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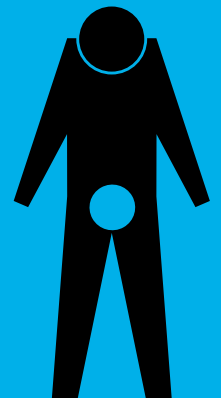
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PROSTATE INFORMATION ●

Treatments for advanced prostate cancer:

Hormone therapy for advanced prostate cancer explained



Introduction

Being told by the cancer specialist doctor (oncologist) or clinical nurse specialist (CNS) that you have advanced prostate cancer can come as a shock, and are words that you and your family didn't want to hear. Although this news may be very upsetting, and it may be some time before you take it all in, there are a range of treatments that your oncologist may offer; for instance there are different types of hormone therapy, radiotherapy and chemotherapy to help you live as full and active a life as possible with advanced prostate cancer.

If there is a prostate cancer support group in your local area, you may want to consider getting in touch as you will most likely meet others many of whom are living active lives with advanced prostate cancer. This lets you know that you and your family are not alone and gives you a sense of what is possible.

What is advanced prostate cancer?

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

Cancer cells sometimes break away from the original tumour and can 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.

The most common places for prostate cancer to spread to are your bones, lymph nodes or 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). Secondaries may also appear in the lungs and liver.

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 has, so it's not bone cancer.

Can advanced prostate cancer be cured?

Metastatic prostate cancer is an advanced form of cancer so it's not possible to cure the cancer. There are a range of treatments that can control or manage your prostate cancer for many months or years to help you live as full and active a life as possible.

What is the aim of treatment?

The 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 or growing.

What treatments are available?

Once prostate cancer has spread away from the prostate to other parts of the body a treatment is needed that tackles the cancer cells wherever they are. The drugs used to control or manage metastatic prostate cancer are called systemic therapies because they travel throughout the body to attack the cancer cells wherever they are.

Treatments include:

- Hormone therapy
- Chemotherapy (For more information please see booklet 2b)
- Treatment for bone pain (For more information please see booklet 2c)

The way advanced prostate cancer is treated has been changing and is continuing to change and improve. More treatments are becoming available and the way these treatments are being used is changing and developing.

Hormone therapy is still the mainstay of treatment for advanced prostate cancer. However, some men may be offered:

- Chemotherapy alongside hormone therapy. Chemotherapy may be started much earlier now than was previously done and can be continued after hormone therapy;
- In the future, Abiraterone drug treatment may be offered alongside hormone therapy. At the time of writing (October 2017), this has not been approved by the Scottish Medicines Consortium.

Your consultant oncologist will be aiming to find a good balance between fighting your prostate cancer and keeping you feeling as well as possible throughout the course of your treatment. Because every man is different and the stage of his cancer may be different, the oncologist will decide which of the treatments or combination of treatments will be the most effective way of treating your prostate cancer.

Once the oncologist or CNS has explained the treatment to you, it's important that you follow their instructions exactly. This means taking the right drug, the correct amount or dose of the drug(s) and at the right time.

If you forget to take your usual dose at your usual time then take it as soon as you remember. If you forget completely do not try to make up for missing the previous day's tablets or capsules by taking double or extra doses the next day. If you are at all unsure, check with your CNS, GP or oncologist or phone NHS 24 on 111.

You should **never** stop taking any of your treatments without first talking this over with your oncologist or CNS.

This booklet is to help you, your spouse or partner and your family understand more about treating your prostate cancer with hormone therapy; it explains - what it is, the different types of hormone therapy, how it might be prescribed and some of the potential side-effects associated with it.

About the male hormone testosterone and its role in prostate cancer

Hormones control the activity and growth of all normal cells and so are naturally present in your body. One of the male hormones, testosterone, is

mainly produced in the testicles (testes) but a small amount is also made in the two adrenal glands which are just above the kidneys. Testosterone is responsible for many of the male bodily characteristics.

Prostate cancer grows in response to testosterone, so without testosterone, prostate cells, including cancerous cells, will shrink or grow more slowly.

