



PROSTATE INFORMATION

Advanced Prostate Cancer Clinical trials explained newer therapies explained





## **Advanced Prostate Cancer**

### Part 1 Clinical Trials Explained

### Part 2 Newer Therapies Explained

This booklet is to tell you more about clinical trials and newer treatments that **may** be available for you. For some men, the doctor treating you may suggest or offer you the chance to take part in a clinical trial or study or the opportunity to have one of the newer treatments.

The section on clinical trials explains to you; what they are, qualifying for entry to a trial, consenting to a trial and the potential benefits and drawbacks. Deciding whether or not to take part in a trial is something that you and your family shouldn't write off straight away nor rush into. It's recommended that you think through what this may mean for you and your family then make your decision.

The section on newer treatments tells you more about two of the newer treatments for advanced prostate cancer; Cryotherapy and High Intensity Focused Ultrasound (HIFU).

If your consultant has suggested cryotherapy as a possible treatment choice then you can read more about cryotherapy. At the time of writing, cryotherapy is the only newer treatment available in Scotland and is based at the Beatson Hospital in Glasgow.

The other treatment, High Intensity Focused Ultrasound (HIFU), is only available to men taking part in a clinical trial but at the time of writing was not available in Scotland. However, some information is included in the booklet should it become available in Scotland at a later date.

There is a very useful little booklet called "Life with prostate cancer" as part of this series. Part of this booklet is entitled 'Making decisions about treatment and clinical trials' so reading this may help you decide whether or not to take part in a trial, or whether you want to consider



some of the newer treatments. You may have already been given this by your doctor, but if not, you can get it from Prostate Scotland either by downloading from the website www.prostatescotland.org.uk or by phoning us on 0131 226 8157.

Page	What's included
4 8 11 12	<b>Clinical trials, making the decision on whether to take part</b> An introduction to clinical trials What happens during a trial Potential benefits and drawbacks Questions you may want to ask your doctor about clinical trials
14 15 16 18 19	<b>Cryotherapy</b> When might it be suggested What happens Possible side-effects Potential benefits and drawbacks Questions you may want to ask your doctor about clinical cryotherapy
20 20 21 22 22	<b>High Intensity Focused Ultrasound (HIFU)</b> When might it be suggested What happens Possible side-effects Potential benefits and drawbacks Questions you may want to ask your doctor about HIFU
24	Contact details of useful organisations
25	Other booklets available 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.

At any point on your cancer journey you may be asked to take part in a clinical trial. You and your family may have very mixed feelings about what this means. Choosing to take part in a clinical trial is an important decision for you to make, similar to deciding on which treatment would be best for you. So, it's often helpful to talk to others - your doctor, family, friends, specialist nurse, men in a support group and the doctor heading up the trial. Try to get as much information as you can on the trial and think about the potential benefits and potential drawbacks.

#### Introduction

#### What is a clinical trial?

Clinical trials or clinical studies are carried out to test new ways to treat prostate cancer. Men who have volunteered to take part in a clinical trial for prostate cancer may be involved in testing new treatments or existing treatments in combination e.g. a different way of giving treatment, before these are approved for wider use with other men.

So, a clinical trial is done to find out more about a new investigation or treatment:

- If it will work better than the treatment(s) already used
- If it doesn't work
- If it's safe to use for more men
- What the side-effects are
- If the side-effects are worse than with present treatments
- If it helped you feel better



However, being part of a clinical trial doesn't always mean that you get the new treatment. You may find that you are randomly chosen to be a part of the 'control group' to compare the standard treatment with the new treatment. Even if you are part of the 'control group' you will still have the standard treatment but with the added advantage of two specialist teams looking after your care.

Clinical trials are set up by a research team which will include doctors, nurses and research assistants. This team will work very closely with other health professionals, perhaps lab technicians, pharmacists, dietitians or social workers. The doctor who is treating your cancer, and who may in fact have referred you for the trial, will be kept up-to-date with what is happening so this can be recorded in your case notes.

