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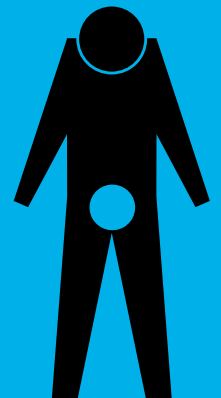
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## Treatments for advanced prostate cancer:

### Treatments for bone pain and spinal cord compression explained





## Treating bone pain and spinal cord compression

When prostate cancer spreads, the most common places for it to spread to are your bones, lymph nodes/ glands, areas close to the prostate, such as the urethra (water pipe that takes urine from the bladder). Sometimes the cancer can affect the tubes leading from the kidneys to the bladder as well as the back passage (rectum). When it's in the bones, it can weaken and cause the man pain in the affected bone. He may feel this pain as a dull ache or sharp pain that can get worse when you moving around.

This booklet is to help you, your spouse or partner and your family understand more about treating pain in your bones from prostate cancer; it explains - what the treatments are, how these are given and some of the potential side-effects associated with these.

- Pain relief medicines;
- External beam radiotherapy;
- Radioisotope injections (Radium 223);
- Drugs called bisphosphonates (Zometa, Denosumab).

## Spinal cord compression (SCC)

In addition the booklet covers spinal cord compression. Although SCC is rare and only occurs in a small number of men, it is something you need to be aware of, letting your oncologist, clinical nurse specialist (CNS) or GP know about immediately if you experience any of the symptoms it can cause. The section from pages 22 - 27 explains what it is, signs and symptoms, tests that you might have done to confirm SCC, treatments and any help that you may need to recover.

## What is advanced prostate cancer?

When the cancer is no longer contained inside and has spread outside the prostate, it is called advanced prostate cancer. You may also hear this called secondary cancer (secondaries) or metastatic prostate cancer.



Cancer cells can break away from the original tumour and spread to other areas in your body through the bloodstream or lymph channels. On reaching a new site or sites, the cancer cells may then start to grow causing another tumour or tumours.

Even if the cancer has spread to other areas in your body, it's still prostate cancer. For example, prostate cancer that has spread to a bone in your hip still has the same prostate cancer cells that the original tumour in your prostate had, so it's not bone cancer.

## Can advanced prostate cancer be cured?

Advanced prostate cancer means that the cancer has spread outside the prostate to other areas in the body so at this stage it's not possible to cure the cancer. There are a range of treatments that can control or manage your prostate cancer to help you live as full and active a life as possible for as long as possible.

## Prostate cancer that has spread to the bones

When prostate cancer has spread to the bones it can cause weakening of the affected bone(s) 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.

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. 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;
- If there are any particular times or days that you feel the pain is worse.

### **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 side-track 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 oncologist do to help with pain?**

Many men worry about being in pain. Your oncologist 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 oncologist can take to help get your pain under control. In fact, you may find that your doctor combines some medicines to help get the best pain relief for you.

Step 1 if your pain is mild.

Step 2 if you have mild to moderate pain.

Step 3 if you have moderate to severe pain.

There are various different drugs to help with pain:

- the type of pain you have eg nerve pain or bone pain;
- these are given in different ways eg taking these by mouth or as a patch

Once the oncologist or CNS has explained the pain relief treatment plan to you, it's vitally important that you follow their instructions exactly. This means taking the right drug, the correct amount or dose of the drug(s), at the right time. Don't miss taking the tablets prescribed because you think the pain has gone or is not as bad as before.

### **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.

Try to include at least 5 portions of fruit and vegetables in your diet and drink 6-8 glasses of fluid each day (around 2000mls).

*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 the dose/amount that your oncologist has prescribed. If you have any concerns about this, talk it over with someone from your oncology team.

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 oncologist** 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;
- Try other combinations of pain-killers.

### **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 as 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**

*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/your oncology team and follow their instructions.*

#### ***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.

However, radiotherapy may not be the right kind of treatment for all men.

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 oncologist or CNS 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 to have warm (not hot) showers and avoid using soaps or shower gel with perfumes;
- Being a bit more tired than usual, especially in the first week or so, but this may continue 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 a bit 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. Your oncologist or CNS you will talk this over with you.

