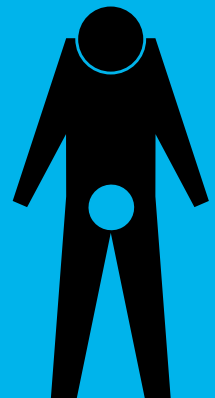


Treatments for advanced prostate cancer:

- Hormone therapy explained
- Bone pain & spinal cord compression explained
- Chemotherapy explained



Although we have included the range of treatments for advanced prostate cancer, you may choose to read only about the type of treatment you are having at the moment or that your doctor has suggested. So the booklet has been divided into 3 sections.

1. Hormone therapy; what it is and what happens

Hormone therapy is the mainstay treatment for advanced prostate cancer. So, for the majority of men, this will be the first treatment that will be given.

2. Treating bone pain and spinal cord compression; what the treatments are and what happens

If prostate cancer has spread to bones, some men will experience pain in the bones. If you have found this to be a problem, then this section talks about how it can be treated.

3. Chemotherapy; what it is and what happens

Chemotherapy will most likely be the treatment option if prostate cancer becomes resistant to hormone therapy, which means that hormone therapy isn't controlling the disease any longer.

If, or when, chemotherapy is started varies from man to man. As chemotherapy is usually only given after treatment with hormone therapy first of all, you may choose to read this section only when it is the treatment option for you.

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 at which your cancer is developing

Perhaps you are reading this booklet because your doctor has suggested one of the treatments to you and you want to find out more about it, or, you and your doctor have decided that hormone therapy or chemotherapy is the treatment option for you at the moment and you are just about to start the treatment.

If you have bone pain, then you may find the section on treating bone pain and spinal cord compression helpful.

Please note:

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

What's in this booklet

Page	What's included
	Hormone therapy
6	Hormone therapy
7	How hormone therapy works
8	The different types of hormone treatment are discussed – - Maximum androgen blockade (MAB) - Treatment with LHRH agonists or antagonists, anti-androgens and orchidectomy
9	Continuous or intermittent hormone therapy The side-effects of hormone therapy - erectile dysfunction, hot flushes, breast swelling, tiredness, bone thinning, sore joints, weight gain, mood swings, difficulty in sleeping
15	Treating hormone resistant prostate cancer
16	Abiraterone acetate
17	Questions you may want to ask your doctor about hormone therapy
	Treating bone pain and spinal cord compression
18	An introduction to pain in the bones
20	Analgesics Pain relief with pain-killing drugs
22	Radiotherapy When it is used, what it is, how it works, how it helps, what happens, how long before it starts to help, side-effects, what happens now
24	Strontium 89 How it works, benefits, how it is given, how long before it starts to work, guidelines after having Strontium 89, treatment card to carry, side-effects
27	Bisphosphonates What they are, when they are used, how they help, how they

- 30 are given, side-effects
Osteonecrosis of the jaw
Bisphosphonates and dental treatment
- 31 Spinal Cord Compression
What it is, symptoms or signs to look out for, tests you may have, treatment, after treatment finishes, pain
- 34 Questions you may want to ask your doctor about bone pain and treatment

- 35 **Chemotherapy**
An introduction to chemotherapy and when it's used
- 36 What is chemotherapy and how it works
- 37 How chemotherapy is given and how long the treatment is given for
- 39 Steroid medication
- 39 Side-effects and their treatment
- 42 Neutropenic sepsis
- 44 Trapeze study and STAMPEDE trial
- 44 Questions you may want to ask your doctor about chemotherapy

46 **Contact details of other organisations**

47 **Additional booklets in the Prostate Scotland series on Advanced Prostate Cancer**

Hormone therapy

Hormone therapy is the mainstay or standard treatment for advanced prostate cancer. So, for the majority of men with advanced prostate cancer this will be the first treatment. Hormone therapy may be successful in keeping many men's cancer in check for several, and in some cases, many years.

Hormone Therapy or treatment

Introduction

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 common 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)**.

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. Recent studies suggest that starting hormone treatment early may be more effective than delaying the start of hormone treatment. This is something you can talk over with your doctor.

Hormones control the activity and growth of all normal cells and so are naturally present in your body. Men produce a hormone in their testes, called testosterone. Testosterone is responsible for many male characteristics. In order to grow, prostate cancer needs this testosterone. So, by reducing the amount of testosterone, cancer cells wherever they may be in the body, shrink or don't grow as fast.

Testosterone levels can be reduced by hormone therapy. This could be by:

- i. Luteinising hormone-releasing hormone agonists (LHRH agonists).
These drugs are given by an injection and stop the testes producing testosterone

Gonadotrophin-releasing hormone antagonists (GnRH antagonists).
These drugs are given by an injection and also stop the testes producing testosterone
- ii. Anti-androgens. These drugs are taken as a tablet and block the effect of testosterone in the tissues
- iii. Orchiectomy. This means that all the testes or the parts of the testes which make testosterone are taken away during an operation. Although this used to be the standard treatment, it is much less common now because hormone therapy gives similar results and may be slightly less upsetting for the man.

Your doctor may suggest one of the drug treatments above (LHRH agonists or anti-androgens or GnRH antagonists) on its own in the first instance.

If you have already been treated with one type of hormone treatment your doctor may advise you to change to a different type.

Overleaf is a quick guide to ADT.

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

Drug/treatment	Name of drug/treatment	Brand name of drug	What it does	How it's done or given
LHRH agonists	Goserelin	Zoladex® Zoladex LA®	Stops the testes making testosterone	By injection – monthly, 3 monthly, 4 monthly or 6 monthly
	Leuprorelin	Prostap® SR Prostap 3		
	Triptorelin	De-capeptyl® SR		
	Historelin	Suprefact®		
GnRH antagonists	Degarelix This can be most useful for men newly diagnosed with advanced prostate cancer and who have a lot of pain or are at risk from spinal cord compression	Firmagon®	Very quickly switches off the testes making testosterone	Monthly injection. This will be started in hospital and then given by your GP
Anti-androgen (non steroidal)	Bicalutamide	Casodex®	Block or switch off testosterone	Tablet
	Flutamide	Chimax® Drogenil®		
Anti-androgen (steroidal)	Cyproterone acetate	Cyprostat®	Blocks testosterone being produced in adrenal glands	Tablet
Surgery	Orchidectomy		Testes removed which removes source of testosterone	Operation with general or local anaesthetic

Maximal androgen blockade MAB or complete androgen blockade CAB

This is usually used if you have been on a single hormone treatment and it stops working. The doctor may recommend that you take LHRH agonists and anti-androgens together. This treatment works in two ways:

- i. LHRH agonists stop the testes making testosterone
- ii. Anti-androgens block the testosterone from reaching the cancer cells

However, this type of treatment may increase the chances of side-effects.