Before setting up a trial the research team will have thought very carefully about what they want and need to find out. They will have developed an action plan (or protocol) for the trial that explains:

- The reason for doing the study
- How many men will be in the study
- What will happen during the study
- What tests or examinations the men will have
- What kind of information will be collected
- Guidelines for men who can and cannot take part in the trial. These are agreed at the start. These guidelines are called eligibility criteria and this explains why you might be eligible (or suitable) for some trials but not others

Clinical trials are usually based in hospitals. This could be the hospital where you are normally treated or you may have to travel to another hospital. Often, many hospitals around the country take part in the same clinical trial to give researchers more results to find out if this would benefit other men with prostate cancer. Sometimes, if your GP practice is involved with the trial, you may be seen there. As research like this can take a long time it may take a few years before men with prostate cancer will benefit. Unfortunately, not all clinical trials will result in new and better treatment.



#### Why you might be asked to take part in a clinical trial

Right from the start the trial will have guidelines that set out who can take part in the trial called 'inclusion criteria' and who can't take part called 'exclusion criteria'. These will depend on what the research team wants to look into and helps them to get accurate results. These criteria are based on things such as age, stage of your cancer, treatment you have already had, length of time since you last had treatment, results of certain tests, medicines you are taking and possibly any other health issues. The criteria are there to make sure that researchers get the most suitable men for the trial and to make the trial as safe as possible for the men taking part. So, you may be asked to join a study because you fit the criteria that the researchers are looking for, or in other words you qualify for the study.

#### **Informed consent**

In all probability you have signed consent forms in the past agreeing to have a particular procedure or treatment e.g. biopsy, surgery or radiotherapy. However, informed consent for taking part in a clinical trial involves more than reading and signing a form. Before taking part in any trial you will be given information about it and asked to sign a form agreeing to participate. This is called 'informed consent'. Informed consent isn't a contract and you can pull out of the trial at any time you want to. Informed consent is made up of 2 parts:

Part 1: Learning more about the trial and deciding if you want to take part

Part 2: If you take part, then you will continue to learn more about the trial as it goes on to help you decide whether you want to continue taking part in the trial



#### Part 1 may include

The doctor referring you to the trial will give you some information about the trial and why they think it might be suitable for you

The doctor or nurse from the research team will explain more about the details of the trial to you, your partner or family

The doctor or nurse from the research team will give you a form, called an informed consent form, which will give you details of the trial in writing. If you decide to take part in the trial then this is the form you would need to sign. As it contains all the information about the trial, you can look back over it throughout the time you are taking part in the trial

The details will include:

- The reason for the trial i.e. what researchers are hoping to find out
- The treatment you will be given
- What will happen to you during the trial e.g. tests and examinations that you may need to have
- If the trial involves various groups whether you might be put into a 'control' group
- Risks involved
- Benefits in taking part
- Drawbacks in taking part
- How long the trial will go on for
- Your rights as someone taking part in a trial
- Who to contact in the research team with any questions or concerns
- What happens when the trial has finished



#### Part 2 will include

The doctors or nurses keeping you informed about the trial. For instance this could be:

- New benefits
- New risks
- New side-effects
- Anything that comes to light which might affect you wanting to continue in the trial

If you have been given more information about the trial, the research team may ask you to sign another informed consent form

#### What happens during a trial?

Many clinical trials split volunteers into groups, which will each receive different treatments. Usually one group will get a new, untested treatment that the research team thinks may be better than a standard treatment. The other group will get the standard, tried and tested treatment. Therefore, during the study the researchers can compare the two treatments to find out if one is showing better results than the other.

At the start of a trial you will possibly:

- Have a check up on your general health
- Have more tests and scans depending on what the researchers want to find out
- Be given specific instructions to follow

During the trial, the research team will keep a careful check on you and possibly stay in touch once the trial has finished.



#### Phases

Trials are carried out in phases, from 1-4. The trials at each phase have a different aim and help the research team answer different questions.

Phase 1	Uses a small group of volunteers, around 20-80, to see whether the trial treatment or procedure is safe, has any side-effects and to find out a safe dose to use
Phase 2	Uses a larger group of volunteers, around 100-300, to find out if the treatment or procedure is effective (how well it's working) and to look for any more side-effects
Phase 3	Uses a much larger group of volunteers, anything up to 3000, to make sure that the treatment or procedure is working, collect more information about side-effects over a longer period of time and compare the results for the new treatment with the standard treatment
Phase 4	Researchers continue to collect information about side- effects, risks, benefits, safety or any other problems after the drug has been approved to be used

#### What might I have to do?

In the informed consent form, it should tell you if you have to do or record anything so the research team can collect this information. It is important to attend all the appointments.