Aim of hormone therapy

As testosterone fuels the growth of prostate cancer, the aim of hormone therapy is to remove as much of this testosterone as possible. By reducing the amount of testosterone, it causes cancer cells wherever they are in the body, to shrink or grow less fast. As a result, the PSA level is most likely to fall (PSA is a protein that is produced by prostate cells and is detected in the blood). Although hormone therapy when used on its own is not a cure for prostate cancer, it may be successful in keeping the cancer in check for several, and in some cases many years.

It should be emphasised that hormone therapy does not involve giving "female" hormones to men.

When might hormone therapy be suggested?

- Hormone therapy alone is the standard treatment for men with locally advanced or metastatic prostate cancer;
- For some men hormone therapy may be combined with chemotherapy;
- Other drugs may be available alongside hormone therapy. Up until now, Abiraterone has only been available after hormone therapy has stopped working, (ie the cancer has become hormone resistant prostate cancer) however this may change in future. (For the most up-to-date information on this, please check our website www.prostatescotland.org.uk)
- Hormone therapy alone may be the sole treatment of choice for those men who would not benefit from surgery or radiotherapy because of their age or other medical problems;

What are the types of hormone therapy to reduce testosterone levels?

(The information that follows about hormone therapy is meant as general guidance. As procedures may vary slightly from hospital to hospital, ask for more advice from staff at the hospital you are attending. If you have been given any specific guidance by the hospital you attend then it is important that you follow their instructions.)

LHRH agonists (luteinising hormone –releasing hormone agonists)

GnRH antagonists (gonadotrophin-releasing hormone antagonists)

Both of these medications stop the testes from making testosterone and are given by an injection. Depending on the medication, injection sites may be beneath the skin in the tummy or in the muscle of the buttock.

Medication	Type	Brand name	What it does	How it's given
LHRH agonists	Leuprorelin	Prostap SR® Prostap 3®	Stops testes making testosterone. Because of the way LHRH agonists work, there may be a temporary rise or flare in testosterone levels before it reduces. Anti-androgens (see overleaf) will usually be given initially.	Zoladex, Prostap and Decapeptyl may be given monthly or 3 monthly.
	Triptorelin	Decapeptyl SR®		
	Goserelin	Zoladex® Zoladex LA®		Decapeptyl may also be given 6 monthly.

Medication	Type	Brand name	What it does	How it's given
GnRH antagonists	Degarelix This can be particularly useful for men newly diagnosed with advanced prostate cancer and who are at risk of spinal cord compression.	Firmagon®	Very quickly switches off the testes making testosterone. Because of the way it works, it does not cause a rise or flare in testosterone levels so anti-androgens will not be necessary.	Monthly injection. This will normally be started in hospital and then given by your GP. However, because of prescribing changes (2014), your GP may now start your first dose of Firmagon.

ii Anti-androgens

These work in a different way from LHRH agonists and GnRH antagonists. These block the cancer cells' ability to use testosterone.

Medication	Type	Brand name	What it does	How it's given
Anti-androgen (nonsteroidal)	Bicalutamide	Casodex®	Block the action of testosterone and the ability of the cancer cell to use it.	As a tablet.
	Flutamide	Chimax® Drogenil®		
Anti-androgen (steroidal)	Cyproterone acetate	Cyprostat®	Block cancer cells ability to use testosterone and reduces amount produced in adrenal glands.	As a tablet. It's taken after meals and tablets should be spread evenly throughout the day if taking more than one tablet.

Your doctor may suggest one of the drug treatments above 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.

Dual androgen blockade

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

Surgical treatment or orchidectomy

This means that all the testes or the parts of the testes which make testosterone are taken away during an operation. This type of treatment is permanent and can't be reversed. Although this used to be the standard treatment, it is much less common now because LHRH agonists give similar results. Reducing testosterone through medication rather than through surgery may be preferable for some men.

Prescribing hormone therapy

In some situations, doctors may prescribe hormone therapy for you to take all the time. This is *continuous hormone therapy*.