### Radium 223 dichloride (brand name Xofigo®)

Your oncologist may suggest treating you with Radium 223.

In Scotland, Radium 223 is available for men with hormone-resistant prostate cancer that has spread chiefly to the bones. However, it is not suitable for some men. Because Radium 223 only treats bone disease, it can't be given if there is any internal organ disease such as lung or liver metastases (cancerous growths) or if there are enlarged lymph glands above 3 cm in size.

### What is Radium 223 dichloride?

It is a radioactive, therapeutic drug. It is a clear, colourless fluid that is given by injection.

### How does it work?

Radium 223 helps to control the effect of cancer in your bones and may help you live longer.

Radium acts in a very similar way to calcium in the body finding its way to bones that are growing, just like calcium. If your prostate cancer has spread to your bones, then these are areas of bone that are growing very quickly and radium 223 collects at these areas. Radium 223 treatments use a type of radiation called alpha particles to kill cancer cells allowing the therapy to be delivered exactly where it is needed while limiting damage to normal healthy cells. So it is a kind of internal radiotherapy. The radium will work to destroy the cancer cells if there are cancer cells in more than one area of bone. This helps to reduce the cancer growths and the pain that these growths can cause.

### How will it help me?

It is used to treat prostate cancer that has spread out-with the prostate to the

bones and the cancer is no longer responding to hormone treatment. You might hear this called hormone (castrate) resistant prostate cancer.

Always ask the oncologist or clinical nurse specialist (CNS) if you have any doubts about what you can do.

### What should you look out for and let the oncologist know about?

Let your oncologist know about any symptoms that you are having wherever this happens to be in your body, even if you don't think it might have anything to do with your cancer. These might be weakness, pain, difficulty in moving around or difficulties with how you are standing.

You should also let the oncologist know if:

- You are taking calcium or any other supplements. You will most likely be asked to stop taking calcium before your treatment starts;
- You are taking any other kinds of medicines.

*(Throughout the leaflet, information is given as a guide on how things might be done. However, as there is more than one approach, if you are given specific information or guidance by your oncologist, CNS or GP then it is important that you follow their instructions)*

### What is likely to happen when I have this treatment?

Once the oncologist has decided and discussed Radium 223 with you, it's handy to know what might happen and if there is anything you need to do to prepare for the treatment.

- After you have agreed to have Radium 223, you will most likely be asked to sign a consent form;
- You will have Radium 223 as an out-patient so you won't need to stay in hospital;

- To make sure that your blood counts are normal or satisfactory, you will have to have a sample of blood taken before your treatment/injection can go ahead. Often this is arranged at your local GP surgery;
- The dose/amount of radium 223 you will have will be calculated for you by the oncologist looking after you;
- Although you will have had the treatment explained to you beforehand, if you have any questions you should be able to ask these before your first treatment begins.

Radium 223 is given by injection. A small needle/tube (you may hear this called a cannula) is put into a vein in your hand or arm and is first of all flushed through with saline. Then the drug is given slowly, over a minute, through this needle and finally flushed through with saline again. So, the whole procedure should only take a few minutes and shouldn't cause any discomfort, other than having the cannula put into your vein.

The needle will be taken out and a small plaster put over the needle site. (Unless you have an allergy to plasters)

After your treatment, you can continue with your day as normal.

A very, very small number of men may find that there is some pain or swelling around the site of the injection.

### **How long will I have this treatment?**

This will be given once every 4 weeks up to a total of 6 injections.

To get the most benefit from your treatment, it's important that you attend all your appointments - for your blood tests and to have your 4 weekly injection.

If you can't manage appointments for any reason, it's important to let the clinic/ day unit know as soon as possible.

### **Is there anything I should do after the treatment?**

Radium 223 only affects the areas in your body where it collects so you can continue to be with other people as you normally would. There's no problem about someone giving you a hug, being with friends or playing with grandchildren and having them sit on your knee.