Prescribing hormone therapy

Continuous therapy.

Some doctors prescribe hormone therapy for you to take all the time. This is called continuous therapy.

Intermittent therapy.

Other doctors prefer to give you a few months treatment until your PSA level is low and staying low. The treatment is stopped for a period of time until the PSA rises. You may find that the time off the drug can vary from a few months up to about a year, then the treatment can be started again. You can continue on this stop start treatment for as long as it is working for you.

It seems that both of these treatments work just as well. However, the benefit of having intermittent therapy is that you may not have as many side-effects when you are not taking the drug.

Side-effects of hormone treatment

The side-effects of hormone treatment vary from man to man. Some men say that they hardly notice any side-effects but for others the side-effects have a big impact on their quality of life. While some men learn to accept these others can be quite unhappy and upset by them. Unfortunately there is no way to predict which of the side-effects you might get or how much they might affect you. The side-effect you might get also depends on the type of hormone treatment you have been prescribed. Often when the drug is stopped or changed the side-effects ease off. The advantage of having an orchidectomy is that testosterone is not produced, but a possible drawback is that the side-effects can't be reversed, although they can be reduced with treatment.

Before starting treatment, it might help to know what the side-effects are likely to be, so you can talk over your worries with the doctor or specialist nurse. You and the doctor will need to strike a balance between the benefits of controlling the cancer and symptoms and the impact the side-effects of hormone therapy might have on your quality of life.

Information on each of the most common symptoms is given overleaf – what they are and what may be done to help if you find any of these to be a problem.

Erectile dysfunction (ED) sometimes called impotence.

Because of the way hormone treatment works (switching off or blocking testosterone) 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 these difficulties.

All this may be upsetting and worrying for a man and his partner but there are now many things that can be done to help. If your doctor has decided on intermittent therapy (stopping and starting treatment) then during the 'stop' time there may be a possibility that you get back some of your desire and you are able to have the same kind of erection that you did before hormone therapy.

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®), or 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 things to look out for are:

Headaches, dizziness, nausea, blurred vision, flushing of the face, indigestion and tummy upset. Men with heart conditions should check with their doctor before taking these.

Injection

A drug called alprostadil can be injected into the penis and is very successful in producing an erection for some men. The drug makes the blood vessels in the penis swell 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 alprostadil is released into the penis by an applicator into the urethra (waterpipe) helping to cause an erection.

Some of the ways this may affect you include a painful long lasting erection, some pain, or mild injury 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.

Loss of Libido

Another common side-effect is losing interest in having sexual 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.

Sweats and hot flushes

Possibly one of the most common complaints from men on hormone treatment is sweating along with hot flushes. A hot flush is a sudden strong feeling of heat in your face, neck, chest or back. The flushes and sweating can last for just a few minutes or can go on for up to an hour. Some men find that this gets a bit easier as time goes on and so may not need any treatment.

Hot flushes are more common if you take LHRH drugs as these stop testosterone being made altogether.

- Sometimes sweats and flushes can be set off by drinking hot liquids or eating hot foods
- Sweating may be very noticeable at night and may stop you from sleeping or wake you up
- Being stressed may cause a hot flush
- Sometimes hot flushes can just hit you out of the blue

Things you could try to help:

- You may want to make a list of foods which you think sets off your flushes and avoid them e.g. spicy foods or having large meals
- Cutting down on alcohol
- Cutting down or cutting out smoking
- Cutting down on drinks with caffeine such as tea and coffee may help ease this problem
- Wearing a few layers of clothing so you can take something off to help you cool down
- Having fewer covers on at night might help to keep you cool. It may help to have the window open to keep your bedroom cool
- Not having too hot a bath or shower
- Making sure you are having enough fluids as you can lose a lot of fluid when you sweat
- Using a fan to keep the room temperature cool

If your hot flushes are proving to be a real problem, then let your doctor or specialist nurse know. There are some medications that might help so tell your doctor about these.

The doctor may try you on:

- Cyproterone acetate (Cyprostat®). This is possibly the treatment most commonly used and may help cut down the number of hot flushes and sweating
- A short course of hormones called progestogens, such as Medroxyprogesterone which some researchers recommend as the best treatment for hot flushes
- Venlafaxine (which is usually used to treat depression) may help with hot flushes
- Gabapentin (Neurontin®) as some studies show this may reduce hot flushes

If you decide to try some complementary therapies such as evening primrose oil, sage and acupuncture, then you should let your doctor know.

Breast swelling and tenderness (also called gynaecomastia)

Some of the drugs used in hormone treatment (particularly flutamide or bicalutamide) may cause one or both of the breasts to swell or become tender. For some men, this can be just a slight tenderness but for others this can be quite painful. Let the doctor or specialist nurse know if this is becoming a problem for you.

Your doctor may advise:

- A small, one off dose of radiation to the breast tissue before or soon after hormone treatment has started to help stop this from happening
- A low dose of the drug Tamoxifen as this may help reduce swelling but it may not be suitable for all men
- Any painful or swollen areas could be removed by surgery

Tiredness

Hormone therapy can make you feel very tired and may hold you back from doing your normal day-to-day activities. If this is the case then you may want to think about:

- Planning your day so that you can have a rest or a short nap
- Doing only the things you really need or want to do
- Taking some regular exercise can actually help you get over some of the tiredness
- Asking family or friends to give you a hand with everyday jobs that you find are tiring you out

Bone thinning (osteoporosis)

Bones need testosterone to help keep them strong and healthy. When testosterone is reduced, over time this can cause the bones to thin so they might break quite easily. This may be a particular problem with bones in the hips, spine and forearms. This is a concern if you have had an orchidectomy (surgical removal of the testes) or if you are likely to be treated with LHRH agonists for a long time.

What you can do:

- Try to do regular weight bearing exercises such as a walking and include

some hills, taking the stairs instead of the lift, golf, dancing or tennis. It is important to check with your doctor before starting to exercise and possibly asking for more advice from a physiotherapist

- Resistance exercises are especially good as they work the muscles in the arms, legs and trunk of the body. This could include gentle weight lifting or an exercise programme. It is important to check with your doctor before starting to exercise and possibly asking for more advice from a physiotherapist
- Cut down or cut out smoking
- Cutting down alcohol
- Calcium and vitamin D is necessary for strong bones. Calcium is found in dairy foods like milk, cheese and yoghurt, but also in dark green leafy vegetables, some breakfast cereals, nuts and whole fish like sardines. Vitamin D is needed so that calcium can be used properly in the body. Vitamin D is made in the body by the rays of the sun shining on the skin. Vitamin D is found in oily fish

Sore joints

Tell your doctor if this is a problem as they may be able to prescribe pain-killers. You can try having warm relaxing baths to ease aches and pains and taking some regular exercise may help but always check with your doctor before starting any exercise.