#### Does everyone on a clinical trial get treatment?

It's important to understand that with prostate cancer, you will still get the treatment you need. However, you may or may not be put into the group who are having the newer treatments or procedures.

#### What happens if I change my mind?

Even though you have signed the informed consent form you can change your mind and pull out of the trial whenever you want – before the trial



starts, during the trial or during the follow up time. If you want to pull out during the trial, make sure you ask the research team how you do this e.g. if it was a new drug trial if you can stop the drug straight away.

#### What happens when the trial is over?

At the end of the trial, the researchers look very carefully at the results and consider if they think the results are significant and whether this could become a new standard treatment. Usually, the results of trials will be published in medical or scientific journals. When results are published your name will not be used. If you want to read what has been published about a clinical trial that you took part in ask the doctor or nurse from the research team or ask your doctor. You will need the name of the journal, date it was published, lead author and title of the study.



#### What are the benefits and drawbacks?

Before agreeing or refusing to take part in a clinical trial, it may help if you look over the list below and think about the potential benefits and drawbacks.

Potential benefits	Potential drawbacks
Participants can get new treatments that are generally only available to those taking part in a trial	If the trial is comparing a new treatment with the standard treatment you won't get a choice of which group you go into, so you may still only get the standard treatment
The new treatment may be more effective than the standard treatment and so trial participants may be the first to benefit from it	Because the treatments are new and their effects not completely clear, it can't be guaranteed that your condition will improve or how effective the new treatment is likely to be
Participants are very carefully monitored by both the research team who are often leading doctors in cancer research, as well as by the doctor who is treating their cancer	The new treatment may not be better than the standard treatment. It may have side-effects that the doctors didn't expect and are worse than the standard treatment
Being more involved in your own healthcare	Participants may need to make more trips to the hospital doing the research, have more tests, more treatments, time away from work, take the correct dose of medicines at the correct time and possibly follow complicated instructions from the research team
The results of the trial may help other men in the future	It may be quite time consuming as you may have to fill in questionnaires, keep a record of how you are feeling and carefully record any side-effects



#### Questions you may want to ask about clinical trials.

Before deciding to take part in a clinical trial, you may have some questions to ask the doctor or nurse on the research team. A list of possible questions is given below. Think about what you would like to know, so perhaps you would only need to ask a few of these, or you may have questions of your own.

- What is the trial for?
- Why do you think this may be a suitable trial for me?
- Has this been tested before?
- How is the safety of the trial being checked?
- How long will the trial last?
- How long am I likely to be on the trial for?
- What will I have to do during the trial?
- What will happen to me and my treatment when the trial has finished?
- If the new treatment suits me, will I still be able to have it even after the trial has finished?
- What are the possible short-term benefits of taking part?
- What are the possible longer-term benefits of taking part?
- What are the possible short-term risks of taking part?
- What are the possible longer-term risks of taking part?
- What are the possible side-effects?
- Could being part of the trial make me feel worse?
- What treatment(s), procedures, tests or examinations am I likely to have during the trial?
- How familiar is the research team in giving the new treatment or doing the procedure?
- Are any of these likely to cause pain?
- What will I have to do during the trial?
- Will I need to stay in hospital?
- How will you know if it's working?
- Can I take my normal medicines while on the trial?
- What should I do if any problems crop up while I am on the trial?
- Who should I contact if I have any problems or concerns?
- Where do I have to attend while on the trial?



- Will this involve extra appointments?
- What effect could the trial have on my normal day-to-day routine?
- Can I talk to other men already on the trial or who are thinking about it?
- Could being on this trial affect my future treatment choices?
- What kind of long-term follow-up care is part of the trial?
- Can I be on more than one trial at a time?
- What is the outlook for me after taking part in the trial?
- How soon do I need to make the decision?
- When does the trial start?