However, for about a week after your treatments, radium will be present mainly in your stools but also a small amount in urine, blood or if you are sick. If the hospital that you attend gives you advice then it's important that you follow their guidelines. If not, as a safeguard, you should follow these simple rules for the first 2 weeks:

- ALWAYS wash your hands thoroughly after going to the toilet or wiping up spillages of any body fluid;
- You should use a toilet rather than a urinal and sit down when passing urine so you are less likely to dribble on the seat. Flush the toilet twice afterwards;
- If you have an accident and spill urine, blood, sickness or diarrhoea, wipe up with tissue and then flush the tissue away.
- Use disposable gloves when mopping up any spillages. This applies too, to anyone who is caring for you;
- If your clothes or bed sheets become stained with urine, blood, sickness or diarrhoea, you or anyone caring for you, should handle these with disposable gloves. Wash stained items straight away in a washing machine, keeping the items separate from other washing;
- 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 on how to do this;
- Please ask at the hospital for more advice on how to dispose of the gloves you use to wipe up any spillages;



- ix. If you use incontinence pads or have a catheter bag, please ask your oncology team what you should do and how to dispose of these;
- x. If sexually active, you should use a condom during intercourse.

For the week after your injection, please make anyone treating you aware that you have had Radium 223. This includes providing urine, blood or stool samples for testing, if you have to have medical treatment for some other condition, if you are admitted to hospital or if you require an operation.

### **Treatment card**

You should be given a treatment card by the hospital that you should carry with you all the time for the first three months after you have had this treatment. Details of your treatment with Radium 223 can be filled in. You should show this card to any medical staff that may be treating you or if you are having other tests (eg urine test), so that they know you have had this kind of radiotherapy treatment.

There is also a treatment card included within this folder that the oncologist, CNS or you can fill in yourself with details of your treatment. This can be found in the pocket at the back of this booklet. You can take this out and keep it with you at all times.

### **How long might it take to make me feel better?**

For a couple days after your injection, you might find you have a bit more pain than usual. If this happens continue with your usual pain-killing medicine. Sometimes it may be necessary to take more pain-killers or you might have to take a stronger pain-killer. Your consultant, CNS or GP will be able to guide you on this. This should settle as the treatment starts to work and the pain should improve.

### **Potential side-effects**

Radium 223 is generally very well tolerated at the beginning. However because it can be taken up by other organs in your body, such as the bone marrow and digestive system, you may find some side-effects relating to these healthy

tissues, although not everyone will have side-effects. Radium 223 is normally avoided in people who have active inflammatory bowel disease such as Crohn's disease or ulcerative colitis.

You should let your oncologist know if you have any side-effects, especially those that are bothering you or don't go away. Mention to your oncologist how you are feeling in general and any other particular symptoms that are perhaps not listed below.

Probably the most common side-effects are nausea (feeling sick), being sick, diarrhoea and your legs, ankles, feet or arms swelling. If these are troublesome everyday, then your oncologist or GP may be able to prescribe something to help.

### *Temporary reduction in the number of certain blood cells in your body*

This is the reason for you having blood samples taken before your treatments so the oncologist can check that your blood count is satisfactory. It's essential that you have these before your treatment appointment. Let the oncologist, CNS or GP know about any signs of your blood count being low such as:

- Unusual bleeding such as nose or gums bleeding ;
- Unusual or excessive bruising;
- Infection (symptoms of this can include fever or chills);
- Shortness of breath;
- Tiredness;
- More prone to infections such as catching colds more easily and more often.

It may be that your oncologist will arrange for you to have another blood test to check what's going on.



### Dehydration (thirst or dryness)

Symptoms of dehydration that you should tell your oncologist or CNS about include; dry mouth, being thirsty, not passing much urine. It's very important to drink enough fluid each day. This may be even more important if you are being sick or having diarrhoea.

### What happens if I don't want to have this treatment?

If you decide not to go ahead or want to stop this treatment, you should talk this over with your oncologist or CNS as soon as possible.

### My treatment plan is:

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 is a separate information sheet included in the pocket at the back of this booklet, that you can fill in with all these details. You can take the insert out and perhaps pin up on the fridge or beside your phone so you can see the information.

