your doctor about anything that's troubling you as they may be able to help or put you in touch with other people or organisations that can help. So, this booklet sets out to give you guidance on; making decisions about your treatment or taking part in clinical trials; some of the difficulties you may come across such as possible problems with passing urine; getting and keeping an erection and how the palliative care team can help at any point on your cancer journey.

Page	What's included
3-7	<b>Part 1 Making decisions</b> What you need to know to help you make decisions about treatment or taking part in a clinical trial or study
8-11 11-12	<b>Part 2 Dealing with some of the potential difficulties you may come across</b> TURP for problems passing urine Treatments for erectile dysfunction (ED)
13-15 17	<b>Part 3 Living with advanced prostate cancer</b> An introduction to palliative care and what the team can offer Additional booklets in the Prostate Scotland series on Advanced Prostate Cancer

**Please note:**

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

## Part 1

### **A guide to making decisions about treatment and taking part in a clinical trial or study.**

Whilst this may sound daunting to you at first, it has been shown that the more you and your family are involved in helping to make the decision about treatment, or taking part in a clinical trial, the more satisfied and confident you are likely to be. You will not need to make decisions on your own - doctors, nurse specialists and often other men who have been in this same position are available to give you information, help and support along the way.

## Introduction

It is recommended that you spend some time thinking about what is right for you when deciding on treatment or taking part in a clinical trial for your prostate cancer. Ask the doctor, specialist nurse or member of the research team when you need to make your decision by. It's easy to understand why some men want to start treatment right away. 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 important decisions too quickly. Try looking at the videos and information about treatments on the Prostate Scotland website, too.

If you have been offered the opportunity to take part in a clinical trial and you are thinking about it ask the doctor, specialist nurse or member of the research team for more information or if you are not sure about anything and when you need to make your decision by.

### **Who can I talk to?**

- Members of the multi-disciplinary team (MDT) from the hospital who are looking after you – consultant urologist, consultant oncologist, specialist nurses in cancer or urology
- If you are thinking about taking part in a clinical trial, then talk to the research team
- Your GP
- Your partner
- Your family and friends
- Prostate cancer support group whose members have experienced prostate cancer

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

- Your general health
- The grade of your prostate cancer
- The size and position of the cancer within the prostate
- Your PSA level and how quickly it is rising
- 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 well-being 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 these might be to your family.

There may be a leaflet included in the pocket at the back of the booklet which may help you reach a decision, if not, you can ask staff in the hospital for a copy or download it from our website [www.prostatescotland.org.uk](http://www.prostatescotland.org.uk). It's called 'Deciding on treatment: a step on your journey'. While you are working this out, it may be worthwhile to ask someone else to help you e.g. the specialist nurse, speaking to someone on a telephone helpline or someone from a prostate cancer support group.

3. If you are deciding whether to take part in a clinical trial or not, then you can speak to a member of the research team. If you already have the informed consent form, then look through this and list any questions you may have. There is a booklet available from Prostate Scotland called 'Clinical Trials and Newer Therapies Explained' and your consultant may already have given you a copy of this. If not, then you can download the booklet from the website or contact Prostate Scotland at [info@prostatescotland.org.uk](mailto:info@prostatescotland.org.uk) or by phoning 0131 226 8157 and a copy can be sent to you. There is a list of possible questions in the booklet that you may like to ask the research team so that you can make the most of your appointment with the doctor from the team.
4. Many men and their partners find it helpful to meet with the urology surgeon and oncologist to talk over the treatment choices or the research team if taking part in a trial.
5. Look over the list of questions that are given at the end of each section in booklet 2, 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 or trial are likely to be and think about how this will affect all aspects of your life e.g. 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 or who have taken part in a trial. This will give you an idea of what actually happened in practice and how they felt.

However, it's important to consider that different men will put different values on the possible outcomes of treatment, as some things are more important to some men than others. It's important that you feel that you have made the best choice for you.