At the time of writing, there continues to be ongoing trials for new treatments for prostate cancer, some of which may lead to these new treatments becoming available. There are trials in the United States and the UK for Photodynamic therapy for prostate cancer and another study on radiofrequency ablation treatment. Updates of new treatments approved for use in Scotland will be detailed on our website www. prostatescotland.org.uk





#### Part 2

#### **Newer Therapies Explained**

This section explains more about cryotherapy and high intensity focused ultrasound Another very new treatment, Radium-223 Chloride that is just in the trial stage is also briefly mentioned

#### Cryotherapy (or cryoablation)

Please remember that this is meant as general guidance. As treatment procedures may vary slightly you can ask for more specific advice from staff at the hospital, and always follow their instructions.

At the time of writing the cryotherapy service in Scotland is based at the Beatson Hospital in Glasgow and accepts referrals from all over Scotland.

#### What is cryotherapy?

Cryotherapy involves quickly freezing then thawing the whole prostate with the aim of destroying the prostate and the cancer cells. This is very carefully controlled to make sure that only the prostate is frozen, and, as far as possible, the urethra (water pipe) and other organs nearby aren't affected.

Special needles are put into the prostate and a special gas is passed through the needles causing little balls of ice to form which freeze the prostate. This destroys the prostate and the cancer cells inside it, but the prostate is not taken out.

#### When might cryotherapy be suggested?

Cryotherapy may be an alternative if you have already been treated with external beam radiotherapy (EBRT) or brachytherapy but your cancer has come back in the prostate but not elsewhere in the body. If your prostate is large, then you may be given hormone therapy to shrink the prostate so cryotherapy has the best chance of working.



#### What happens?

- To make sure that your bowel is empty you will have an enema (liquid put into the back passage to make your bowels open). This will probably be done the day before your operation. This makes sure that the doctors have a clear picture of your prostate on a screen so the special needles are put in the correct place
- A catheter with warm water flowing through it is put into your penis. This protects the urethra from being damaged by the cold
- Special needles are guided into your prostate through the skin between your scrotum and back passage. The doctor checks that the needles are in the correct place.
- When the needles are in the correct place a special gas flows through the needles making the temperature drop very quickly. Little balls of ice form freezing the prostate, and destroying the prostate and cancer cells. The doctor watches carefully as the prostate is frozen and thawed
- The prostate is allowed to 'thaw', then frozen again
- The doctor checks for any damage to the urethra and bladder
- A catheter is put in place to drain urine

#### Will I have an anaesthetic?

Yes, cryotherapy is normally done with a general anaesthetic (you will be asleep) and the operation lasts about 2 hours.

#### Will I have a catheter?

Yes. Because the prostate swells during cryotherapy, a catheter is put in place during the operation to drain urine from the bladder into a bag. You will still have a catheter when you go home. The catheter will be taken out about 1 - 2weeks later.

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

Yes. This is usually for 2 nights – the night before and the night after you have your operation.



#### Are there any side-effects?

Some short-term side-effects might be:

Constipation

This is quite common so you may be given a gentle laxative to help you open your bowel and prevent you from straining

- Bruising or bleeding around the area where the needles were inserted While in the ward, you will most likely have a dressing on the area where the needles were put into the prostate but it will probably be taken off before you go home. However, it's important to keep this area clean and dry. When you get home, and if you notice some light bleeding, then put a dry dressing over the area. If the bleeding gets worse or is very heavy then get in touch with your GP or NHS 24
- Blood in the urine
   You may see blood in your urine from time to time for a few weeks after your treatment. Don't worry, this is quite common
- Swelling

You might notice some swelling in your scrotum but this should gradually settle down

• Urinary problems

Urinary problems following cryotherapy, are different for each man and may in fact improve over time. A number of men find that they only have a slight leak of urine, while others find it difficult to control their bladder.

To help:

- You may need to wear pads to prevent urine leaking out onto your underwear
- A specialist physiotherapist (or perhaps the specialist nurse) may advise you on exercises to do to help strengthen muscles and regain control of the bladder. You may be advised to do these exercises before and after cryotherapy



• Erectile Dysfunction, ED (difficulties with erections) Because the nerves responsible for getting and keeping erections lie very close to the prostate, there is a fairly high risk that these may be damaged when the prostate is frozen. There is more information on treatments for ED in the booklet called "Living with advanced prostate cancer" but possible treatments include tablets, injections, applicators and vacuum pumps.