Injection 1	Where	Date	Time
Blood test			
Treatment with radium 223			

Contact number if questions or to cancel:

Injection 2	Where	Date	Time
Blood test			
Treatment with radium 223			

Contact number if questions or to cancel:

Injection 3	Where	Date	Time
Blood test			
Treatment with radium 223			

Contact number if questions or to cancel:

Injection 4	Where	Date	Time
Blood test			
Treatment with radium 223			

Contact number if questions or to cancel:

Injection 5	Where	Date	Time
Blood test			
Treatment with radium 223			

Contact number if questions or to cancel:

Injection 6	Where	Date	Time
Blood test			
Treatment with radium 223			

Contact number if questions or to cancel:

To help you keep track of appointments there is also a very handy Prostate Log Book that you can download at [www.prostatescotland.org.uk](http://www.prostatescotland.org.uk) or contact us and we'll send a copy to you or fill in the treatment guides above.

### Strontium 89 (Metastron)

Strontium 89 was previously used to help with bone pain before Radium 223 dichloride was available. It worked in the same way as radium 223, had the same benefits and was also given by injection. Strontium 89 has now been replaced with Radium 223.

### Bisphosphonates

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.

#### What are bisphosphonates?

Bisphosphonates don't treat the cancer itself but work by strengthening the bones.

In certain situations, they may help with:

- Pain;
- Thinning of the bones, weakness, and, rarely, your bones(s) breaking;
- Improving the man's quality of life;
- Treating or preventing high levels of calcium in the blood when the bones start to thin.

There are a couple of bisphosphonates:

- Zoledronic acid (Zometa®). Zometa is the drug most commonly used and is available in several health boards. Your oncologist will be able to advise you on the policy in the health board.
- Denosumab (Xgeva®). At the time of writing in October 2017 this was not available for men with advanced prostate cancer in Scotland on the NHS.

#### When might bisphosphonates be 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. When bones are damaged by cancer spreading to the bones, calcium can be lost and leak into the bloodstream. A high level of calcium in the bloodstream is called hypercalcaemia. It is found by having a blood test. Hypercalcaemia can cause symptoms such as nausea, vomiting, tiredness, moodiness and sometimes confusion. Bisphosphonates can help to reduce high levels of calcium.

#### About zoledronic acid and how it works

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. Although new bone is still made it is abnormal and weaker than normal bone. This can cause pain and may lead to bones breaking more easily.

At the same time, calcium is lost out of the bone so 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 is zoledronic acid given?

- You will need to go to a day unit or outpatients ward at hospital every 3 to 4 weeks;
- A needle with 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 oncologist, CNS or nursing staff in the day unit.

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

Although this may help with pain or help prevent bones breaking zoledronic acid can have some side-effects. This varies with the individual; some men may have few side-effects whilst others have more. That said most men cope with this treatment quite well and any unwanted side-effects often improve as your body gets used to the having a new medicine. Let your oncologist or CNS know if side-effects are or become troublesome.

#### *Being in more pain*

For a short time, you may find that pain in the bone actually gets a bit worse. Your oncologist or CNS may prescribe another pain killer to take until the effect of zoledronic acid kicks in.

#### *Being feverish*

This shouldn't last for long and you may only have mild symptoms that can include a high temperature, chills or shivery, aches and pains. Your oncologist or CNS will advise you on what you can take to help. Try to get some rest during the day and make sure you are having enough fluid.

#### *Sore itchy or watery eyes*

If this becomes a problem, your oncologist or CNS may prescribe some eye drops to help.

#### *Feeling or being sick*

Try having small, frequent meals and make sure you are having enough fluid so you don't become dehydrated. Your oncologist may prescribe medicines called anti-emetics to help.

Although these don't happen often, some side-effects are more serious and you need to get in touch with your oncologist, CNS, emergency contact number or GP straight away if you have any of the following:

- Shortness of breath;
- Difficulty in breathing;
- Chest pain;
- Your face swelling or throat closing;
- Fever with a temperature of 38°C.

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's more common 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 you doctor or dentist know about these symptoms as soon as possible.