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

- The type and amount of treatment you are advised to have
- What the treatments involve
- Any other treatments that may be available
- The possible side-effects and how these will affect your life
- Whether you want to take part in a trial or not

**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, multi-disciplinary team or research team.

1. Being diagnosed with prostate cancer can stir up lots of strong feelings – fear, worry and anger. In all probability, it's not only you who will feel like this, it may also affect your partner and family, too. If you are struggling with this, speak to the staff in hospital or your GP about it.
2. Make a list of questions that you want to ask when you see the doctor, and take this with you to your appointment, as it's very easy to forget what you wanted to ask when you are sitting in with the doctor. This makes sure too, that you have asked everything you wanted to. You can jot down answers to your questions so that you can look back over these after your appointment. You could ask the doctor to write down any test results for you, as these will be important later on when he/she talks about your PSA level, Gleason Score or staging of your cancer.
3. As there is often a lot of information to take in, it is usually very helpful if your partner, family member or friend sits in while you see the doctor, as they can also ask questions, take notes or just listen. Then you can talk this over with them after your appointment. Tell the clinic staff, specialist nurse or doctor that you would like someone to sit in with you.

4. If you don't understand what you've been told, let the nurse or doctor know right away so they can explain it again. Your diagnosis, tests, test results, treatment choices and side-effects are not always easy to understand, so lots of people need another explanation and more time to take it all in.
5. You might feel that the doctors and nurses are too busy to answer your questions, but it's important that you are clued up on what will happen now and when the treatment or trial 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. If you are thinking about a trial then the informed consent form may also help.
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, or need to, in the comfort of your own home, where you may be feeling less stressed. You can buy a digital audio-recorder or Dictaphone from most electronic stores. This might also help you to write down any questions that you want to ask the doctor, specialist nurse or research team next time.
7. You can tell the doctor or nurse from the start how much you would like to take part in making the decision about your treatment. For example:
  - If you would like to take control of the decision
  - If you would like the doctor/nurse to make a recommendation/make a decision for you
  - If you would feel comfortable making a decision together with your doctors
8. Keep in mind what worries you and what is important to you.

**Reaching a decision on how you want your prostate cancer treated 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 confident with the treatment or trial if you have had a say in reaching a decision that is consistent with your own personal preferences and values.**

## Part 2

### **Dealing with some potential difficulties.**

If you are worried about any symptoms or if there's something troubling you then it's important to let your doctor or specialist nurse know as they may be able to help or put you in touch with other people or organisations that may be able to help.

This part of the booklet is to give you more guidance on a couple of the difficulties you may come across, such as possible problems passing urine or getting and keeping an erection.

#### **Problems passing urine?**

If you find that you are having difficulties passing urine, it may be because part of the tumour in your prostate is blocking the urethra (the tube that runs through the prostate taking urine from the bladder outside the body). To help with this, the doctor may suggest that you have an operation called a TURP (Trans Urethral Resection of the Prostate). A TURP is a fairly common operation for men who have an enlarged prostate. This operation doesn't take the prostate out, but, 'trims off' the part of the tumour pressing on the urethra which may make it easier for you to pass urine.

#### **What kind of anaesthetic?**

This may be done with a spinal anaesthetic where you will have an injection in your back that makes you numb from the waist down. Alternatively, you may have a general anaesthetic where you will be asleep during the procedure. Ask your doctor which you will have.

#### **What happens?**

(Please remember that this is meant as general guidance. As treatment procedures may vary slightly from hospital to hospital ask for more advice from staff at the hospital you are attending.)



A long thin telescope is passed into the urethra (the water pipe) through the penis. This telescope has a light and an operating insert, called a resectoscope, which has a wire loop. A controlled electric current is applied to the wire to 'trim off' the part of the prostate causing the blockage.

Then, a dilute solution called Glycine is used to wash away any blood and the 'trimmings' or pieces from the prostate. The operation usually lasts about an hour. After the operation, the bladder is washed out through a catheter with a salt solution (normal saline 0.9%). This is to prevent the build up of blood clots in the bladder whilst the effects of the operation settle down.

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

A catheter is a thin, flexible tube which goes up into your bladder, through your penis, and drains urine into a bag after your operation. You might notice that there is some blood in your urine, which will clear before the catheter is removed about 48 hours after your operation. Occasionally you may be sent home with the catheter still in place. The nurses in hospital will show you how to look after the catheter at home and may arrange for a nurse in the community to check on how you are doing.