In other situations, doctors may prefer to give 9 - 12 months of treatment until the PSA level is low and will then discuss stopping the hormone therapy until the PSA level starts to rise again as testosterone levels rise. This is *intermittent hormone therapy*.

Are there side-effects with hormone therapy?

Yes, as with any drugs, there are potential side-effects (or unwanted changes in your body) brought about by hormone therapy, but, there are ways to deal with most of the side-effects. The side-effect(s) that you might get depends on:

- The type of hormone therapy that you are prescribed;
- Your health generally.

The side-effects of hormone therapy are due to the lowering of the testosterone level and can vary from man to man. Some men say they hardly

notice any side-effects but for others the side-effects have a big impact on their quality of life. Unfortunately, there is no way of telling which of the side-effects you might get or how much they might affect you.

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

You may notice some of the following side-effects after starting your treatment:

Sweats and hot flushes

These are often one of the first side-effects you may have and are one of the most common complaints from men on hormone therapy. A hot flush is a sudden, strong feeling of heat in your face, neck, chest or back and can happen even if the temperature in the room has not changed. Hot flushes are most common with LHRH agonists, since these medicines stop your body from making testosterone. (See page 6 for more information on these). The flushes and sweating can last for just a few minutes or can go on for up to a few hours. Some men find night sweats to be a problem too. These are really just hot flushes that occur when you are sleeping and can stop you from getting a good nights' sleep. For some, hot flushes and sweats get a bit easier as time goes on and so may not need any treatment.

Let the CNS or cancer specialist know as there are treatments that can help but you could also try the following:

- Cutting down on alcohol and caffeine and stopping smoking;
- Keeping active during the day and even trying to take some regular exercise (see page 14);
- Having a healthy diet with small regular meals but avoiding spicy foods;
- Keeping your room at a cool, comfortable temperature and possibly having a fan in the bedroom if you suffer from night sweats;

- Keeping up your fluid intake by drinking at least eight glasses/cups of liquid or water each day;
- Having a warm bath or shower instead of having these very hot;
- A herbal remedy that might be helpful is sage in the form of sage tablets. Before starting to take these, check with your CNS or oncologist if these are suitable for you;
- Your oncologist may try you on cyproterone acetate Cyprostat® for a few weeks as around 50% of men find this helps. If you are prescribed Cyprostat®, always follow your oncologist or CNS instructions carefully.

Loss of libido

Another common side-effect is losing interest in having sexual intercourse. Rather than trying to avoid the issue, talk to your spouse or partner about your worries and anxieties. Perhaps you may want to speak to the CNS or oncologist about this issue, either on your own or as a couple.

Erectile dysfunction (ED)

Because hormone treatment works by 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 feel upset by this and perhaps a bit embarrassed talking about something as personal as ED, doctors and CNS's are used to hearing about this and helping men with these difficulties. There are a number of treatments that may help.

Treatments might include medication as a tablet, by injection, using a cream, using an applicator or using a vacuum pump. For more information there is a booklet '*Spotlight on Prostate conditions and erectile dysfunction*' available to download from our website or by calling us and a copy can be sent to you.

Breast swelling and tenderness (also called gynaecomastia)

Hormone therapy can cause one or both breasts to swell, become tender and may also cause nipple tenderness or sensitivity. For some men who take bicalutamide, this can mean just a slight tenderness but for others it can be quite painful. There are some medications such as Tamoxifen available to help

(the medication prescribed varies from hospital to hospital). Alternatively, in more severe cases, any painful swollen areas may be removed by surgery. Speak to the cancer specialist or CNS if breast swelling and tenderness is a difficulty for you.

Fatigue or tiredness

You may find that you get very tired quite easily, even doing your normal day-to-day activities because of the drop in your testosterone level. Fatigue is often the one symptom that many men consider to be their worst problem.

- Don't overdo it. Take plenty of rest when you need to but no more than you have to. Resting too much can in fact lower your energy level, so the more you rest the more tired you can feel. Try to plan your day so you have times where you can rest and times when you can be more active using more energy;
- During hormone treatment, exercise or activity has been shown to be an effective self-help for fatigue. (For more information on exercise see page 14);
- If you have trouble sleeping at night, let your doctor or CNS know as they may be able to prescribe something to help.