#### Bowel problems

Although this doesn't happen very often, there is a possibility of an opening or connection, called a fistula, being made between the bowel and the urethra. This may cause diarrhoea or bladder infections. Another operation will be needed to put this right if this happens.

#### Getting home

The hospital may give you some advice about getting home but a general guide is given below.

Antibiotics to prevent infection	If you have been given antibiotics remember to finish the full course
Tiredness This can be for about 7-10 days after your treatment.	Make sure that you have a rest or snooze during the day
Exercise	Take some light exercise such as walking or gently ease yourself back into your usual day-to-day activities
Lifting	For a few weeks afterwards you shouldn't lift anything heavy
Pain or discomfort	Usually you will be given pain-killers to take
Urinary infection	If you have a high temperature, pain around your lower back or tummy, or have pain when passing urine, then contact your GP or NHS 24





#### Going back to the clinic

You will probably go back to outpatients about 6 weeks after your operation to have your PSA level checked.

The doctor will tell you how often you will have checkups after that. The hospital will most likely let you know your PSA level each time it is done. It's a good idea to keep a record of this and the Prostate Log Book may help with this.

#### Potential benefits and drawbacks:

Potential benefits	Potential drawbacks
It doesn't require a major surgical operation and usually you can get back to your normal day-to-day activities fairly quickly	It's a fairly new treatment, and at present, is only available in one centre in Scotland, so it may involve you in extra travelling
It can be used when cancer has come back (recurred) after having external beam radiotherapy or brachytherapy	It may not be suitable for patients with large prostates or hormone therapy may be needed to shrink the prostate before having cryotherapy. It may be more difficult in patients who have had prostate surgery previously (not a radical prostatectomy)
There is a reduced risk of urinary problems than with other treatments	There is a fairly high risk of erectile dysfunction
The treatment can be repeated if necessary	The technique requires a surgeon who is very experienced in this procedure



#### Questions you may want to ask about Cryotherapy:

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

- Is cryotherapy a suitable option for me to think about?
- Is cryotherapy available in my area and is this a suitable choice for me?
- What do you expect cryotherapy to do to the cancer?
- If cryotherapy is not available in my area, how can I get referred for cryotherapy?
- How often would I need to attend the cryotherapy centre?
- How many patients have been treated by cryotherapy?
- Why do you think this might be the best option for me?
- Could having cryotherapy make me feel worse?
- Can you explain what the potential benefits and drawbacks and sideeffects are likely to be? Are these likely to affect me in the short-term or are they more likely to be longer-term?
- Roughly how many men have problems with incontinence and erectile dysfunction and for how long after cryotherapy?
- 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 cryotherapy?
- Can I visit the unit for more information?
- How long will it take for the treatment?
- What checkups would I have and how often would I need checkups?
- What would be done at the checkups PSA, scan, etc?
- If cryotherapy is not successful then what would be my options?
- Are there other suitable treatment choices that I could think about?
- What is the outlook for me?
- Is there someone that I can talk to who has had the same treatment that I am thinking about?
- How urgent is it that I have this treatment done?



#### High Intensity Focused Ultrasound (HIFU)

At the moment, this is only available for men who are taking part in a clinical trial and not yet available in Scotland. Please ask your doctor for more advice if you are interested in having HIFU.

Please remember that this is meant as general guidance. As treatment procedures may vary slightly from hospital to hospital ask for more advice from hospital staff, and always follow their instructions.

#### What is HIFU?

High Intensity Focused Ultrasound (HIFU) uses powerful, ultrasound waves. It works by producing small, repeated bursts of energy to heat up and destroy cancer cells in the prostate. The areas to be treated are very carefully targeted within the prostate, to avoid damaging the other organs that lie next to the prostate.

#### When might HIFU be suggested?

HIFU may be an option if you have already been treated with external beam radiotherapy (EBRT) or brachytherapy and your cancer has come back in the prostate but not elsewhere in the body.