### **How long might I be in hospital?**

You may be in hospital for about 2 - 3 days. Ask at the clinic for more information. You will usually get home when you start to pass urine or sometimes you may go home with your catheter still in place.

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

- Blood in your urine.

After your operation, you may see some blood or small blood clots in your urine, especially at 7 - 10 days. This is quite usual and might last for a few days. Don't be concerned unless you are having difficulty passing urine or passing large clots

- Pain or discomfort.

For a few days after your TURP, you may have some discomfort so you will be given some pain-killers to help. If you're concerned, or have a lot of discomfort, then you should contact your doctor

- Infection.  
Sometimes you might get a urinary tract infection. You will be given antibiotics if this happens
- Retrograde ejaculation.  
Most men (70 - 80%) who have a TURP will experience retrograde ejaculation after the operation. This means that at the end of intercourse nothing will come out of your penis because the semen has passed backwards into your bladder rather than down the penis. It won't do you any harm and will pass out in your urine the next time you go to the toilet but it will make your urine look cloudy

Retrograde ejaculation can, of course, affect fertility, although libido and fertility may already have been affected if you are receiving hormone treatment.

### **How long will these side-effects last?**

Most side-effects and symptoms settle down over 3 - 4 weeks after your operation, although some urinary symptoms such as urgency and frequency may take longer to settle down and retrograde ejaculation is usually permanent when it occurs.

### **Getting home**

Even though you don't have a wound you have still undergone a significant operation and it will take time to recover. Here are a few simple steps to help with your recovery.

- Heavy lifting. It's best to avoid lifting anything too heavy for the first 2 weeks or so
- Operating heavy machinery. It's best to avoid this for a short period of time.
- Exercise. You may be able to go back to light exercise and activities after a week or so
- Work. You may need to take some time off work
- Driving. It is best not to drive for up to 2 weeks but ask your doctor for more guidance on this
- Drinking (but not alcohol). Try to drink about 8 glasses of water every day to flush the bladder out

- Try to eat plenty of fresh fruit, vegetables, pulses and wholegrain foods to avoid constipation. If you are constipated, you may need a laxative. Ask your doctor for more information about this

### **Erectile dysfunction (ED - sometimes called impotence)**

With some of the treatments for your cancer, you may find that a common side-effect is not being able to get or keep an erection firm enough to have sexual intercourse. Although you may not find it easy, or you might feel a bit embarrassed, talking about something as personal as erectile dysfunction, the doctors and specialist nurses are used to hearing about this and helping men with this difficulty.

Another common side-effect is losing interest in having intercourse. You might hear this called loss of libido.

Rather than trying to avoid the issue, talk to your partner about your worries or anxieties. In all probability, your partner will be very understanding about how you are feeling. Perhaps you may want to speak to the doctor or nurse about this together.

All this may be upsetting and worrying for the man and his partner but there are now many things which can be done to help. The doctor or specialist nurse can give advice and may suggest you try some kind of medication, so don't be afraid to ask.

### **Tablets**

Tablets that may help can be prescribed by your doctor; such as Sildenafil (commonly known as Viagra®), Vardenafil (also called Levitra®), Tadalafil (which is known as Cialis®). These work by increasing the blood supply to the penis to help you have an erection.

If you take these, some side-effects to look out for are: headaches, dizziness, nausea, blurred vision, flushing of the face and indigestion and tummy upset. Men with heart problems should check with their doctor before taking these.

### **Injection**

A drug which is injected into the penis is very successful for some men. The

drug makes the blood vessels in the penis swell and so it becomes erect.

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

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

This time, a small pellet containing the drug is released into the penis helping to give an erection.

Some of the ways this may affect you include a painful long lasting erection, some pain, slight damage to the urethra.

### **Vacuum pumps**

If injections or tablets haven't helped or if you prefer another option then you can try a vacuum pump. This works by suction drawing blood into the penis helping to make the penis erect.

### Part 3

#### **Living with advanced prostate cancer.**

Although you (and your family) would probably prefer to live without the diagnosis of advanced prostate cancer, this doesn't necessarily mean that you can't have as full and active a life as possible and carry on with many of your normal day-to-day activities. Each one of you may have all sorts of concerns and a whole host of feelings at the moment.