Changes to your body shape

You may find that you gain some weight and some men notice this especially around their middle. At the same time you might notice that you lose some muscle tissue. Having a healthy well-balanced diet combined with some regular, resistance exercise may help deal with these difficulties. Taking some regular exercise, such as brisk walking, can also help with any feelings of tiredness (fatigue) that you may have. If weight gain becomes a problem for you then your CNS may give you more advice on suitable exercises to do. You may be referred to a weight loss clinic for advice on changes to make to your diet to help manage your weight.

Bone thinning

Because bones need testosterone to keep them healthy and strong, over time hormone therapy can cause bones to thin and become weak or brittle so they may break more easily.

Men at particular risk are those who are on long-term steroids or drink excessive amounts of alcohol.

To help prevent this make sure you:

- Have enough calcium in your diet, the main sources being from dairy products, such as milk, cheese and yoghurt. Calcium is also found in green vegetables such as cabbage and broccoli and fish such as sardines and pilchards (where the bones are eaten);
- Vitamin D is needed in order for your body to use calcium. Our bodies naturally make vitamin D when the sun shines on our skin; this is the main source of our vitamin D. So being outside in the summer months for short periods of time without sun screen will probably give enough vitamin D. (But be mindful about sun safety – the information given is only for short periods a few days a week).

Vitamin D is found in margarine, oily fish, salmon, and egg yolk. Your doctor may suggest taking a supplement of 400 units of vitamin D and 500 mg of calcium in addition to the calcium you get from your daily diet;

- Cut down on caffeine and alcohol. Too much caffeine or alcohol can keep your body from getting the calcium it needs to strengthen your bones;
- Don't smoke. Smoking is associated with an increased risk of bone thinning and low bone density;
- Again taking some regular, resistance and weight bearing exercise may help. However, if this does not help there may be the option of medication;
- For some men at high risk of osteoporosis, the oncologist may prescribe Adcal tablets. Adcal tablets provide extra calcium and vitamin D. These may be prescribed when the level of calcium and vitamin D in your body needs to be increased.

Mood swings

It is understandable that men who are having treatment for prostate cancer (and their families) 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. So speak to your CNS or oncologist early on if you feel very low as it may be possible to change your treatment or get some additional help. It is often helpful to go along to a support group to chat with other men and their families who have been in a similar situation.

Hair loss

Men who have hormone therapy for just short periods may not notice any difference to body hair. However, long-term hormone therapy may lead to a loss of hair on your arms, legs, underarms and genital area and you may not need to shave facial hair as often.

Heart problems

When your testosterone level drops, your blood pressure and cholesterol level may increase and some studies suggest that this may put the man at greater risk of developing heart problems. The longer you are on hormone therapy the greater the risk becomes. The team looking after you will respond to any concerns that might arise.

It may be helpful to think about some healthy lifestyle changes such as stopping smoking, not drinking more alcohol than the healthy guideline limits, having a well- balanced diet and taking exercise.

What should I tell the doctor or CNS about when I go to my appointment?

It's only by telling the doctor or CNS about any side-effects, changes in your body or in how you are feeling that they may be able to help you. It may be helpful to make a note of any of the following before going to your appointment or indeed writing down any questions that you have so you and the doctor make the most out of your appointment.

- Any symptoms that are bothering you;
- Any pain that is bothering you or is new to you;
- Any difficulties such as tiredness or fatigue, hot flushes, trouble sleeping and weight gain/loss that are keeping you from getting on with day-to-day life;

- Any worries or anxiety that you may have, feeling very low or down or being very tearful or upset more easily.

Exercise

Throughout the booklet, mention has been made to the importance of exercising regularly. Regular exercise has a wide range of health benefits which includes:

- Helping you maintain independence and wellbeing and a healthy weight;
- Helping you maintain healthy bones, muscles and joints;
- Helping with fatigue;
- Reducing the chance of other diseases such as heart disease, stroke and high blood pressure;
- Helping with depression;
- Helping you sleep better;
- Generally helping to improve quality of life.