### How long might I have zoledronic acid?

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

### Is there anything I can do or should be aware of while taking this drug?

- Tell your oncologist or CNS about any medicines that you are taking including over-the-counter medicines, vitamins, herbal or complementary medicines;
- Tell your oncologist or CNS if you have or have had any problems with your kidneys;
- Before starting on this your doctor may advise you to see your dentist for a check- up and then continue to have regular check-ups. If you need to have any dental treatment then it is better to have this done before starting zoledronic acid;
- Let your dentist know that you will be starting on this drug;
- Tell the oncologist or dentist about any mouth infection as you may need to have an antibiotic;
- Clean your teeth regularly.

### Denosumab (Xgeva®)

This is very similar to zoledronic acid but at the time of writing (October 2017) is not recommended/ available to men with advanced prostate cancer on the NHS in Scotland.

### Spinal Cord Compression SCC

Although SCC is rare and only occurs in a small number of men, it is something you need to be aware of, letting your oncologist, clinical nurse specialist (CNS) or GP know about immediately, as the oncology team looking after you need to act fast. If SCC is left untreated it can cause severe disability which may end up being permanent.

### What is SCC?

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

- Cancer cells have spread to the spine or bones very close to the spine and start to grow;
- When this secondary tumour grows, it can cause swelling and so the blood supply to the spinal cord and nerve roots is reduced.

The symptoms of SCC are brought about by the increased pressure on the spinal cord and nerves, called compression. 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?

**If you notice any of the following signs or symptoms, it is essential that you get in touch with your oncologist, CNS or GP immediately:**

Pain in your back	Back pain is often one of the first signs and may start off as just a slight pain but then get worse. It can be anywhere from your neck down. 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. It might also feel like a tingling or heaviness in your arms or legs.
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 can't pass urine at all.
Bowel	You might find that you have difficulty controlling your bowels or you might find it difficult to open your bowels.

Once your doctor knows about these symptoms, it is likely that he/she will carry out some tests to confirm it is in fact SCC. When SCC is diagnosed early, then there is a better chance that the treatment will be more successful.

If you have any of the following you should contact your oncologist, CNS or GP immediately:

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

There is a separate information sheet on spinal cord compression included in the pocket at the back of this booklet. You can take the insert out and perhaps pin up on the fridge or beside your phone so you can see the information

### What might the doctor do?

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

#### *MRI scan:*

An MRI scan uses magnets rather than x-rays to produce detailed pictures of your prostate, surrounding tissues, bones and other organs. This will show if your spine and nerves are affected by any growths of cancer cells and where these are.

During the scan you will be asked to lie very still, flat on your back on a narrow table which slides into the scanning machine. The machine is like a long tunnel and covers most of your body. The scan will take about 30 to 40 minutes. Although it won't hurt at all, you may find it uncomfortable to lie still and in the same position for that amount of time. For more information about MRI scans 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 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's important to get you back to the way you were before. After explaining why you need treatment, about the treatment itself and any potential side-effects, the oncologist may ask how you feel about having treatment for SCC. If you decide to go ahead, you will have to sign a consent form before you can be treated.

Before starting treatment for SCC, you may want to take time to think about what you feel is best for you. This might mean:

- Talking through options with the oncology team looking after you;
- Understanding what the aim of the treatment is and what the benefits will be for you;
- Talking it over with your family;
- Knowing what the side-effects of the treatment may possibly be;
- Then making your decision.

After having thought and considered what treatment *might* mean for you, you can talk to the oncology team if you have any more questions, concerns or worries. This might include chatting about whether you want to go ahead with treatment or not. The team will talk you through what might happen if you decide to go ahead or not with treatment.

There are various ways that SCC can be treated and you may have a combination of any of these.

#### *Steroids*

These are usually started straight away as they help reduce swelling, ease the pressure around the spinal cord and can quickly help 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*

For the vast majority of men, radiotherapy is the usual way to treat spinal cord compression (SCC) and will be started as soon as possible. Before this treatment can begin the oncology team will work out a treatment plan for you.

Radiotherapy 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.

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 that you might be treated by radiotherapy; most men will have a short course of 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;
- Sore throat (this depends on where you have the radiotherapy treatment).