In many areas there are prostate cancer support groups that you may like to attend where you and your family can go along and speak to other men who may have had a similar diagnosis or treatment.

There are many ways and many people who can help you enjoy and get the most out of life.

No matter what kind of treatment you've had and where you are on your cancer journey, it's important that you (and your family) benefit from having the best quality of life that you can.

This is where palliative care can help. Palliative care is treatment aimed at relieving the symptoms of advanced prostate cancer (or in fact any serious illness) which can't be cured, providing support and improving the person's quality of life. This is not only for you but for your family and loved ones too.

Palliative care can begin at any time during your cancer journey and research has shown that the earlier palliative care is begun the more likely you are to live longer, get all the emotional support needed and plan ahead for the future.

Palliative care is not what a lot of people think it is. Many people connect palliative care with the final stages of terminal illness or hospice care but this is not necessarily the case, although hospices can play an important role in palliative care. In all probability, there will be a team of people (Palliative Care Team) who will work alongside the other doctors and nurses you see for your treatment.

### **Who might I meet in a palliative care team?**

All palliative care teams will be made up slightly differently, so it's good to get to know who is on the team in your area. As a general guide, there may be:

- Doctors who specialise in palliative care
- Nurses who specialise in palliative care
- Pharmacists who specialise in palliative care
- Social workers
- Physiotherapists
- Occupational therapists
- Dietitians
- Counsellors
- Those able to give emotional or spiritual support

Remember, there is one person who has the most important role in all of this – YOU (and your family). Your role as part of the team is a very important one. You know best how you are feeling, your symptoms, the amount of discomfort or pain you have and so you may be in the best position to let the palliative care team know or ask for help with something that is troubling you.

### **What might palliative care teams be able to offer?**

This is certainly not a complete list as the palliative care team in your area may offer much, much more but, generally, things such as:

- Advice on dealing with and getting relief from pain
- Giving practical advice on some of the symptoms you may have like feeling sick, diarrhoea, constipation
- Listening and talking to you and your family

- Perhaps encouraging you to join in a wide range of activities that you had never thought of before
- Perhaps encouraging you to try some of the complementary therapies available

If you would like more information on palliative care and the palliative care team, then ask the doctor or specialist nurse for more information.

### **Money worries**

Some people living with advanced prostate cancer may worry about money. Whilst financial issues are not included in this booklet, there is a range of information available on the Macmillan Cancer Support website [www.macmillan.org.uk](http://www.macmillan.org.uk) including a booklet called “Help with the cost of cancer”. There is also an area on their website dedicated to financial matters that includes – ‘Benefits made clear’, financial information or talking to a cancer support specialist and how to contact a benefits adviser in your area. You can also contact Macmillan on 0808 808 000.

**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 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 will 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 1 An introduction to advanced prostate cancer</p>	<p>This is the first in the series of booklets about advanced prostate cancer and explains:</p> <ul style="list-style-type: none"> <li>• About the prostate and prostate cancer</li> <li>• How advanced prostate cancer is diagnosed</li> <li>• Test results and what they mean</li> <li>• The next steps after getting your results</li> <li>• A brief guide to treatments</li> <li>• A brief guide to making decisions about treatments and clinical trials</li> <li>• Contact details of useful organisations</li> <li>• Other booklets in the Prostate Scotland series on advanced prostate cancer</li> </ul>
<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 may be treated with pain-killing drugs, radiotherapy, using Strontium 89 and bisphosphonates</li> </ul>

- What chemotherapy is, when it's used, which drugs are used and some of the potential side-effects
- Questions you may want to ask your doctor
- 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

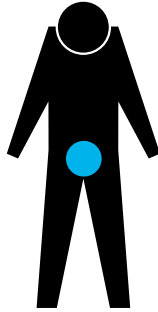
High Intensity Focused Ultrasound (HIFU)  
(not available in Scotland)

- What it is, what happens, possible side-effects and

	<p>possible advantages and drawbacks. It puts forward questions you may like to ask your doctor</p> <ul style="list-style-type: none"><li>• Contact details of useful organisations</li><li>• Other booklets in the Prostate Scotland series on advanced prostate cancer</li></ul>
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.



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