Men with prostate cancer treated with hormone therapy can experience a loss of muscle and strength. Men on long-term hormone therapy (greater than one year) are most likely to notice muscle loss and weight gain.

Getting started

If you already exercise or take an active part in some type of sport (eg golf, bowling) that's great; but many men don't exercise regularly. The best way to get started is to try to bring exercise into your everyday life; going for walks is good, getting off the bus one or two stops earlier and walking the rest of the way, cleaning the car, mowing the lawn, getting on your bike, dancing or even using the stairs instead of using a lift or escalator. Or you could join a local club or exercise group or class. You're more likely to stick with it if you find something that you really enjoy doing. It doesn't have to be very energetic to start.

If you haven't exercised for a long time, check with your doctor or team looking after your cancer care to make sure that you are fit enough and that they are aware of what you are doing. For more information on suitable exercises speak to your CNS or oncology team.

In general, you are aiming to do 30 minutes of exercise, 5 days a week.

Resistance type exercises (making your muscles work against a weight or force) may help reduce symptoms of fatigue as well as strengthening muscles that may have become weak because of hormone therapy.

Weight bearing type exercises are good for bones by strengthening bones.

Please check with the CNS or oncology team if these exercises might be suitable in your particular circumstances:

For more information, you might the following websites helpful:

<https://www.nhsinform.scot/healthy-living/preventing-falls/keeping-well/strength-and-balance-exercises>

<http://www.nhs.uk/Livewell/fitness/Pages/strength-exercises-for-older-people.aspx>

<http://www.nhs.uk/Livewell/fitness/Pages/flexibility-exercises-for-older-people.aspx>

<http://www.nhs.uk/Livewell/fitness/Pages/sitting-exercises-for-older-people.aspx>

<http://www.nhs.uk/Livewell/fitness/Pages/balance-exercises-for-older-people.aspx>

How do I know if hormone therapy is working?

The doctor or CNS will continue to check your PSA level which often falls quickly and then stays at a lower level for as long as the treatment is working effectively.

Other tests you might have

Bone scan

Your doctor may want you to have a bone scan to check whether the cancer has spread to the bones. A bone scan may be done if new symptoms develop or if a new treatment such as radiotherapy is planned.

CT scan or MRI scan

Both of these scans are used to get detailed pictures of your prostate and surrounding areas to check whether the cancer has spread outside the prostate.

Hormone resistant prostate 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. The usual sign is a rising PSA level. This is called castrate-resistant prostate cancer or hormone refractory prostate cancer.

The treatments available at this stage will therefore depend on any previous treatments and on individual circumstances.

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 the action of any remaining testosterone.
Dual androgen blockade	Stop anti-androgens completely	Anti-androgens can change from 'switching off' testosterone receptors to switching them 'on'. Sometimes by withdrawing the anti-androgen this can slow down the growth of the cancer.
Orchidectomy	Anti- androgen tablets	Block the action of any remaining testosterone.

Steroids

Sometimes an addition of a small dose of steroid such as dexamethasone to the injections can bring about a fall in PSA. Normally side-effects are minimal as only a small dose is used but the man may experience indigestion and weight gain.

Novel (new) hormonal therapies

Type	Brand name	What it does	How it's given
Enzalutamide	Xtandi®	Blocks the action of testosterone.	As a tablet.
Abiraterone	Zytiga®	Reduces production of testosterone by the body.	As a tablet. Tablets should be taken altogether at the same time either 2 hours after food or one hour before food.

Enzalutamide and Abiraterone

The drugs, Enzalutamide and Abiraterone have been introduced fairly recently, and they work in a different way from other hormone therapies. They are usually given when traditional hormone therapies alone, such as LHRH injections, are not working any longer.

Research suggests, that in certain circumstances, Abiraterone may be combined with hormone treatment earlier in the man's treatment (though at the time of writing, October 2017, this has not been made available on the NHS in Scotland by the Scottish Medicines Consortium or SMC). For the most up-to-date information on this please check our website www.prostatescotland.org.uk

It is likely that you would be recommended to receive one but not both drugs as the use of Enzalutamide after Abiraterone or vice versa has not been well studied. Because Enzalutamide and Abiraterone work differently one of

these will be given in combination with the LHRH injections detailed earlier.