Weight gain

You may find that you gain some weight and some men notice this especially around their middle. Having a healthy, well balanced diet and taking exercise can help with this although it may take quite a long time to lose the extra pounds. If this is becoming a real problem then the doctor may refer you to a dietitian in hospital.

Mood swings

It is understandable that men (and their families) who are having treatment for cancer are going through a very difficult time. You may feel angry, depressed and worried about what the future holds. Hormone therapy can also make you much more emotional and you may get upset more easily and

feel quite tearful. Speak to your doctor or specialist nurse early on if you feel very low as it might be possible to change your treatment or get you some additional help.

Taking part in activities you enjoy, spending time with family and friends, taking regular exercise and chatting it over with other people who understand often helps with how you are feeling.

Difficulty in sleeping

This could be because of sweating or hot flushes or being anxious about everything that is going on. Try to relax before bed by having a warm bath, a milky drink, reading, listening to music or doing relaxation exercises. For a short time your GP may prescribe sleeping pills.

Hormone Resistant Cancer

Once hormone therapy has been started it is usually ongoing.

However, over time, prostate cancer may start to grow again even if the testosterone levels are low, although it's not clear why this happens. It's thought that some of the cancer cells are able to grow even though you may have very low levels of testosterone. This is called hormone resistant prostate cancer or you may also hear it called hormone refractory cancer or castrate resistant prostate cancer.

What are the signs for this?

- Rising PSA level even though testosterone levels are low
- The PSA level increasing quite quickly

What treatments could be offered now?

This will depend on the type of hormone treatment you had first of all.

Hormone treatment you had first (first line treatment)	Hormone treatment to try next (second line treatment)	How it works
LHRH agonists	Add or change anti-androgens	Block side-effects of any remaining testosterone
Maximal androgen blockade	Stop anti-androgens completely	Anti-androgens can change from 'switching off testosterone' production to 'switching it on'. Sometimes by withdrawing the anti-androgen this can slow down the growth of the cancer
Orchidectomy	Anti-androgen tablets	Block side-effects of any remaining testosterone

Abiraterone or Abiraterone acetate

This is a new type of hormone therapy that is being used for men with advanced prostate cancer when usual hormone therapy isn't working any longer. At the time of writing, (September 2011) Abiraterone (also known under its brand name of Zytiga®) is licensed for use but has yet to be considered by Scottish Medicine Consortium (SMC). Please ask your doctor for more information on whether abiraterone can be prescribed.

Abiraterone is taken as a tablet once a day and works in a different way from other hormone therapies. It blocks an enzyme needed to make testosterone in the adrenal glands so that the testosterone is no longer produced from this source. It is important that you follow exactly the instructions from your doctor or specialist nurse on how to take the medication.

Possible side-effects may include:

- Swelling of or pain in the joints
- Muscle aches
- Hot flushes
- Urinary tract infection
- Cough

- Headache
- Tiredness

Your doctor may keep a check on:

- If there is a change in the amount of sodium and potassium in your blood
- A rise in blood pressure

The advantages of abiraterone seem to be:

- PSA levels are more likely to fall
- On average it took longer for these levels to rise again
- Tumour growth seems to be delayed

Questions you may want to ask your doctor or specialist nurse

Before starting on hormone therapy, 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.

- Why have you recommended hormone therapy?
- What do you expect hormone therapy to do to the cancer?
- Why do you think this might be the best option for me?
- Could having hormone therapy make me feel worse?
- Can you explain what the 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?
- Is there anything I could do to help with the side-effects?
- When and where would I have hormone therapy?
- What type of hormone therapy are you recommending for me and why?
- How long am I likely to have hormone therapy for?
- What checkups would I have, how often would I need checkups and where would I have these? What would be done at the checkups – PSA, scan, etc?
- If hormone therapy doesn't work for me or stops working 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?
- If abiraterone is suitable for me, can this now be prescribed?

Treating bone pain and spinal cord compression

If prostate cancer has spread to bones, some men will experience pain in the bones. If you have found this to be a problem, then this section talks about how it can be treated.

Introduction

Prostate cancer, when it spreads, most commonly spreads to the bones first of all (called secondaries or metastases), weakening the affected bone, and for some men causing pain. Bones nearest to the prostate such as your pelvic bones, hips and lower spine, may be the first to be affected but over time metastases may spread to other areas. You may feel this pain as a dull ache or sharp pain that can get worse when you move around.

Although spinal cord compression is not very common, it is something you need to be aware of, letting your doctor or GP know immediately if you experience any of the symptoms it can cause.

If you fall into the group of men who think you should just be able to cope with pain and 'grin and bear it' then you may want to think again. Let your doctor know about any pain you have as there are several ways to relieve it.

Can anything be done about the pain?

Pain shouldn't be a normal part of living with cancer; controlling pain is part of your cancer treatment. Some days though, you might find that your pain is worse than on other days. Pain from cancer or bone pain can usually be well controlled although it can take time to find the best type of pain relief for you. You may also find that you have aches and pains that are nothing to do with your cancer.

However, when you don't have pain, you will probably be able to sleep and eat better, carry on with your normal day-to-day activities such as work and hobbies, and enjoy being with your family and friends.

Talking with your doctor about pain

The first step in getting your pain under control is to let your doctor know about the pain. Tell your doctor things like:

- Where you have pain
- What it feels like (sharp, dull, throbbing, constant, burning, or shooting)
- How much pain you have
- How long it lasts

So, why is pain sometimes not talked about?

- Some men feel that they don't want to 'bother' their doctor to tell them about their pain
- Some men may be worried that the pain means that their cancer is getting worse
- Some men don't tell the doctor about the pain or tell them how much the pain is bothering them because they're worried about what doctors or others might think of them if they complain
- Some men feel that because they have cancer they are supposed to have pain and be able to deal with it
- Some men think that by talking about their pain this will sidetrack their doctors from working on ways to help treat their cancer
- Some men worry that they won't be seen as 'good' patients or should be 'strong' and able to cope with the pain

What can your doctor do to help with pain?

Your doctor will prescribe medicine(s) to help with your pain based on the kind of pain you have and how severe it is. You might hear these called analgesics. There are 3 steps that your doctor can take to help get your pain under control. You may find that your doctor combines some of the medicines to help get any pain under control.

Please remember, this is meant as general guidance. If your doctor or specialist nurse has given you specific advice or prescribed other medication then it's important that you follow their instructions. If you are at all unsure about your medication then ask your doctor or specialist nurse.