#### *Surgery*

Surgery is very rarely used for prostate cancer that has spread to the spine. Very occasionally, it may be necessary to treat spinal cord compression with an operation. This depends on where the tumour is and how unstable the spine might be. It 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.

#### *Pain*

One of the most troubling symptoms is often pain. Your oncologist will prescribe pain-killers for you, remember to take these as he/she has directed. Let the oncologist/ oncology team know whether these are controlling your pain well. It may be that they have to try a few different types to get your pain under control. 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, lying completely flat to help prevent any more damage to your spinal cord. Your oncologist will want to check on any improvement and may do a series of tests to check on movement, reflexes and if you can feel touch. Ask for more advice on this.

## 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.

## Questions you may want to ask your oncologist or CNS

Before starting on any treatment for SCC you may have some questions to ask your oncologist or CNS. 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.

- Do you think I might be at risk of spinal cord compression?
- Who should I contact if I have any concerns about this? Is there a specific number I should call and what about out-of-hours?
- How urgent is it that I have/get treatment?
- What information will I need to provide about my condition and concerns?
- Is there any particular sign that I should look out for?
- How long should I wait before getting in touch if I have a concern – a day or two, a week, a couple of weeks?
- What tests might I have to confirm SCC?
- Which treatment might be recommended for me?
- How do you expect this treatment to help?
- 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 prevent SCC?
- How will you know if there is an improvement?
- What is the outlook for me?
- Is there someone that I can talk to who has had SCC?

## For more information...

If you have any questions, then you can speak to your oncologist, CNS, GP or staff in the day unit. 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.

There may be a prostate cancer support group in your area where you can talk to other men (and possibly their family) who have been diagnosed with prostate cancer. These support groups may provide you with additional information. Often these men will share their experiences about when they were diagnosed with prostate cancer, how they decided on treatment and about their experiences before and after treatment. However, it's important to remember that each man's experience will be different, so what happened to another man may be completely different from what you may experience.

Organisation	Website	Contact number	Helpline available
Prostate Scotland	<a href="http://www.prostatescotland.org.uk">www.prostatescotland.org.uk</a>	0131 603 8660	Telephone information service (not a helpline) 0300 666 0236
Cancer Treatment Helpline			0800 917 7711
Beatson Cancer Treatment Helpline	Only for those who attend the Beatson West of Scotland Cancer Care Centre.		0141 301 7990
NHS 24	<a href="http://www.nhs24.com">www.nhs24.com</a>	111	
Prostate Link UK	<a href="http://www.prostate-link.org.uk">www.prostate-link.org.uk</a>		
Prostate Cancer UK (includes some support group contact details)	<a href="http://www.prostatecancer.org.uk">www.prostatecancer.org.uk</a>	0141 314 0050	✓ 0800 074 8383



Organisation	Website	Contact number	Helpline available
Macmillan Cancer Support Support nurses	<a href="http://www.macmillan.org.uk">www.macmillan.org.uk</a>	020 7840 7840	✓ 0808 808 0000
Cancer Research UK Cancer Information Nurses	<a href="http://www.cancerresearchuk.org">www.cancerresearchuk.org</a>	020 7242 0200	✓ 0808 800 4040
Edinburgh and Lothian Prostate Cancer Support Group. Livingston Group for West Lothian Both groups run a buddy programme for additional support	<a href="http://www.elprostatecancersupport.co.uk">www.elprostatecancersupport.co.uk</a>  Email: <a href="mailto:charliehogg@blueyonder.co.uk">charliehogg@blueyonder.co.uk</a>	07933 260 066  01506 845 981	✓
Prostate Cancer Support Group, Maggie's Dundee	Email <a href="mailto:Lorna.McGoldrick@maggiescentres.org">Lorna.McGoldrick@maggiescentres.org</a>	01382 632999	
Prostate Cancer Support Group Maggie's Gartnavel General Hospital, 1053 Great Western Road Glasgow G12 0YN	<a href="mailto:glasgow@maggiescentres.org">glasgow@maggiescentres.org</a>	0141 357 2269	
UCAN Care Centre Ward 209, Aberdeen Royal Infirmary	<a href="http://www.ucanhelp.org.uk">www.ucanhelp.org.uk</a>	01224 550333 (voicemail)	
Prostate Cancer Support Network Fife	Maggie's Centre, Victoria Hospital, Kirkcaldy	01592 647 997	
Scottish Borders Prostate Cancer Support Group	Macmillan Centre Borders General Hospital	01721 722 655	
Highland Prostate Cancer Support Network	Maggie's Centre, Raigmore Hospital, Inverness	01463 706306	
Webmd	<a href="http://www.webmd.com">www.webmd.com</a>		
Patient UK	<a href="http://www.patient.co.uk">www.patient.co.uk</a>		
Medicine net	<a href="http://www.medicinenet.com">www.medicinenet.com</a>		