Both Enzalutamide and Abiraterone seem to have much the same benefits; generally, an increased feeling of well-being, a better chance of living longer, pain may be reduced, possible delay in the tumour(s) growing and a possible improvement in quality of life. Your oncologist or CNS will most likely go over with you the reasons for suggesting one of these drugs.

Enzalutamide (Xtandi®)

Enzalutamide is available in Scotland for men with advanced prostate cancer where the cancer has spread and become resistant to standard hormone therapy (the monthly/3 monthly injections). Enzalutamide can be prescribed, depending on clinical need, **before** the man starts chemotherapy **or after** a course of chemotherapy. The option of when to consider Enzalutamide or other alternatives will be discussed with you by your oncology team.

About Enzalutamide

Enzalutamide is provided as a capsule with the usual dose being 4 capsules once a day. These should be taken at the same time each day with a full glass of water and should be swallowed whole. As you need close monitoring initially when taking Enzalutamide, it will be prescribed by your cancer specialist. As he/she may alter the dose you have it's very important that you follow exactly the instructions from the cancer specialist or CNS on how to take the medication. When taking Enzalutamide, it's very important that your blood count is satisfactory. A few days before a new course of Enzalutamide is started, you will be asked to have a blood test, usually carried out at your GP surgery.

Possible side-effects may include:

- Fatigue, feeling much more tired than usual and muscle weakness;
- Back pain, pain in your joints, muscle or bone pain;
- Swelling in your hands, arms, legs or feet;
- Dizziness, high blood pressure;
- Some men report headaches and poorer concentration/memory.

Just as with any other medicines, side-effects can affect some men more than others. Most likely you will not experience all the symptoms listed above and there may be other side-effects not mentioned here that your oncologist or CNS will speak to you about.

Always let your oncologist or CNS know about any side-effect(s) that is troublesome, or bothering you or doesn't go away.

Most likely your oncologist will want to see you regularly to check how you are, ask about any side-effects and do some blood tests to check that your kidneys and liver are working well while you're taking Enzalutamide.

Abiraterone or Abiraterone acetate (Zytiga®)

Abiraterone is available via the NHS in Scotland for men with advanced prostate cancer where the cancer has spread and become resistant to standard hormone therapy (the monthly/3 monthly injections). Abiraterone can be prescribed, depending on clinical need, **before** the man starts chemotherapy **or after** a course of chemotherapy. The option of when to consider Abiraterone or other alternatives will be discussed with you by your oncology team.

About Abiraterone

The usual dose is 4 tablets, once a day. These should be taken 2 hours after eating and you must wait an hour after taking them before eating food. As you need close monitoring initially when taking Abiraterone, it will be prescribed by your cancer specialist. As he/she may alter the dose you have, it's important that you follow exactly the instructions from the cancer specialist or CNS on how to take the medication. When taking Abiraterone, it's very important that your blood count is satisfactory. A few days before a new course of Abiraterone is started, you will be asked to have a blood test, usually carried out at your GP surgery.

Possible side-effects may include:

- Increase in blood pressure;
- Fluid retention leading to swelling in the legs or feet or pain in the joints;

- Fatigue or tiredness;
- Muscle weakness and aches.

Just as with any other medicines, side-effects can affect some men more than others. Most likely you will not experience all the symptoms listed overleaf and there may be other side-effects not mentioned here that your oncologist or CNS will speak to you about.

Always let your oncologist or CNS know about any side-effect(s) that is troublesome, or bothering you or doesn't go away.

To help reduce these side-effects your doctor will also prescribe steroid tablets called prednisolone or prednisone which you should take every morning after breakfast. Just as with Abiraterone, it's important that you follow exactly the instructions from your cancer specialist or CNS and don't stop taking the prednisone tablets unless your doctor has told you to stop.