	Type of pain you have	Treatment your doctor may prescribe. Depending on the kind of pain and how severe it is, your doctor may start your pain relief at any of the steps below	
Step 1	Pain	To help with pain your doctor may try simple analgesics	<i>Paracetamol, aspirin, ibuprofen, diclofenac</i>
		If your pain is moderate or if your pain is continuing or getting worse then your doctor may try Step 2	
Step 2	Mild to moderate pain	To help with pain your doctor may try simple opiates	<i>Codeine, tramadol</i>
		Simple analgesics may be given alongside the opiates	<i>Paracetamol, aspirin, ibuprofen, diclofenac</i>
		If pain is quite severe or if your pain is continuing or getting worse then your doctor may try Step 3	
Step 3	Moderate to severe pain	To help with pain your doctor may try full opiates	<i>Morphine, oxycontin, diamorphine</i>
		Simple analgesics may be given alongside the opiates	<i>Paracetamol, aspirin, ibuprofen, diclofenac</i>

At steps 1 - 3 you may need additional pain-killers such as:

- gabapentin for neuropathic pain
- steroids for inflammatory pain
- lignocaine patch for topical pain
- Fentanyl patch if you are not tolerating morphine

Ibuprofen, diclofenac.

If you have had stomach ulcers, significant heart burn or kidney problems, you should let your doctor know about these problems and not take ibuprofen or diclofenac. If you are concerned about whether you can take these or not, then you should check with your GP, consultant or specialist nurse.

Are there any side-effects from having the stronger pain-killers?

Constipation.

This is quite common when you start taking opiate pain-killers. When starting on opiate pain-killers, your doctor will probably prescribe a laxative to help you open your bowels. If not, ask your doctor about giving you laxatives to take.

Feeling a bit sick or being sick.

Usually this only lasts for the first few days of taking the opiate pain-killer.

Feeling drowsy.

If you haven't been sleeping well because of the pain, you may find that when you start taking the opiate pain-killer you are able to sleep better as you are not in pain any longer. Feelings of drowsiness, usually go away after a few days.

If I take these strong pain-killers, am I likely to get addicted to them?

Some men worry so much about becoming addicted to their pain medicine that they don't take it. However, whilst taking pain medicine for your cancer is not likely to get you addicted to it, you should not take more than your prescribed dose. If you have any concerns about this, talk it over with your doctor or specialist nurse.

You may find that, over time, your pain-killing medicine doesn't work as well as it did before and you need to take larger doses of pain-killers to help with your pain. You should never increase the amount of pain-killer you are taking on your own. **Your doctor** may decide to:

- increase the amount (or dose) of pain-killer you have
- increase the number of times you take the pain-killer
- change the type of pain-killer you have been prescribed

What can you do to help with your pain?

- Take the correct amount of pain-killers at the times that you have been told by your doctor to stop the pain from starting or getting worse. This is one of the best ways to stay on top of your pain
- Don't skip doses of your pain medicine

- Don't try to 'hold off' between doses because your pain might get worse
- Tell your doctor if your pain medicine isn't helping you any longer
- Tell your doctor if you are taking more or less of the pain medicine you have been prescribed
- Some men find that complementary therapies can be helpful
- Tell your doctor if you are using any over-the-counter medicines, herbal medicines or alternative therapies

Radiotherapy for bone pain

Radiotherapy

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

When would this be used?

Radiotherapy is given to help relieve pain from the cancer that has spread to the bone and to help you feel better generally. You may hear the doctor, radiographer or nurses calling this palliative radiotherapy.

Radiotherapy may not be the right kind of treatment for all men though. Whether this may be an option for you will depend on your age, your general health, where your cancer has spread to, if it's causing you some upsetting symptoms, and what kind of treatment you may have had already for your prostate cancer. The doctors treating you will explain all about the treatment and why it may or may not be a suitable choice for you.

What is radiotherapy?

A special machine called a linear accelerator produces high-energy x-ray beams, which are then very carefully and accurately aimed at the area of cancer cells in the bone. The aim is to destroy these cancer cells while trying not to damage healthy cells. Palliative radiotherapy uses very low doses of radiation and you may have only one or a few radiotherapy treatments.

How does it work?

Radiotherapy damages the cancer cells in the treated area. While normal

healthy cells can recover more easily from this damage, cancer cells can't and start to die off. So radiotherapy may help by:

- Reducing the size of the cancer in the bone which may give you some pain relief as the cancer may not now be pressing on the nerves
- Slowing down the growth of the cancer cells giving the bones time to repair and get stronger

How will it help me?

It may:

- Help with your pain
- Make you feel better generally
- Slow down the growth of the cancer cells in the area being treated
- As the radiotherapy works quickly, you could feel the benefits within a few weeks and maximum benefit can be up to six weeks

What is likely to happen?

Before you begin your radiotherapy treatment, you will have an appointment to carefully plan your treatment. This will involve the doctors and radiographers using a special x-ray machine called a simulator, to make sure that the area to be treated is accurately targeted. A tiny permanent mark will be made on your skin.

When you are having your treatment, you might find that the lights will dim for a minute or two and the radiographer will leave the room, but they can still see and hear you.

You may have the radiotherapy:

- As a single treatment all at once
- Divided into smaller doses or 'fractions', which are given over a short period of time. With this treatment you will have to go back to the hospital more often

How long before I start to feel better?

For the first few days after treatment you might find that the pain becomes slightly worse before starting to get better. You can ask your doctor or specialist nurse for advice on what you can take to help with the pain during this time.

Some men might find that the pain improves fairly soon after treatment but for others this can take a few weeks. It may go on relieving pain for about 3 months.

What about side-effects?

Side-effects from the treatment can vary from man to man. Most men find that they have few side-effects when they have palliative radiotherapy. Some of the more common ones are:

- A slight reddening or itchiness of your skin in the area where you had the treatment, but this should get better in a few days. If it happens, it's best not to use soaps or shower gel with perfumes
- Being a bit more tired than usual, especially in the first week or so, but this may go on for a few weeks. If you can, try to carry on with your usual day-to-day routine but have a rest when you feel you need to
- Feeling a bit sick. This should settle down after a few days and your doctor may give you some tablets to help with this
- Depending on the area where you had the treatment, you may have some diarrhoea but again this should settle fairly quickly. Let your doctor know as they may be able to give you something to help

Side-effects may be more noticeable if a larger area has been treated with radiation.

If you are feeling very sick then your doctor may give you some pills (anti-emetics) to help with this. You might need to stay in hospital for a few days.

What happens now?

This is a case of 'wait and see'. Let your doctor know if your pain hasn't improved or if it comes back again. You may be offered another course of radiotherapy but you will need to talk over additional treatments with the doctors looking after you.

Strontium 89 (Metastron)

If hormone therapy isn't working any longer, and your prostate cancer has spread to the bones causing pain, then your doctor may suggest treating you with Strontium 89. Bones are made of calcium, and Strontium 89 acts like calcium in the body and is taken up into the bones where there is increased bone destruction and growth. It collects in areas where there are metastases (secondaries). There, it releases very small amounts of radiation over many days. The radiation targets and kills the cancer cells within your bones, so it is a kind of internal radiotherapy.