## Important helpline information

### Cancer Treatment Helpline - 0800 917 7711

There is a national cancer treatment helpline in Scotland available 24 hours a day. Patients who are worried about symptoms or feel unwell whilst having certain chemotherapy or radiotherapy treatment for cancer can get in touch with the helpline. There will be someone available at the end of the phone who will be able to consider and review your symptoms and then either:

- Offer advice;
- Arrange for you to see or speak with a cancer nurse or oncologist.

This means that you will get the most appropriate, effective and timely care, if you think you are feeling worse than before. You will be able to use this helpline for up to 6 weeks after your treatment has finished.

### Call 0800 917 7711 to get in touch with the Cancer Treatment Helpline in Scotland.

### Beatson Cancer Treatment Helpline - 0141 301 7990

This helpline is only for patients on radiotherapy or chemotherapy who attend the Beatson West of Scotland Cancer Care Centre. It means that there is direct access to specialist oncology advice and staff who are specially trained to answer your calls and consider and review your symptoms. This runs 8am-8pm seven days a week; calls between 8pm each evening and 8am, will be re-directed to the National Cancer Treatment Helpline. You will be able to use this helpline for up to 6 weeks after your treatment has finished.

Call the Beatson radiotherapy helpline on 0141 301 7432. (only for those treated with radiotherapy and who attend Beatson Cancer Centre, Glasgow)

### Maggie's Centres

Maggie's centres offer free practical, emotional and social support to people with cancer and their families and friends. Help is offered freely to anyone with any type of cancer. Simply drop in or phone at any time.

**Maggie's Aberdeen**, Aberdeen Royal Infirmary, Elizabeth Montgomerie Building,  
Westburn Road, Foresterhill, Aberdeen, AB25 2UZ, telephone 01224 645928, email  
aberdeen@maggiescentres.org

**Maggie's Dundee**, Ninewells Hospital, Tom McDonald Avenue, Dundee, DD2 1NH, telephone 01382 632999, email [dundee@maggiescentres.org](mailto:dundee@maggiescentres.org)

**Maggie's Edinburgh**, The Stables, Western General Hospital, Crewe Road, Edinburgh, EH4 2XU, telephone 0131 537 3131, email [edinburgh@maggiescentres.org](mailto:edinburgh@maggiescentres.org)

**Maggie's Fife**, Victoria Hospital, Hayfield Road, Kirkcaldy, KY2 5AH, telephone 01592 647997, email [fife@maggiescentres.org](mailto:fife@maggiescentres.org)

**Maggie's Centre Forth Valley**, Forth Valley Royal Hospital, Stirling Road, Larbert, Stirlingshire, FK5 4WR, telephone 01324 868 069, email [forthvalley@maggiescentres.org](mailto:forthvalley@maggiescentres.org)

**Maggie's Glasgow**, Gartnavel General, 1053 Great Western Road, Glasgow, G12 0YN, telephone 0141 357 2269, email [glasgow@maggiescentres.org](mailto:glasgow@maggiescentres.org)

**Maggie's Highlands**, Raigmore Hospital, Old Perth Road, Inverness, IV2 3FL,  
telephone 01463 706306, email [highlands@maggiescentres.org](mailto:highlands@maggiescentres.org)

**Maggie's Lanarkshire**, Monklands Hospital, Monks court Avenue, Airdrie, ML6 0JS,  
telephone 01236 771199, email [lanarkshire@maggiescentres.org](mailto:lanarkshire@maggiescentres.org)

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

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