Your doctor will most likely keep a check on:

- Your blood with regular blood tests. Blood tests to check on your liver function and the level of potassium in your blood are usually done 2 weekly for 3 months then checked weekly. (Potassium is a salt found in your blood). These tests are done as Abiraterone can sometimes interfere with liver function and cause a drop in the potassium level in your blood;
- Any rise in blood pressure. Most likely this will be checked in partnership with your GP.

Enzalutamide and Abiraterone can have an unwanted or possibly harmful effect with some other medicines. So if you are taking medicines that have been prescribed, other over-the-counter medicines, herbal medications, vitamins or if you are started on a new medicine, you should let your oncologist or CNS know about these. It might even be a good idea to keep an up-to-date list of all the medicines that you take to show the list to the oncologist or CNS so you won't forget to mention any.

What happens if you forget to take Enzalutamide or Abiraterone?

If you forget to take your dose at your usual time, then you can take them as soon as you remember that same day. If you forget to take them completely, take your normal dose at your usual time the next day. Do **not** try to make up for missing the previous days tablets/capsules by taking double or extra doses the next day. If you are at all unsure, check with your oncologist or CNS what to do.

Questions you may want to ask your cancer specialist or CNS

Before starting on hormone therapy, 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, 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 potential 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 any potential side-effects?
- When and where would I have hormone therapy?
- What type of hormone therapy are you recommending for me and why?
- For how long am I likely to have hormone therapy?
- What check-ups would I have, how often would I need check-ups and where would I have these? What would be done at the check-ups – 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?

My treatment regime is:

Date	Name of medication	Form eg tablet, capsule, injection	How often	If by injection where?	By whom?	Special instructions

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	www.prostatescotland.org.uk	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	www.nhs24.com	111	
Prostate Link UK	www.prostate-link.org.uk		
Prostate Cancer UK (includes some support group contact details)	www.prostatecancer.org.uk	0141 314 0050 020 7840 7840	✓ 0800 074 8383
Macmillan Cancer Support Support nurses	www.macmillan.org.uk		✓ 0808 808 0000

Organisation	Website	Contact number	Helpline available
Cancer Research UK Cancer Information Nurses	www.cancerresearchuk.org	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	www.elprostatecancersupport.co.uk Email: charliehogg@blueyonder.co.uk	07933 260 066 01506 845 981	✓
Prostate Cancer Support Group, Maggie's Dundee	Email Lorna.McGoldrick@maggiescentres.org	01382 632999	
Prostate Cancer Support Group Maggie's Gartnavel General Hospital, 1053 Great Western Road Glasgow G12 0YN	glasgow@maggiescentres.org	0141 357 2269	
UCAN Care Centre Ward 209, Aberdeen Royal Infirmary	www.ucanhelp.org.uk	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	www.webmd.com		
Patient UK	www.patient.co.uk		
Medicine net	www.medicinenet.com		

Maggie's Centres

Maggie's Centres offer free practical, emotional and social support to people with cancer and their family 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

Maggie's Edinburgh, The Stables, Western General Hospital, Crewe Road, Edinburgh, EH4 2XU, telephone 0131 537 3131, email edinburgh@maggiescentres.org

Maggie's Fife, Victoria Hospital, Hayfield Road, Kirkcaldy, KY2 5AH, telephone 01592 647997, email 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

Maggie's Glasgow, Gartnavel General, 1053 Great Western Road, Glasgow, G12 0YN, telephone 0141 357 2269, email glasgow@maggiescentres.org

Maggie's Highlands, Raigmore Hospital, Old Perth Road, Inverness, IV2 3FL, telephone 01463 706306, email highlands@maggiescentres.org

Maggie's Lanarkshire, Monklands Hospital, Monkscourt Avenue, Airdrie, ML6 0JS, telephone 01236 771199, email lanarkshire@maggiescentres.org

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

Other booklets from Prostate Scotland that you might find helpful:

- **Advanced prostate cancer explained**
- **Prostate conditions and erectile dysfunction**
- **Prostate logbook**
- **Chemotherapy for advanced prostate cancer explained**
- **Treatments for bone pain and spinal cord compression explained**