If you decide to go ahead with this treatment then the doctor looking after you will most likely give you details about what will happen, explain any safeguards you need to take and probably ask you to sign a consent form.

What might be the benefit for me of this kind of treatment?

- Helps ease pain in the bones for several months
- May help delay other treatments, such as external beam radiotherapy
- Most men have very few problems with Strontium 89
- May improve your quality of life

How is it given?

Because Strontium 89 is a radioactive material, it is given by staff who are specially trained in giving this type of treatment. So, you would need to go into a hospital clinic or day area, usually as an outpatient.

Strontium 89 is given as an injection into a vein in your arm or hand and only takes a minute or two. It shouldn't be painful but you may find it a bit uncomfortable. Usually, you can go straight home afterwards.

Don't worry about being 'radioactive' around your family and friends; it won't do them any harm.

If you are already having treatment with calcium, your doctor will probably take you off this about 2 weeks before you have the Strontium 89 injection.

How long before it starts to work?

It often takes around 2 weeks before the treatment really starts to work and it may take slightly longer before you notice any benefit. Although some men find that the pain gets slightly worse, called a 'flare', for the first few days after the injection, most men don't. If this does happen, tell the doctor as you may be given some other pain-killing medicine for a few days to help you get through this time.

Once it starts to work, you should have the benefit of pain relief for several months and Strontium 89 can be given again in the future if it helped.

Is there anything I have to do after the injection?

The effect of Strontium 89 is kept to the small area where it collects in the bones and helps with pain. However, for the first 2 weeks after the injection,

there will be some Strontium 89 in your urine so you must take extra care when passing urine.

If you are incontinent, (not able to control your urine) then your doctor may decide that it's best for you to have a catheter before your Strontium injection and for the first 2 weeks after the injection.

Perhaps the hospital that you are attending will give you advice and it is important that you follow their guidelines. If not, as a safeguard you should follow these simple rules for the first 2 weeks:

- Whenever possible use a normal toilet rather than a urinal
- Sit down to pass urine rather than standing up so you are less likely to dribble on the seat
- Flush the toilet twice
- Wipe up any dribbled urine with a tissue and flush the toilet twice
- Always wash your hands thoroughly after using the toilet
- If clothes, bed sheets or covers get stained with urine wash these straight away, separately from other clothes, and rinse thoroughly
- If urine gets on to your underwear, then wash underwear immediately and separately from any other clothes
- If you cut yourself, wash away any blood
- If you have to collect or test your urine for any reason, ask your doctor for more advice
- If you use incontinence pads, then ask your doctor or specialist nurse for more advice on what to do with the used pads for the two weeks following your injection
- Your doctor will let you know if you need to do anything else after you have the injection
- Make sure you keep any appointments for follow up blood tests
- Ask the doctor or specialist nurse if there is anything you are unsure about

Treatment card

You should be given a treatment card which you should carry with you all the time for the first three months after you have had this treatment. You should show this card to any medical staff that may be treating you, so that they know you have had this kind of radiotherapy treatment.

What about side-effects?

Usually, there are not many side-effects, although you may feel a bit sick or have some diarrhoea. You may have a drop in the white blood cell-count. This doesn't normally cause any problems but your doctor may want to check your blood levels.

If you have any concerns, get in touch with your doctor to ask for advice.

Bisphosphonates

As zoledronic acid may only be obtainable as part of a clinical trial and not available in all areas of Scotland, this section may not be relevant to you. However, this section is to help you understand a bit more about bisphosphonates – what they are, how they work, how they are given and their possible side-effects. You should ask the doctors or nurses involved with your care for more specific advice about your region.

What are bisphosphonates?

Bisphosphonates are drugs that, in certain situations, can help protect your bones against some of the effects of cancer such as pain, thinning, weakness, possible breaks and may help improve the man's quality of life. They can't treat the cancer itself but work by strengthening the bones.

They can also be used to treat or prevent high levels of calcium in the blood when the bones start to thin.

There are a few bisphosphonates but zoledronic acid (Zometa®) is the one that is licensed for use here. In addition, a new medicine called denosumab (Xgeva®) has also recently been licensed by the European Union for use in the treatment of bone loss from prostate cancer but (at the time of writing December 2011) has yet to be put forward to the Scottish Medicines Consortium for consideration.

When are bisphosphonates used?

Hormone resistant prostate cancer (HRPC)

When hormone therapy has stopped working as effectively and the cancer has spread to the bones.

Hypercalcaemia (High levels of calcium in the blood)

Calcium helps to strengthen bones but when bones are damaged by secondary deposits of cancer the calcium can be lost and seep into the bloodstream. High levels of calcium in the bloodstream are detected by a blood test and is called hypercalcaemia. Hypercalcaemia can cause symptoms such as nausea, vomiting, tiredness, moodiness and sometimes confusion. Bisphosphonates can help to reduce high levels of calcium.

How do Bisphosphonates help?

In healthy bone, there is a balance between two types of bone cells- osteoclasts and osteoblasts. They work together constantly to shape, rebuild and strengthen bones:

- Osteoclasts – destroy old bone
- Osteoblasts – build new bone

Cancers in the bone produce chemicals that change the balance between destroying old bone and building new bone. New bone is made but it is abnormal and weaker than normal bone. This can cause pain and may lead to bones breaking more easily.

Because calcium is lost out of the bone at the same time the level of calcium in the blood rises.

Bisphosphonates work by restoring the balance to strengthen bone, help with pain and reduce the amount of calcium lost from bones. Bisphosphonates don't affect normal bone.

How are bisphosphonates given?

- You will need to go to a day unit or outpatients ward at hospital every 3 to 4 weeks
- A thin tube (cannula) will be put into a vein in your arm. A fluid containing the drug will run through this tube into the vein
- This treatment usually takes about 15 minutes but may take slightly longer
- You might feel a little discomfort at first but it shouldn't last long

As each hospital might do things a little differently you can ask for more information from your doctor or nurse.

Are there any side-effects?

Although Bisphosphonates may help with pain or help prevent bones breaking they can have some minor side-effects, but after a short time most men cope with this treatment quite well.