#### What happens?

The night before or on the day of your operation you will be given an enema to help empty your bowel.

The surgeon will pass a small, lubricated instrument into your back passage until it reaches your prostate. This will give out ultrasound waves that are focused on the prostate and will heat up and destroy the cancer cells in the prostate. The surgeon can see exactly what is happening and control how much tissue is being destroyed by using ultrasound monitoring.

#### How long does it take?

This will depend on the size of your prostate and how much of your prostate is being treated but it can take anything up to 3 hours.



#### Will I have an anaesthetic?

Yes, usually you will have a general anaesthetic (you will be asleep) and you may be allowed to go home on the same day.

In some cases, you may be given an epidural anaesthetic which means that you will be numb from the waist down.

Ask the doctor which you are most likely to have.

#### Will I have a catheter?

Yes, you will have a catheter for between 5 - 14 days. The catheter will drain urine from your bladder into a bag.

#### What are the side-effects?

The short-term side-effects might be:

- Some swelling in your scrotum and penis but this should get better after a few days
- Blood in your urine which can last for up to 8 weeks
- Needing to pass urine more often and without much warning
- A burning feeling when passing urine
- An infection in your urinary tract. To help cut down on the risk of this it is important that you finish the full course of antibiotics
- Tiredness

Longer-term side-effects might be:

- Stress incontinence. This means that some urine could leak out when you cough, sneeze, laugh or get up from sitting
- Difficulties with erections. You may not be able to get or keep an erection firm enough for intercourse and you may not be able to ejaculate
- You will be infertile so you will not be able to have children in the normal way
- Damage to your back passage causing diarrhoea but this is very rare

#### **Going home**

• You will probably be able to go home on the same day when you are feeling up to it



- You won't be able to drive so you should arrange to be picked up and taken home
- If you are given antibiotics, you should finish the whole course
- If you are in pain then taking some over-the-counter pain-killers should help. However ask the doctor or nurse in hospital for more advice on this

You should contact your GP or NHS 24 if you have:

- Pain which is getting worse and normal pain-killers aren't helping
- A high temperature
- More blood than before in your urine
- Difficulty in passing urine

#### Potential benefits and drawbacks:

Potential benefits	Potential drawbacks
It is minimally invasive	Usually a general anaesthetic is given but sometimes an epidural
Usually done as a day operation so you can go home the same day	Takes quite a long time to do, anything up to 3 hours
Shorter time for you to recover	Some pain or discomfort
Can be done again if necessary	Some difficulties with erections
	Will need a catheter
	Not available in Scotland and only as part of a clinical trial

#### Questions you may want to ask about HIFU:

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



- As HIFU is not available in my area, how could I be referred to have this treatment?
- If I am interested in having HIFU, how do I go about this?
- Is HIFU a suitable option for me to think about?
- What would you expect HIFU to do to the cancer?
- How familiar is the team in performing HIFU?
- Why do you think this might be a possible option for me?
- Could having HIFU make me feel worse?
- Can you explain what the benefits and drawbacks 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 HIFU, roughly how many men do you find have problems with incontinence and erectile dysfunction and for how long?
- 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 HIFU?
- How long will it take for the treatment?
- What checkups would I have and how often would I need checkups? What would be done at the checkups – PSA, scan, etc?
- If HIFU is not successful then what would be my options?
- Are there other suitable treatment choices that I could think about?
- What is the outlook for me?
- Is there someone that I can talk to who has had the same treatment that I am thinking about?
- How urgent is it that I have this treatment done?

#### Radium-223 Chloride.

At the time of writing, December 2011, Radium-223, known as Alpharadin<sup>™</sup>, is still undergoing trials and has yet to be licensed, but the results in treating advanced prostate cancer have so far been very promising. The new drug seems to accurately target tumours using alpha particles, that doctors say are the most effective form of radiation to eliminate cancer. It also appears to do less damage to surrounding tissue.



#### 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	0131 226 8157	
NHS 24	www.nhs24.com	0845 24 24 24	1
Prostate Link UK	www.prostate-link.org.uk		
Prostate Action	www.prostateaction.org.uk	020 8788 7720	
The Prostate Cancer Charity (Includes some support group contact details)	www.prostate-cancer.org.uk	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	020 7242 0200 0808 800 4040	1
Edinburgh and Lothian Prostate Cancer Support Group	www.elprostatecancersupport.co.uk	0131 208 3067	1
Prostate Cancer Group, Maggie's Inverness	email: highlands@maggiescentres.org	01463 706306	
Prostate Cancer Support Group, Maggie's Dundee	email: Lynn.Downie@maggiescentres.org	01382 632999	
National Institute for Health Research	www.peopleinresearch.org/home		
List of clinical trials	www.ukrcc-ctu.org.uk/ resourcefinder/Pages/Scotland		
Clinical research	www.cmcc.nihr.ac.uk/ppi		



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

Prostate Log Book	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
Booklet 1 An introduction to advanced prostate cancer	<ul> <li>This is the first in the series of booklets about advanced prostate cancer and explains:</li> <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>
Booklet 2 Hormone Therapy, Treating Bone Pain and Chemotherapy Explained	<ul> <li>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.</li> <li>It explains:</li> <li>What hormone therapy is, when it's used, which drugs are used and some of the potential sideeffects</li> <li>How bone pain is treated with pain-killing drugs, radiotherapy, using Strontium 89 and bisphosphonates</li> </ul>



	<ul> <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</li> </ul>
Booklet 3 Life with prostate cancer	advanced prostate cancer This booklet may be beneficial at any stage on your cancer journey. It is in 3 parts: <b>Part 1</b> focuses on helping you think about treatment decisions and taking part in clinical trials. It gives: - Useful tips to help you make decisions about treatment or taking part in a clinical trial or study - Some hints on how to get the most out of your
	<ul> <li>appointment with doctors, specialist nurses or the research team</li> <li>Part 2 touches on some of the possible difficulties you may come across such as:</li> <li>Difficulties in passing urine</li> <li>Erectile dysfunction (ED or difficulties in getting or keeping an erection) and how these can be helped</li> </ul>
	<ul> <li>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</li> <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 or by contacting us on info@prostatescotland.org.uk or 0131 226 8157 and copies can be sent to you.



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: Mr. Alan McNeill, Consultant Urologist, Western General Hospital, Edinburgh (Chair of PAGES) Karen Edwards, Specialist Urology Physiotherapist, Western General Hospital, Edinburgh Mr Graham Hollins, Consultant Urologist, Ayr General Hospital Lesley McKinlay, Deputy Charge Nurse Urology, Western General Hospital, Edinburgh Frances McLinden, Clinical Service Manager Urology, Greater Glasgow and Clyde Rita O'Dea, Clinical Nurse Specialist, Western General Hospital, Edinburgh Roy Partington Peter Phillips Dr Barbara Phipps, GP, Edinburgh Mr. Ben Thomas, Consultant Urologist, Borders General Hospital/Western General Hospital, Edinburgh Prostate Scotland staff: Adam Gaines, Director, Mae Bell, Information and Advice Coordinator We would also like to acknowledge support from: Patricia Chalmers Mr Brian Corr, Urology Clinical Nurse Specialist, Raigmore Hospital, Inverness Mr David Douglas, Consultant Urologist, Raigmore Hospital, Inverness Dr Alastair Law, Consultant Oncologist, Western General Hospital, Edinburgh Dr Duncan McLaren, Consultant Oncologist, Western General Hospital, Edinburgh Mr. Grant Stewart, Specialist Registrar in Urological Surgery, Western General Hospital, Edinburgh Mr. Mark Underwood, Consultant Urologist, Glasgow Royal Infirmary

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

Prostate Scotland would like to thank the Scottish Government and Sir Tom Farmer through the Farmer Foundation, for their kind funding of the Information and Advice Project.

#### Contact Us

Prostate Scotland, Gf2, 21-23 Hill Street, Edinburgh EH2 3JP Tel: 0131-226 8157 Email: info@prostatescotland.org.uk www.prostatescotland.org.uk

Date: December 2011 © Prostate Scotland

Prostate Scotland is a charity registered in Scotland (SCO 37494). Prostate Scotland is a company registered in Scotland (SC 306268).