Probably the most common side-effects are:	Things which may help:
The bone pain gets slightly worse when you first start having zoledronic acid	Tell your doctor or nurse and they may give you pills to help with this pain or a slightly stronger pain-killer until this settles down
Flu-like symptoms – chills, fever, headache, aching joints or muscles	Ask your doctor or pharmacist if you can take paracetamol to help
Feeling or being sick	This usually only lasts for a few days but your doctor may give you pills to help
Tiredness	Try to get plenty of rest
Constipation	Try to include more fibre in your diet or ask your doctor or specialist nurse for more advice
Red or sore eyes	The doctor may prescribe eye drops or your pharmacist may be able to suggest some suitable eye drops

While you are on this treatment you may find that the doctor will:

- Check that your kidneys are working properly
- Measure the levels of calcium, magnesium and potassium in your blood
- Check your blood pressure

Osteonecrosis of the jaw

This doesn't happen very often. It is more usual if you have bisphosphonates for longer than a year and if you have any dental treatment whilst taking

bisphosphonates. It means that the healthy bone in the jaw dies and it may cause the following symptoms:

- Pain, swelling, or redness in the gums
- Gum infections
- Teeth becoming loose or falling out
- Gums not healing properly after dental treatment
- A heavy or numb feeling in your jaw

You should let your doctor or dentist know about these symptoms as soon as possible.

How long might I have bisphosphonates?

Your doctor may advise that you stay on these for as long as they are helping you.

Is there anything I should do?

- Before starting on bisphosphonates your doctor may advise you to see your dentist for a check up and then continue to have regular checkups. If you need to have any dental treatment then it is better to have this done before starting bisphosphonates
- Let the dentist know that you will be starting on this drug
- Tell the doctor or dentist about any mouth infection as you may need to have an antibiotic
- Clean your teeth regularly

Spinal Cord Compression

What is spinal cord compression?

Although this is not a very common problem, it is something you need to be aware of and let your doctor or GP know immediately if you experience any symptoms that may indicate it is happening.

Spinal cord compression is caused by pressure on the spinal cord because:

- The cancer has spread to the bones or the spine
- This secondary tumour grows causing compression of the spinal cord

As a result, there is swelling and pressure on the spinal cord and nerve roots.

If this goes on for a long time it can lead to the spinal cord nerves being permanently damaged.

What should you look out for?

Pain in your back: This can be anywhere from your neck down, particularly if it is associated with any numbness or tingling in the legs. People often say that the pain feels like a 'band' around their chest or tummy or describe the pain as burning or shooting

Numb feeling: A numbness or 'pins and needles' in your toes, fingers or over your bottom.

Unsteady: You might notice that you are a bit more unsteady on your feet, walking might become a bit more difficult and your legs may feel weak.

Problems passing urine: You might find that it is a bit more difficult to hold urine in your bladder or that you don't pass very much urine or sometimes none at all.

Bowel: You might find that you have difficulty controlling your bowels.

If you have any of the following you should contact your GP immediately:

- **Any new difficulty walking**
- **Reduced power/altered sensation**
- **Bowel/bladder disturbance**
- **Shooting pain that goes down your leg or new pain that feels like a band around your chest or stomach**

What might the doctor do?

To be sure of what is causing these symptoms your doctor may want you to have some tests.

MRI scan: This is done so the doctors know where the spine or nerves are affected. For more information about this please see Booklet 1: Introduction to Advanced Prostate Cancer page 21.

How can it be treated?

As soon as the doctor confirms that you have spinal cord compression then treatment is started straight away, this aims to shrink the tumour and so ease the pressure on the nerves. The quicker the treatment is given, the sooner your symptoms will improve and the less likely it will be for permanent injury to the nerves in the spinal cord.

Before starting you on treatment the doctor will think about:

- Your general health and fitness
- The part of your spine affected
- Any treatment you have already had
- The possible side-effects on you
- Your views on the treatment

Treating spinal cord compression (SCC)

As far as possible and as soon as possible, it is important to get you back to the way you were before. The doctor will explain the options to you and you will have to sign a consent form before any treatment can go ahead.

You may be advised on:

Steroids

These are usually started straight away as they help reduce swelling, ease the pressure around the spinal cord and this helps reduce any pain. The steroid most commonly used is dexamethasone. Once your symptoms have started to get better, the doctor will gradually reduce the dose of the steroid until you no longer need it. For some men, dexamethasone will be continued after radiotherapy has started, then the dose will gradually be tapered off.

Radiotherapy

Radiotherapy is the usual way to treat spinal cord compression (SCC).

This means that high energy x-ray beams from outside the body are aimed at the tumour in or near the spine, to kill the cancer cells.

Before radiotherapy can begin the doctors work out a treatment plan. To make sure that the correct area is treated there will be a tiny, permanent mark made

on your skin. Although treatment takes just a few minutes and you won't feel anything, you may have to stay in hospital.

There are different ways of giving radiotherapy; most men will have 5 treatments whilst others will have a single treatment.

Possible side-effects of this radiotherapy

Side-effects are mild and not usually a problem but can include:

- Feeling more tired than before the treatment started
- Your skin going a bit red in the area being treated
- Feeling a bit sick
- Diarrhoea

Surgery

Very occasionally, it may be necessary to treat spinal cord compression with an operation. This would involve removing part, or all, of the tumour in the spine to relieve pressure on the nerves. In some instances, this is combined with surgery to stabilise the spinal column. However, in the context of prostate cancer this form of treatment is rather unusual and radiotherapy is the usual treatment in the vast majority of cases.

What happens after treatment?

You may see a physiotherapist or occupational therapist to help get you moving again. They may suggest exercises for you to do to help build up your strength.

Pain

One of the most troubling symptoms is often pain. Your doctor will prescribe pain-killers for you. Let the doctor know whether these are controlling your pain well. Another option may be to see a doctor who specialises in controlling pain.

Rest in bed

In certain circumstances, your doctor may advise you to rest in bed. Ask for more advice on this.

Questions you may want to ask your doctor or specialist nurse

Before starting on any treatment for bone pain, 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. Perhaps you would only need to ask a few of these, or you may have questions of your own.

- Which treatment are you recommending for me?
- Why do you think this might be the best option for me?
- How do you expect this treatment to help?
- What are the main benefits for me in having this treatment?
- Are all of these treatments available in my area?
- How familiar is the team in giving these treatments?
- Could having the treatment make me feel worse?
- Can you explain what the 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?
- Is there anything I could do to help with the side-effects?
- When and where would I have the recommended treatment?
- How long will I have the treatment for?
- What checkups would I have and how often would I need checkups? What would be done at the checkups – PSA, scan, etc?
- If the recommended treatment doesn't work for me, 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?

Chemotherapy

This section concentrates on chemotherapy for advanced prostate cancer.

Usually, chemotherapy will be the treatment choice when hormone therapy is no longer working for you, in other words your prostate cancer has become resistant to being treated with hormone therapy.

When, or if, you are treated with chemotherapy varies from man to man so your doctor will talk this over with you.

As chemotherapy is usually only given after hormone therapy you may choose to read this section only when it becomes a treatment option for you.

Introduction

Chemotherapy actually means giving drugs to kill or stop the growth of cancer cells and to help you live longer. These drugs are usually given through a drip or sometimes as tablets.

When would it be used?

Chemotherapy is used when hormone therapy isn't controlling the disease anymore. At this stage, it isn't possible to kill all the cancer cells so advanced prostate cancer can't be cured. When this is the case, chemotherapy is given to help relieve pain from the cancer growth in the bone, help control your prostate cancer and help improve survival.

Chemotherapy may not be the right treatment for all men though. The doctor looking after you will need to consider:

- If you would benefit from having this type of treatment
- How the side-effects would affect your quality of life
- If you are fit enough to deal with any side-effects

So, before starting this kind of treatment you will probably find that the doctor will check on your general health by making sure that your heart, liver, lungs and kidneys are working properly.

What is chemotherapy?

Chemotherapy uses certain drugs to kill cancer cells wherever they are in the body so it acts throughout the whole body and it isn't limited to particular sites or areas (this is called systemic treatment). In the past, chemotherapy wasn't used very often to treat prostate cancer but this has changed and more doctors are now using chemotherapy to help with pain but also to help some men live longer.

The most common drug used is docetaxel or you might know it by the name Taxotere®. The doctor who is caring for you will tell you more about the treatment - which drug you will be given, how often you will have it, how long for and the possible side-effects. It's a lot to take in. If you are unsure about anything then there's no harm in asking the doctor or specialist nurse to explain it to you again. In turn, you should let medical staff know if you are taking any dietary supplements or complementary medicines.

How does chemotherapy work?

Cancer cells in the body divide very quickly. Chemotherapy works by targeting, and rapidly killing growing cancer cells as they divide wherever they are in your body. Because cancer cells divide more quickly than healthy cells, chemotherapy drugs kill more cancer cells than healthy cells. This should help slow down the growth of the cancer. A benefit of this may be that you are not in as much pain and you may feel better generally.

A drawback of chemotherapy drugs is that they may also damage healthy cells in your body. Healthy cells, like hair follicles, bone marrow cells, and those in your digestive system (gut) divide quite quickly too so they can grow and repair from everyday wear and tear. Understanding that some healthy cells are killed by chemotherapy drugs, helps explain a number of the side-effects you may have heard about or experience.

How do I have this?

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.

The dose of chemotherapy drugs used varies from person to person. The doctor will take into account things like your height and weight, stage of your cancer and how healthy you are in general and will plan your treatment, and times for your treatment very carefully. So, it's important that you attend all your treatment dates. In between treatments, look out for any potential side-effects and follow what the staff at the hospital have told you about what to do and who to contact for help and advice.

You will most likely have to go into the hospital clinic or day area as a day patient to have your treatment.

A usual chemotherapy session might be:

- Your blood being checked before you have each chemotherapy treatment to make sure that your blood count is satisfactory, so you can safely have the treatment. Often this is arranged for the day before at your local GP surgery
- A nurse putting a drip (a needle attached to a small flexible tube) into a vein and allowing the drug to gently run into your body (infusion) for about an hour
- The staff will keep a close eye on how you are for the first few minutes of the infusion starting. It's important to let the doctor or nurse know if you are not feeling well when the drip starts

How long will it be given for?

Chemotherapy is given as cycles of treatment. This is to make sure that as the new cancer cells try to grow they are killed off every few weeks. It also gives your body some time to recover between cycles.

The table gives general information about how treatment may be given, but your doctor will advise you on what is most suitable for you.

Currently available

Type of treatment	Drug used	Number of cycles	Time apart	Why this might not be given
1st line treatment	Docetaxel (Taxotere®)	6–10	21 days	If your blood count has not suitably recovered then your chemotherapy dose may be reduced or it may be postponed to a later date
If this works well then you may have a second course of treatment		4–6	21 days	
2nd line treatment	Mitoxantrone (Novantrone®)	6–10	21 days	

Not currently available

The following treatment, whilst licenced for use in the UK has been turned down by the Scottish Medicines Consortium for inclusion on the NHS formulary

Type of treatment	Drug used	Number of cycles	Time apart	Why this might not be given
2nd line treatment	Cabazitaxel (Jevtana®)	6–10	21 days	Cabazitaxel is licensed for use in the UK but is not included by the Scottish Medicines Consortium (SMC) on the NHS formulary

Anything else?

You will need to take a steroid medicine on the day of, and the day after your chemotherapy.

This may help prevent certain side-effects of docetaxel. Try not to miss any doses of your steroid medication. Tell the doctor or nurse if you haven't taken this medicine before your chemotherapy treatment.

What about side-effects?

The side-effects you may have are linked to the way the chemotherapy drug works. Understanding that it kills some of the healthy dividing cells in the skin, hair follicles, bone marrow and digestive system (gut) helps explain some of the side-effects.

With side-effects remember:

- How chemotherapy affects you may be different from other men who have had chemotherapy. Some men get a lot of side-effects while others have very few. It's something no-one can predict but it's important to let your doctor or specialist nurse know about, they may be able to offer something to help
- There is a lot of information on how the treatment might make you feel, but pay attention to how you feel, note it down then tell the doctor or specialist nurse

The most common side-effects are:	What can be done to help?
<p><i>Fatigue or feeling extremely tired</i></p> <p>You may feel that you have very little energy, are tired all the time and can't be bothered with the things you enjoyed doing before</p>	<p>Although it may sound strange try taking some gentle, regular exercise like going for short walks</p> <p>Sitting down or resting whenever you feel tired at whatever time that might be</p> <p>Trying to get enough sleep at night – if this is a problem ask your doctor for more advice</p> <p>Getting help with everyday jobs like cleaning, work, shopping, gardening</p>

The most common side-effects are:	What can be done to help?
<p><i>Hair loss</i> Hair thinning is quite common and for some there may be total hair loss. Because of this, you may find you will be quite cold going outside</p>	<p>Wearing a hat may help or in some instances it might be possible to get a wig. The good news is that your hair should start to grow back after your treatment finishes</p>
<p><i>More difficult to fight off infections</i> Chemotherapy can reduce the number of white blood cells being made by the bone marrow, putting you more at risk of catching an infection Contact your doctor immediately if you:</p> <ul style="list-style-type: none"> • Have a high temperature • Start to feel unwell very suddenly • Feel cold and shivery • Have a headache • Have a sore throat or a cough <p>Your hospital will most likely tell you who to contact for help and advice</p>	<p>Washing your hands thoroughly to kill off any germs</p> <p>Keeping away from others who have colds, coughs, sore throats or any other illnesses so that you don't pick up any infection</p>
<p><i>Bruising or bleeding</i> Chemotherapy can impair your blood clotting mechanisms</p>	<p>Let your doctor or specialist nurse know immediately about any bruising, nosebleeds or if your gums bleed</p>
<p><i>Anaemia</i> This can make you feel tired and breathless</p>	<p>If necessary, your doctor may suggest a blood transfusion or prescribe iron tablets</p>

The most common side-effects are:	What can be done to help?
<i>Feeling or being sick</i>	Your doctor will prescribe drugs (anti-emetics) that can help, or you can speak to the specialist nurse about this
<i>Sore mouth</i> Because the treatment can affect your mouth and gums you might notice small mouth ulcers	Brush your teeth regularly but gently in the morning, after eating and at bedtime using a very soft toothbrush. Ask the specialist nurse for more advice about using a mouthwash
<i>Feeling low</i> It's quite common to feel a bit down in the dumps or unhappy around this time. You might find that your mood gets better and you feel happier after your treatment finishes	The doctor or specialist nurse may be able to help if this continues after your treatment finishes. Joining a support group or contacting organisations who provide telephone helplines may help
<i>Not having much of an appetite</i> You may find that food doesn't taste the same – more salty, bitter or metallic	Try having small regular meals and snacks throughout the day. If this is a real concern the doctor might refer you to a specialist dietitian

After your treatment finishes you will probably find that these side-effects gradually settle down and become a thing of the past even though it may have been difficult and upsetting to deal with them during your treatment.

Neutropenic sepsis

When you start on chemotherapy your doctor or specialist nurse will almost certainly give you special advice about a very important potential side-effect of chemotherapy called neutropenic sepsis.

What is neutropenic sepsis?

Bone marrow normally produces different types of blood cells – red cells, white cells and platelets. The growth of all these types of blood cells will be reduced when you start chemotherapy.

Neutrophils are one of the types of white blood cells and are very important in protecting the body against infection.

Neutropenic or neutropenia means that there are a low number of neutrophils in your blood.

So what does this mean?

It means that you will be more prone to catching an infection and your body won't be able to fight the infection as well as before. Catching an infection can have very serious consequences, so it is important that you know what to look out for and what you should do.

Signs you should look out for:

- High temperature of 37.5°C or above. As it is important to be able to check your temperature accurately, it is a good idea to buy a digital thermometer from a chemist
- Shivering or sweating
- Feeling hot or flushed
- Feeling generally unwell
- Having a headache, cough or sore throat
- If you notice any of these signs especially 7 - 10 days after your chemotherapy treatment

What should you do?

It's a good idea to make a record of the following and keep it handy,

possibly letting your wife, partner or a friend know where it is. There may be a form included with this booklet that you can fill in with all these details, if not you can download a copy from our website www.prostatescotland.org.uk, email us at info@prostatescotland.org.uk or call us for a copy on 0131 226 8157.

	An idea of information that you may like to keep handy	Information
Contact numbers	<ul style="list-style-type: none"> • Your GP's name and telephone number • The hospital telephone number • Any emergency telephone contact details that your hospital has given you • NHS 24 number • Name of your consultant and telephone number 	0845 24 24 24
Your details	<ul style="list-style-type: none"> • Date of birth • Hospital number (if you have this) • What chemotherapy treatment you have • When did chemotherapy start • The date of your last treatment 	
Act quickly	<ul style="list-style-type: none"> • If you're not feeling well, it is a good idea to check your temperature • If you're not feeling well and your temperature is higher than normal, then contact your GP or the emergency contact number you have been given by your hospital doctor or specialist nurse 	
Making the call	<ul style="list-style-type: none"> • Tell the person you (or your family call) that you are having chemotherapy treatment and the date you had the last treatment 	

What about treatment?

If you think you have neutropenic sepsis, it is vital that antibiotic treatment is started straight away so you may find that you will be admitted to hospital to have antibiotics by a drip so that they act very quickly.

Trapeze Study

This is a study or trial that is being undertaken in some hospitals throughout Scotland. It started a few years ago and is due to complete recruitment around December 2011 although it will be some time after this before the results are available.

All patients in this trial receive docetaxel but may in addition be randomised to receive zoledronic acid and/or strontium 89.

Usually these treatments are given independently of each other and are used to treat prostate cancer which has spread to the bones.

This trial is to find out if these drugs work well together when they are combined, which drugs work best together and finally what the side-effects are.

At the time of printing the trial hadn't been completed so no results were available.

STAMPEDE Trial

This trial is taking place across the UK and Switzerland and involves men with prostate cancer where they are embarking on hormone therapy and either are newly diagnosed with high risk prostate cancer, or who have had radiotherapy or radical prostatectomy surgery and are relapsing.

The aim of this trial is to try to prevent tumour re-growth by adding other treatment to the hormone therapy. The trial is using new drugs in different combinations with hormone therapy called docetaxel, zoledronic acid and abiraterone acetate.

The trial is ongoing until 2013 so results are not yet available.

Questions you may want to ask your doctor or specialist nurse

Before starting chemotherapy, 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.

- Why have you recommended chemotherapy?
- What do you expect chemotherapy to do to the cancer?
- Why do you think this might be the best option for me?
- Could having chemotherapy make me feel worse?
- Can you explain what the 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?
- Is there anything I could do to help with the side-effects?
- When and where would I have chemotherapy?
- Which drug am I likely to be put on and why?
- How many sessions of chemotherapy am I likely to have?
- What checkups would I have and how often would I need checkups?
- What would be done at the checkups – PSA, scan, etc?
- If chemotherapy doesn't work for me 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?

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	✓
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	✓
Macmillan Cancer Support Support Nurses	www.macmillan.org.uk	020 7840 7840 0808 808 0000	✓
Cancer Research UK Cancer Information Nurses	www.cancerresearchuk.org	020 7242 0200 0808 800 4040	✓
Edinburgh and Lothian Prostate Cancer Support Group	www.elprostatecancersupport.co.uk	0131 208 3067	✓
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	
Webmd	www.webmd.com		
Patient UK	www.patient.co.uk		
Medicine net	www.medicinenet.com		

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"> • About the prostate and prostate cancer • How advanced prostate cancer is diagnosed • Test results and what they mean • The next steps after getting your results • A brief guide to treatments • A brief guide to making decisions about treatments and clinical trials • Contact details of useful organizations • Other booklets in the Prostate Scotland series on advanced prostate cancer
<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>Part 1 focuses on helping you think about treatment decisions and taking part in clinical trials It gives:</p> <ul style="list-style-type: none"> - 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 appointment with doctors, specialist nurses or the research team <p>Part 2 touches on some of the possible difficulties</p>

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

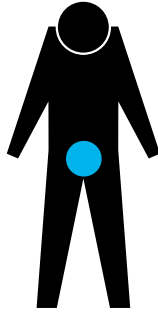
High Intensity Focused Ultrasound (HIFU)

- 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 or you can contact 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 leaflet 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).

Notes:

