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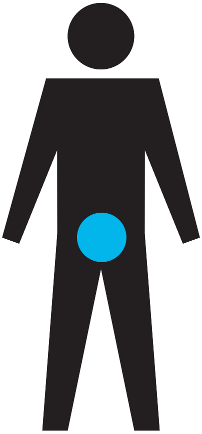
prostate scotland

PROSTATE INFORMATION ●

SPOTLIGHT ON

Hormone Therapy for Prostate Cancer



Introduction

Our is aim is to help all those affected by prostate problems whether it is the benign condition BPE (an enlarging prostate), the benign disease prostatitis or prostate cancer. It is anticipated that most of our information will be suitable, relevant and helpful for men and those born biologically male who still have a prostate. However, there might be times when your health care (such as appointments and treatment(s)) may be slightly different from our information. Our information will not be as applicable for those men born without a prostate. Most of our publications will use the term 'you' but there may be times that we will have to use the terms man, men or male.

It might be helpful if you are comfortable and willing to make your healthcare team aware of your gender identity so that they can provide the most relevant information and appropriate health care for you.

The news that you are starting on hormone therapy may come as a bit of a shock to you and your family. It's normal to have a wide range of feelings or emotions – fear, worry, sadness, guilt, anxiety, stress, feeling very low and depressed. Although all these feelings are quite normal, they can have a huge impact on your life and on your family.

The first step is to let someone from your health care team know that you're having difficulty in coping with starting on hormone therapy. There is lots of help and support out there to help you and your family. There are some helpful contacts and more information on pages 35-44.

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 ways that it might be used, who it might be suitable for, the different types of hormone therapy, how it might be prescribed and some of the potential side-effects associated with it.

About prostate cancer

Prostate cancer occurs when the cells in the prostate develop abnormalities, multiply and grow faster than normal. This causes a growth or tumour. As the prostate is inside the body this growth can't be seen and in the early stages often causes no symptoms.

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

Aim of hormone therapy

As testosterone fuels or feeds 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, cancer cells **wherever they are in the body**, shrink or don't grow as fast. This can therefore reduce the growth and extent of the tumour. 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. The effect of the treatment may be monitored via blood testing and will most likely cause a fall of PSA levels over the subsequent months. (PSA is a protein that is produced by prostate cells and is detected in the blood).

(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.)

When might hormone therapy be suggested?

Hormone therapy can used in different ways and might be suggested when the man is diagnosed with:

- Localised prostate cancer (the cancer is still inside the prostate)
- Locally advanced (when the cancer has spread just outside the prostate)
- Advanced prostate cancer (cancer that has spread to lymph nodes, bones or other organs)

External beam radiotherapy treatment (EBRT) with hormone therapy

Hormone therapy might be used along with external beam radiotherapy treatment (EBRT). This might be before EBRT starts or after EBRT has finished.

Neo-adjuvant hormone therapy

This means hormone therapy is given as a first step to help shrink the tumour before the main treatment starts, in this case EBRT. Hormone therapy may be given for 3-8 months before radiotherapy treatment starts with the aim of shrinking the cancer so that radiotherapy has a higher/better chance of working.

Adjuvant hormone therapy

For men with high- risk prostate cancer, hormone therapy is continued for up to 2-3 years after EBRT has finished as it has been shown to reduce recurrence rates and improve survival.

Prostate brachytherapy

Hormone therapy might be used prior to prostate brachytherapy for a few months to shrink the prostate if it is too large for the seed implants.The prostate volume will be measured after about 3 months to check if the prostate has shrunk enough to allow the implants to go ahead. You may also hear this called **neo-adjuvant hormone therapy**.

Primary hormone therapy

This means hormone therapy is used as the main treatment for prostate cancer. It will not cure the cancer but is designed to control the cancer and delay progression of the disease, manage any symptoms and may be successful in keeping the cancer in check for several, and in some cases many years.

Hormone therapy may be given after treatment with surgery or radiotherapy if the cancer has come back, called recurrent prostate cancer. In this case, hormone therapy may be given as the main treatment. You may also hear this called primary hormone therapy.

Hormone therapy alone

This may be the treatment of choice for those men who would not benefit from surgery or radiotherapy because of their advancing years or other medical problems.

Advanced (metastatic) prostate cancer (cancer that has spread to lymph nodes, bones or other organs)

Although hormone therapy does not cure prostate cancer it is the standard treatment for men with advanced metastatic prostate cancer. This is because hormone therapy affects cancer cells wherever they have spread to in the body eg lymph nodes, bones and other organs. When prostate cancer has spread outside the prostate to other areas in the body, these areas of tumour growth are called secondaries or metastases and you may hear this called metastatic prostate cancer. Even though the cancer has spread to these other areas, it is still prostate cancer.

Hormone therapy works well for most men with advanced prostate cancer and can often keep the prostate cancer in check for several, and in some cases, many years before other options may need to be considered.

You can ask your oncologist or urologist for more information in your particular circumstances.

Combining hormone therapies

Recent research has shown that for some men combining hormone therapies can be very beneficial. If this combination treatment is suitable for you, the advantages seem to be maintaining your quality of life, enabling you to live longer and delaying prostate cancer from spreading.

Depending on your individual circumstances the oncologist will talk over if this might be an option for you and recommend what he/she thinks is best. You may be given one of the following combinations:

i. Hormone therapy with Abiraterone and prednisolone (See page 26 for more information)

ii. Hormone therapy with Darolutamide (See page 21 for more information)

iii. Hormone therapy with Enzalutamide (See page 29 for more information)

iv. Hormone therapy with Apalutamide (See page 23 for more information)

Hormone therapy and Docetaxel (chemotherapy)

Recent research shows that it may be beneficial for some men who have just been diagnosed with advanced (metastatic prostate cancer) to be offered docetaxel chemotherapy along with hormone therapy. If your oncologist suggests this, docetaxel will usually be started between 3 and 12 weeks after you start hormone therapy to give your body some time to get used to hormone therapy first of all. This combination can help the man to live longer, may delay the disease from growing and spreading and may help to delay symptoms such as pain.

Because of some of the side-effects of chemotherapy, chemotherapy can take its toll on a man's body, so it is not a suitable option for all men, especially if they have other health conditions.

Prescribing hormone therapy

Continuous hormone therapy

For some men, the oncologist/urologist may prescribe hormone therapy for the man to take all the time.

Intermittent hormone therapy

For other men, the oncologist/urologist may prefer to give 9 - 12 months of treatment until the PSA level is low and will consider and discuss stopping the hormone therapy until the PSA level starts to rise again as testosterone levels rise. The oncologist will then chat over options with you.

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 reducing the amount of testosterone. Side-effects can vary from man to man. Some men say they hardly notice any side-effects but for others the side-effects can have a big impact on their quality of life. Being on hormone therapy for a longer time makes side-effects more likely.

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 Clinical Nurse Specialist (CNS), urologist or oncologist. Perhaps look over the questions on page 32 to ask your CNS, urologist or oncologist. You and the clinical staff treating you will need to reach a balance between the benefits of getting your cancer under control and symptoms and the impact that the side-effects of hormone therapy might have on your quality of life.

It is important to note that you are unlikely to experience all of the side-effects. Unfortunately, there is no way of telling which of the side-effects you might get or how much they might affect you.

Side-effects can be similar to those experienced by a woman going through the menopause.

You will find more in depth information on side-effects from page 9 to page 15 after the table on types hormone therapy that may be used.

Which types of hormone therapy are used 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.)

MEDICINE	TYPE	BRAND NAME
LHRH agonists	Leuprorelin	PROSTAP SR® PROSTAP 3®
	Triptorelin	DECAPEPTYL SR®
	Goserelin	ZOLADEX® ZOLADEX LA®
GnRH antagonists	Degarelix This can be particularly useful for men newly diagnosed with advanced prostate cancer and who have a lot of pain or are at risk of spinal cord compression.	FIRMAGON®

Anti-androgens These work in a different way from LHRH agonists and GnRH

MEDICINE	TYPE	BRAND NAME
Anti-androgen (nonsteroidal)	Bicalutamide	CASODEX®
Anti-androgen (steroidal)	Cyproterone acetate	CYPROSTAT®

Your urologist, oncologist or CNS 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.

LHRH agonists (luteinising hormone –releasing hormone agonists)
GnRH antagonists (gonadotrophin-releasing hormone antagonists) Both of these medicines 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.

	WHAT IT DOES	HOW IT'S GIVEN
	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-androgen tablets (see below) will usually be given initially for about 1-2 weeks before the first injection and for 2 weeks after.	Zoladex, Prostap and Decapeptyl may be given every month or every 3 months. Usually at your GP practice Decapeptyl may also be given every 6 months. Usually at your GP practice
	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.	An injection every month. This may be started in hospital then given by your GP at the practice. However, because of prescribing changes your GP may start you on your first dose of Firmagon.

antagonists. These block testosterone from reaching the prostate cancer cells.

	WHAT IT DOES	HOW IT'S GIVEN
	Block the action of testosterone and the ability of the cancer cells to use it.	As a tablet. Bicalutamide can be given as a short course of treatment about 1-2 weeks before the first LHRH agonist injections and for 2 weeks after or on its own as a long-term medication.
	Block cancer cells ability to use testosterone and reduces the amount produced in the adrenal glands.	As a tablet. It should be taken after meals and tablets should be spread evenly throughout the day if taking more than one tablet.

Surgical treatment or orchidectomy
The testicles make 90 - 95% of the testosterone in the body. Orchidectomy means that all the testes or the parts of the testes that 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.

Potential side-effects of hormone therapy

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

Sweats and hot flushes

A hot flush is a sudden, strong feeling of heat in your face, neck, chest or back.

Why do these happen?

Hormone therapy works by bringing your testosterone levels down. When testosterone levels are low, this can affect how your body controls its temperature and convince your brain that your body is overheating. The nervous system sends out messages to widen the blood vessels in the skin to get rid of this 'non-existent' or 'imaginary' overheating from the body causing a hot flush.

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. Around 70-80% of men may have hot flushes, and these can happen even if the temperature in the room has not changed. Hot flushes are most common with luteinising hormone – releasing hormone (LHRH) agonists, since these medicines stop your body from making testosterone. See pages 7-8 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 sweating 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 sweating get a bit easier as time goes on and so may not need any treatment.

Let the CNS, urologist or oncologist 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 16)
- 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
- 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
- A herbal remedy that might be helpful is sage in the form of sage tablets. Before starting to take these, check with your CNS, urologist or oncologist if these are suitable for you
- If hot flushes trouble you a lot, try keeping a record of times these happened, what you were doing, what you ate to see if you can pinpoint anything that you've been doing that may have set off a hot flush. You can show these records to the CNS, urologist, oncologist or GP to help them understand how these are affecting you.

Loss of libido

As you know, hormone therapy reduces the amount of testosterone. Because you have less testosterone, you may find that you lose interest in or have a reduced desire for having sex and some men lose their desire completely.

This is another fairly common side-effect. 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, urologist, oncologist or your GP about this together.

It may also help to talk to a sex therapist or counsellor. There are some helpful references at the back of this booklet.

If your urologist, oncologist or CNS advises that you are able to stop taking the hormones, it can take up to 12 months for testosterone to rise back to 'normal' levels. Even then some men often feel things aren't quite the same as they were before. Regaining or recovering your libido could also depend on how things were before starting on hormones. For a very small number of men libido will never go back to normal.

Erectile dysfunction (ED)

Again, 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/hard enough to have sexual intercourse. Although you may feel upset by this and perhaps a bit embarrassed talking about something as personal as ED to CNS's, oncologists, urologists or your GP, they are used to hearing about this and helping men with these difficulties. There are a number of treatments that may help. Again, there are some helpful references at the back of this booklet.

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.

Fatigue or tiredness

Fatigue is the way you feel when you are completely and utterly drained or exhausted and just feel worn out.

With hormone therapy, because of the drop in your testosterone level, you may find that you get very tired quite easily, even just doing your normal day-to-day activities.

It's often the symptom that many men consider to be their worst problem. Some men find fatigue affects their everyday life, for others this has a lesser effect, and some men don't have any problems at all with fatigue. Levels of fatigue can change as you go through your treatment and how much fatigue you experience is a very individual matter.

- 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 16)

- If you have trouble sleeping at night, let your CNS, urologist, oncologist or GP know.

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 mass. (muscle mass is the amount of muscle in your body).

Having a healthy well-balanced diet combined with some regular, resistance exercise may help deal with these difficulties. Taking some regular exercise, such as going for a brisk walk, can also help with any feelings of tiredness (fatigue) that you may have. If you haven't exercised for a long time, check with your CNS, urologist, oncologist or GP before starting to exercise.

If weight gain becomes a problem for you then your CNS, urologist, oncologist or physiotherapist will 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.

Some men also notice that their penis and testes become smaller.

Breast swelling and tenderness (also called gynaecomastia)

Hormone therapy can cause one or both breasts to swell, become tender and may also cause a nipple(s) to feel tender or sensitive. For some men who take bicalutamide, this can mean just a slight tenderness but for others it can be quite painful (see pages 7-8).

There are treatments available such as a small, one off dose of radiation which helps pain but not swelling.

There are some medications such as Tamoxifen available to help (the medication prescribed varies from hospital to hospital). Alternatively, any painful swollen areas may be removed by surgery. Speak to your CNS, urologist or oncologist if breast swelling and tenderness is a difficulty for you.

Anxiety and depression

Not all men on hormone therapy will have feelings of anxiety, depression, feeling very low or worried. Please see pages 35 - 44 for more information

Although it doesn't always happen, these feelings may increase as you go through your treatment..

The best thing you can do is to talk about how you are feeling with your CNS, urologist, oncologist or GP – don't try to cope on your own, hide away how you feel keeping these feelings to yourself. It may also help to talk things over with your wife, partner, family or friends. There are many organisations you can contact for support who will help you through this time.

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, urologist, oncologist or GP early on if you feel very low as it may be possible to change your treatment or get some additional help. It may help to go along to a support group to chat with other men and their families who are or have been in a similar situation.

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. To a lesser extent, 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 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 sunscreen 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 oily fish such as salmon, sardines, pilchards, trout, herring, kippers and cod liver oil contains a lot of vitamin D. Egg yolk, meat, offal and milk contain small amounts and some margarines and breakfast cereals have added vitamin D. Your oncologist *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. He/she will let you know if you should take a calcium and vitamin D supplement.

- 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.
- Stop smoking. Smoking is associated with an increased risk of bone thinning and low bone density. (bone density means how dense and strong the bones are). You can find help on stopping smoking here or visit www.nhsinform.scot/healthy-living/stopping-smoking
- 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. (osteoporosis means weakening of the bones to the point where they can break easily)

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 as often.

Cardiovascular risk

(risk of developing heart problems or disease)

As you know now, in order to treat your prostate cancer, it's necessary to reduce your testosterone levels. Reducing your testosterone levels can increase your blood pressure, your cholesterol levels and can make you gain weight. Taken together these can potentially put you at greater risk of developing heart disease. This may be more of an issue with long-term hormone therapy. The team looking after you will strike a balance in treating your prostate cancer and the added risks of developing heart disease. They will keep a close eye on you, take action and respond to any concerns that might arise.

To help reduce the risk of heart disease, think about some healthy lifestyle changes that you could make:

- Stop smoking. For help to do this www.nhsinform.scot/healthy-living/stopping-smoking or speak to your local smoking cessation team or pharmacy.
- Check out the guidelines on alcohol and don't have more to drink than these guidelines suggest. www.nhsinform.scot/healthy-living/alcohol/low-risk-drinking-guidelines
- A good well-balanced diet. See our leaflet www.prostatescotland.org.uk/wp-content/uploads/resources/A-guide-to-healthier-lifestyle-choices.pdf
- Taking some exercise. See page 16 for more information. If weight gain becomes a problem, your CNS, urologist, oncologist may refer you to a weight management clinic.

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

It's only by telling the CNS, urologist, oncologist or your GP 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 team looking after you get the most out of your appointment.

- Any new symptoms or 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 or weight gain/loss that are keeping you from getting on with day-to-day life
- Difficulties with erections
- 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 of the importance of exercising regularly. Regular exercise has a wide range of health benefits which includes:

- Helping you to keep active and keep on doing the things that you need to/want to do
- A feeling of wellbeing
- 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 or feeling low
- Helping you sleep better
- Generally helping to improve quality of life.

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

Getting started with exercise

If you haven't exercised for a long time, check with your CNS, urologist, oncologist or GP looking after you to make sure that you are fit enough and that they are aware of what you are doing.

Try to do some gentle weight-bearing exercise such as walking, climbing stairs, dancing, as well as some gentle resistance exercise such as lifting light weights or using elastic resistance bands.

If you already exercise or take an active part in some type of sport (eg golf, bowling) that's great; but some men don't exercise regularly or haven't exercised for years. It's not all about going to the gym! The best way to get started is to try to make exercise a part of 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, cutting the grass, getting on your bike, dancing or even using the stairs instead of using a lift or escalator. Or you could join a local club, walking group, 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 with.

For more information on suitable exercises speak to your CNS, urology or oncology team or your GP.

In general, you are aiming to do 30 minutes of exercise, 5 days a week. Resistance type exercises 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 helping to strengthen bones. Low impact exercises – for example swimming - are good for those with joint issues either as a result of other medical problems or as a result of hormone treatment.

COMPASS

Working in partnership with The Exercise Clinic, the Prostate Scotland COMPASS project has developed a special exercise programme for men with prostate cancer. The online exercise programme is available and can be found on our website by visiting www.prostatescotland.org.uk/help-and-support-for-you.

Please always check with the CNS, your urology or oncology team or GP if the exercise programme above or the exercises below might be suitable in your particular circumstances before starting any exercises.

You might also find the following websites helpful:

www.nhs.uk/live-well/exercise/physical-activity-guidelines-older-adults/

www.nhs.uk/live-well/exercise/easy-low-impact-exercises/

www.nhs.uk/live-well/exercise/balance-exercises/

www.prostate.org.au/media/790463/eim-factsheet_prostate-cancer_public2020.pdf

Prostate FFIT (Football Fans In Training)

According to the NICE guidelines (National Institute for Health and Care Excellence) men diagnosed with prostate cancer, especially those on hormone therapy, are advised to undertake a 12-week exercise programme.

Prostate Scotland has already provided exercise courses in partnership with the SPFLT Trust in a number of areas in Scotland at professional football clubs for men with prostate cancer. To check if there might be a course in your area and to register go to https://www.prostatescotland.org.uk/help-and-support-for-you/prostate-ffit)

How do I know if hormone therapy is working?

Your oncologist, urologist, CNS or GP 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.

If PSA starts to rise

If your PSA starts to rise, then you may undergo some other tests.

Bone scan

Your oncologist, urologist or CNS 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.

MRI scan

This scan is used to get detailed pictures of your prostate and surrounding areas to check whether the cancer has spread outside the prostate locally.

CT scan

Your oncologist or CNS may want you to have a CT scan to check whether the cancer has spread outside of the prostate to other organs in the body.

When your PSA level starts to rise

You might also hear this called hormone resistant or castrate resistant prostate cancer.

Once hormone therapy has been started it is usually ongoing. However, over time, your oncologist may find that your PSA levels are rising even though your testosterone level is still low. It means that the standard hormone therapy alone is not working any longer and the cancer is starting to grow again. In other words, the cancer has become resistant to standard hormone therapy. The treatments available at this stage will therefore be dependent on any previous treatment(s) and your individual circumstances. Your oncologist may do a scan to check if the cancer is still only within the prostate or if it has spread outside the prostate. This will help guide what treatment is best for you. Your CNS or oncologist will explain more about your treatment.

Hormone treatment you had first time (first time treatment)	**Hormone treatment you had second time (second time 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 the side-effects are minimal as only a small dose is used but the man may experience indigestion and weight gain.

What is nmCRPC?

Even if prostate cancer becomes castrate resistant, it is quite likely that further treatment options will be available. Further scans may help to decide if you have non-metastatic castrate resistant prostate cancer (nmCPRC) or metastatic castrate resistant prostate cancer mCPRC. This is important as the treatment options may be different depending on which type you have.

You will have been on standard hormone (the monthly/3 monthly injections) to bring your testosterone down to very low levels to stop the growth of prostate cancer cells. Your oncologist will know this is working as your PSA levels drops and will stay low.

However, when your oncologist finds that your PSA levels are rising, and your testosterone level is still low, it means that the standard hormone therapy alone is not working any longer and the cancer is starting to grow again. In other words, the cancer has become resistant to standard hormone therapy.

At this point your oncologist may do a scan to check if the cancer has spread outside the prostate. This will give a guide as to what might be the best, next treatment for you.

When the cancer remains within the prostate with no spread, you will probably hear your oncologist or CNS talk about this as non-metastatic castrate resistant prostate cancer or it's written as nmCRPC:

NM means non metastatic	**CR means castrate resistant**	**PC means**
The cancer is still inside the prostate and has **NOT** spread to other parts of the body	The cancer in the prostate starts to grow even if the testosterone level is very low.	Prostate cancer

Novel Hormone Therapies

This is a rapidly changing area of treatment. New medications and changes in the usage of existing medications can come along at anytime. These medications and their uses were those available at the time of writing.

Darolutamide (Nubeqa®)

Darolutamide is available in Scotland for men when their cancer has not spread to other parts of the body. However, other types of hormone treatment have stopped working and it is likely that the cancer will spread.

This is called non-metastatic (meaning the cancer hasn't spread) castrate-resistant (the cancer has started to grow despite testosterone levels being kept very low with other hormone treatment) prostate cancer.

You might see this written as nmCRPC (nm meaning non metastatic and CRPC meaning castrate resistant prostate cancer. Another name you may hear for this is hormone relapsed prostate cancer.

Most men will continue on their monthly/3monthly/6monthly hormone injections as well.

In October 2023, the Scottish Medicines Consortium (SMC) approved the use of Darolutamide for men with metastatic hormone-sensitive prostate cancer (mHSPC). This means that although the cancer has spread standard hormone therapy is still working for them. It will be used in combination with standard hormone therapy and docetaxel (docetaxel is a chemotherapy drug).

About Darolutamide

Treatment with Darolutamide is used for men when their cancer has not spread to other parts of the body to stop it from spreading outside the prostate. Your oncologist or CNS will talk over the use of Darolutamide, and if this is appropriate for you.

Darolutamide is provided as tablets, with the usual dose being 2 tablets twice a day so 4 tablets in all. Taking the tablets along with food helps Darolutamide get into the bloodstream.

So you should:
Take 2 tablets (swallow whole) with a drink of water at breakfast.
Take 2 tablets (swallow whole) with a drink of water at dinner or your evening meal.

However, depending on your personal circumstances, your oncologist or CNS may advise on a different dose so you should **always** follow their instructions.

Tell your oncologist about any other medical conditions that you have such as problems with your kidneys, problems with your liver or if you have any heart conditions.

Darolutamide may affect the way your other medicines work, and your other medicines may affect how Darolutamide works.

Before taking Darolutamide you should tell the oncologist or CNS about any other medicines that you are taking (possibly prescribed for other health conditions), any over-the-counter medicines that you take, vitamins or herbal supplements. Making a list of all the things you take might be helpful for the oncologist or CNS.

Once you start on Darolutamide, you should **not** stop taking this until you speak to your oncologist or CNS first of all.

If you forget to take your tablets, take your normal dose as soon as possible and certainly before your next dose is due. Do **not** take 2 doses together to make up for a missed dose.

To keep your testosterone level low, you will still need to continue on your standard hormone therapy as before.

Why is Darolutamide being suggested for me?

Studies have pointed to the following potential benefits of taking darolutamide:

i. Delaying the spread of prostate cancer

ii. Potentially a better chance of living longer

iii. Delaying the cancer spreading to bone so lessening problems such as bone pain and bone fractures

iv. Potentially helping give the man a better quality of life and reducing anxiety

Potential side-effects of Darolutamide

- Feeling more tired than usual
- Pain in arm, leg, hand, or foot
- Rashes
- A decrease in the number of white blood cells, called neutropenia. This can lead to a higher chance of getting infections
- Changes in liver function tests

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 and there may be other side-effects not mentioned here that your oncologist or CNS will want to 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.

Monitoring treatment with Darolutamide

As you need close monitoring initially when taking Darolutamide, it will be prescribed by your oncologist. As he/she may alter the dose you have it's very important that you follow exactly the instructions from him/her or the CNS on how to take the medication. It's very important that you don't stop taking the tablets without talking with your oncology team first.

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 Darolutamide.

Apalutamide (Erleada®)

This is also a novel hormone therapy. It can help keep the cancer under control and help slow it from spreading.

Brand name	**Erleada®**
Type of medication	Anti-androgen or an androgen receptor inhibitor.
How it works	This works by blocking the action of testosterone on prostate cancer cells
How it's given	As tablets which are taken in one go with or without food. Tablets should be taken at the same time each day.

When can Apalutamide be given?

Local or locally advanced prostate cancer.

When cancer has not spread to other parts of the body, but other types of hormone treatment have stopped working. This is called non-metastatic (meaning the cancer hasn't spread) castrate-resistant (the cancer has started to grow despite testosterone levels being kept very low with other hormone treatment) prostate cancer and there is a high risk of the cancer spreading.

You might see this written as nmCRPC (nm meaning non metastatic and CRPC meaning castrate resistant prostate cancer. Another name you may hear for this is hormone relapsed prostate cancer.

Advanced prostate cancer

If cancer has already spread to other parts of the body but other types of hormone treatment are still working. This is called metastatic hormone-sensitive prostate cancer.

You might see this written as mHSPC. (m meaning cancer has already spread to other parts of the body and HSPC meaning that other hormone treatments are still working to treat the prostate cancer. Another name you might hear for this metastatic castrate sensitive prostate cancer (mCSPC).

About Apalutamide

If you are already on 'standard' hormone therapy to keep your testosterone levels low, then it is important that you continue with this. Standard hormone therapy usually means having a monthly, 3 monthly or 6 monthly injection with your GP or Practice Nurse.

If you haven't been on 'standard' hormone therapy before and you have now been prescribed Apalutamide then you will also start on a monthly, 3 monthly or 6 monthly injection with your GP or Practice Nurse.

How to take Apalutamide

- This is usually 4 tablets each day all taken in one go
- Decide when to take the tablets then take at the same time each day
- It doesn't matter if you decide to take at mealtimes or between meals
- Swallow whole with some water and don't crush or chew the tablets.

Please note that it is possible that your oncologist or CNS may advise on a different dose so you should **always** follow their instructions.

Potential benefits of Apalutamide

- Generally, an increased feeling of well-being
- A better chance of living longer
- Possible improvement in quality of life

Potential side-effects may include

- Fatigue – feeling very tired and it doesn't go away even if you rest or sleep
- Low blood counts that may put you at risk of infections or bleeding
- High blood pressure
- Diarrhoea
- Skin rash
- Hot flushes
- Dizziness or falling
- Muscle weakness and pain in the joints

A very rare but potentially serious side-effect of Apalutamide is having a seizure (a seizure usually means that the person shakes, loses control of their body or blacks out). Tell your oncologist or CNS if you have had seizures in the past as Apalutamide might not be suitable for you.

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

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

Regular blood tests to monitor you while on Apalutamide

- PSA to check if your PSA is staying the same or rising.
- To check on your liver function and the level of potassium in your blood are usually done 2 weekly for 3 months then checked monthly. (potassium is a kind of salt found in your blood)
- Blood pressure. As Apalutamide can cause your blood pressure to rise then regular blood checks will be organised usually by the CNS or oncologist and may be checked in partnership with your GP. Sometimes an increase in blood pressure needs an additional medication to control blood pressure.

You will also have regular hospital appointments to check on how you are.

About Abiraterone or Abiraterone acetate (Zytiga ®)

This is newer type of hormone therapy and works in a different way from other hormone therapies.

Brand name	**Zytiga®**
Type of medication	Adrenal androgen blocker
What it does	Blocks cancer cells from being able to use testosterone and reduces the amount of testosterone produced in the adrenal glands.
How it's given	As tablets. It's taken 1 hour before food or at least 2 hours after eating food.

When can Abiraterone be given on the NHS in Scotland?

- Newly diagnosed, high-risk metastatic hormone sensitive prostate cancer. (mHSPC)

- Metastatic prostate cancer with a rising PSA despite being on standard hormone therapy called castrate resistant prostate cancer (mCRPC)
- Metastatic castrate resistant prostate cancer after a course of chemotherapy.
- Men with high-risk, hormone sensitive non-metastatic prostate cancer. This is off label use. (NICE describes 'off label' use as "The person prescribing the medicine wants to use it in a different way than that stated in its licence. This could mean using the medicine for a different condition or a different group of patients, or it could mean a change in the dose or that the medicine is taken in a different way.
- May be given for up to 2 years for some men with high risk, non-metastatic disease. This is usually given for this indication alongside a course of radical radiotherapy and a course of ADT.
- For men with low-risk hormone sensitive metastatic prostate cancer where they are unsuitable for other treatments.

About Abiraterone

Abiraterone can be prescribed, depending on clinical need, either before or after a course of chemotherapy.

It is important that you continue on your standard hormone therapy (monthly/3 monthly/6 montlhy injections) alongside Abiraterone to keep your testosterone low.

The usual dose is 4 tablets, once a day. Please note it is possible that your oncologist or CNS may advise on a different dose so you should **always** follow their instructions.

Take 4 tablets (swallow whole) in the morning with a drink of water 1 hour before food or at least two hours after eating food.

Potential benefits of Abiraterone

- Generally, an increased feeling of well-being
- A better chance of living longer
- Pain may be reduced
- Possible delay in the tumour(s) growing
- Possible improvement in quality of life.

Possible side-effects may include:

- Increase in blood pressure
- Fluid retention (build-up of fluid) 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 and there may be other side-effects not mentioned here that your oncologist or CNS will want to 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.

Steroids

To help reduce these side-effects your doctor will also prescribe steroid tablets called prednisolone or prednisone. Your oncologist or CNS will tell you whether to take this once or twice a day depending on if your prostate cancer is responding to standard hormone therapy (hormone sensitive) or not (hormone resistant). Just as with Abiraterone, it's important that you follow exactly the instructions from your oncologist or CNS and don't stop taking the prednisone tablets unless your doctor has told you to stop.

Your oncologist will most likely keep a check on you as you need close monitoring initially when taking Abiraterone. Abiraterone will be prescribed by your oncologist. As he/she may alter the dose you have, it's important that you follow **exactly** the instructions from your oncologist or CNS on how to take the medication. It's very important that you don't stop taking the tablets without talking with your oncology team first.

Tests you will have to monitor you while on Abiraterone

- 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 monthly. (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.

- Blood pressure.

  Abiraterone can cause your blood pressure to rise. Regular blood pressure checks will be organised, usually by the CNS or oncologist and may be checked in partnership with your GP. Alternatively, you could be asked to check your blood pressure yourself and the CNS will call to find out your result. Sometimes an increase in blood pressure requires an additional medication to control it.

Enzalutamide (Xtandi®)

Enzalutamide is available in Scotland for men with

- Metastatic hormone-sensitive prostate cancer (mHSPC) in combination with androgen deprivation therapy
- For metastatic castrate resistant prostate cancer before chemotherapy
- For metastatic castrate resistant prostate cancer after chemotherapy

Brand name	**Xtandi®**
Type of medication	Androgen receptor blocker
What it does	Blocks the action of testosterone
How it's given	As capsules all taken in one go.

The option of when to consider Enzalutamide or other alternatives will be discussed with you by your oncology team.

It is important that you continue on your standard hormone therapy (monthly/3 monthly/6 monthly injections) alongside Enzalutamide to keep your testosterone low.

About Enzalutamide

Enzalutamide is provided as a capsule with the usual dose being 4 capsules once a day. All of the capsules should be taken in one go at the same time each day, with a full glass of water and should be swallowed whole. Please note it is possible that your oncologist or CNS may advise on a different dose so you should **always** follow their instructions.

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.

As you need close monitoring initially when taking Enzalutamide, it will be prescribed by your oncologist. As he/she may alter the dose you have it's very important that you follow exactly the instructions from the oncologist or CNS on how to take the medication. It's very important that you don't stop taking the tablets without talking with your doctor first.

Monitoring you while taking Enzalutamide

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.

Your oncologist or CNS may check your blood pressure before you start on Enzalutamide as Enzalutamide can cause your blood pressure to rise. Regular blood pressure checks will usually be organised, by the CNS or oncologist and may be checked in partnership with your GP. Alternatively, you could be asked to check your blood pressure yourself and the CNS will call to find out your result. Sometimes an increase in blood pressure requires an additional medication to control it.

What if you forget to take Abiraterone, Enzalutamide, Darolutamide or Apalutamide?

If you forget to take your tablets or capsules 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 on what to do.

Taking other medicines, herbal supplements or vitamins while on Enzalutamide, Abiraterone, Darolutamide or Apalutamide.

Taking the medicines listed above can have unwanted or possibly harmful side-effects 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/supplements/herbal remedies that you take to show the list to the oncologist or CNS, so you don't forget to mention any.

Reactions to medicines

Although it's not common some people can have very bad reaction to a particular medicine or drug. You should get in touch with your oncologist, CNS, GP NHS 24 or the National Cancer Treatment helpline 0800 917 7711 or for patients attending the Beatson Tel 0141 301 7990 if you find that you have the following severe symptoms:

- Severe and constant nausea (feeling sick) or diarrhoea

- Finding it difficult or painful to pee or having blood in your pee
- Severe headache, blurred vision
- Slow heart rate, weak pulse, fainting, slow breathing
- Chest pain, sudden cough, wheezing, rapid breathing, coughing up blood
- Signs of a lung infection with fever, chills, coughing up mucus, shortness of breath

Questions you may want to ask your CNS, urologist or oncologist

Before starting on hormone therapy, you may have some questions to ask your oncologist, urologist 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.

Whenever you need more information or have a question someone from your healthcare team will be there to help.

- Why have you recommended hormone therapy?
- For how long am I likely to have 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?
- How long will I be on hormone therapy?
- How do these treatments work and what will happen to the cancer?
- 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?
- What can I do to help manage my symptoms and treatment side-effects?
- What are the benefits for me now and how long are these likely to last?
- What are the advantages and disadvantages of this type of treatment for me?

- When will my hormone therapy start, and where will I have hormone therapy?
- What type of hormone therapy are you recommending for me and why?
- 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 are the practical requirements of the treatment? (e.g. appointments, check-ups, time off work)
- Is there someone that I can talk to who has had the same treatment that I am thinking about?
- How can I make sure I have the best quality of life possible?
- How will the treatment affect my quality of life?
- How will the treatment affect my sexual function or sex life?
- Are there any benefits of delaying the start of hormone therapy?
- What is the outlook for me?
- If one of the novel hormone drugs doesn't work for me, is there a possibility that I will be prescribed another one?

My treatment regime is:

Date	Name of Medication	Form eg. tablet capsule, In jection	How often	If by injection Where?	By Whom?	Special Instructions

The emotional impact of cancer.

In addition to managing the physical side-effects of prostate cancer and treatments, it can sometimes be hard to deal with how you are feeling. There are however many things that can be done to help you manage if you are affected. Everyone is different and not everyone will be affected, or by the same feelings.

Some people going through treatment or after treatment might feel worried about whether they are making or have made the right treatment choice, about the side-effects they are experiencing from treatment or about getting their PSA or scan results. Sometimes people's moods and how they are feeling can be affected as they go through treatment. And for some if their treatment has finished, they may feel relief, but also fearful of the cancer coming back. Some people may find their moods and how they are feeling may go up and down. All these feelings are normal.

What kind of feelings are we talking about?

Some people going through or after treatment may at times have:

Low mood or feeling depressed.

How having a low mood or being depressed might make you might feel:

- Very sad, or very low for most of the day and these feelings persist.
- Not having the energy to do things that you took for granted before.
- Losing interest in hobbies, not taking part in activities you used to enjoy, not feeling up to see family and friends.
- Feeling very tired yet having trouble sleeping.
- Having trouble focusing or concentrating and perhaps not able to make decisions.

Feeling anxious

- Being anxious can affect you in many ways:
- Feeling very worried all the time and finding it difficult to let go of these thoughts.

- It can make it hard for you to carry out everyday jobs and not able to take care of yourself.
- Being very restless, feeling on edge for a lot of the time or jumpy.
- Feeling tired, short tempered, touchy.
- Feeling shaky or trembling.

Feelings of panic

Panic attacks are severe/strong feelings of being anxious or scared. You feel as though you have very little control over them and these can be very scary. These can come on at any time and sometimes for no apparent reason.

For instance, panic attacks may mean that:

- Your heart rate shoots up and you feel the beats almost pounding in your chest.
- You feel hot and sweaty.
- You feel shaky or numb or tingly.
- You feel dizzy, light-headed or feel you might faint.
- It's difficult to catch your breath and you take very small quick breaths or feel that you have difficulty in breathing.

Coping with these feelings

Just like with everything else in life, people find different ways of helping them cope with these feelings. Some people try new activities that they never thought they would enjoy so don't rule anything out.

Here are some ideas for you to think about. Not all of these will be for you but maybe give some a try.

Getting more information

For some men and their family, it helps to know more about everything that is going on, so they feel more in control and more knowledgeable when they go to see the urologist, oncologist, CNS or GP. They have a better grasp of what they are being told during their consultation and can ask questions about anything they don't understand. When searching for more information use reputable/trustworthy websites for example:

https://www.prostatescotland.org.uk/

Prostate Scotland Cancer Navigator App is free to download from Google play or the App store

https://www.cancerresearchuk.org/

https://www.macmillan.org.uk/

https://prostatecanceruk.org/

https://www.maggies.org/

https://www.samh.org.uk/

Remember too that your CNS, urologist, oncologist and GP can provide you with more information and answer your questions.

Talking it out

For some men talking to their partner or spouse or their family and friends provides them with the support that they need. They feel comfortable and at ease showing how they feel – sad, teary, angry etc

Other men might find it easier to talk someone from the team looking after him – the CNS, urologist, oncologist and GP.

The important thing to realise is that you're not alone – others have had similar feelings and thoughts. There are Prostate Cancer Support Groups throughout Scotland where you can talk to other men who have already been on or still on the same journey as you are right now. Some of the groups run a 'buddy scheme' and you can talk to someone who has had/ is having the same treatment as you. (see the Prostate Scotland website for more details).

There are organisations who provide confidential support to let men talk about what they are going through, for example:

https://www.prostatescotland.org.uk/ One-to-One support run in partnership with some Maggie's Centres

https://www.maggies.org/

https://www.cancersupportscotland.org/

Prostate Cancer UK Specialist Nurses tel 0800 074 8383

Macmillan cancer support line call 0808 808 00 00

Cancer research UK, Nurse helpline 0808 800 4040

For some men once they have come to terms with their diagnosis and treatment, like to share their personal stories with others, often to stress the importance of early diagnosis and for men not to bury their head in the sand. This can be through talking to work colleagues, family, friends, sharing their story in the press etc

Here you will find great examples of men sharing their stories. If you don't feel ready to talk about your own experience, it can still be useful to hear other men talk about their experience of prostate cancer, and the videos below allow you to listen without needing to join a group

https://www.theinfopool.co.uk/personal-stories

Keeping track

Some men like to keep a record of their cancer journey from PSA test results to treatments and side-effects. If this is something you would consider then the Prostate Scotland Cancer Navigator App is free to download from Google play or the App store and has a special section where you can do just that including keeping track of your fatigue, recording blood pressure results as well as levels of anxiety. For others it may be as simple as keeping a notebook handy or using the Prostate Scotland Log Book.

You could also try writing down your feelings, worries and concerns and think about any practical things you could do to help yourself.

Time out

Would time away and just forgetting about everything help for a wee while? Trying a new hobby that you've thought about doing for a long time but never got round to it?

- Getting back to a hobby or activity that you enjoyed before - a game of golf, bowls or darts.
- Mending the fence, cutting the grass, putting up the shelf.
- Visiting gardens or historical sites that you've always put off.
- Visiting museums, art galleries, listening to music, trying to paint or sketch,
- Trying yoga, meditation, Tai Chi.

There are so many things out there that you might never have tried so give them a go and have fun!

Looking after yourself

It's all too easy to fall into the trap of thinking about your diagnosis so much that you forget to look after you. Try to have a good diet with plenty of fresh fruit and vegetables. Sleep is important too. Talk to your CNS, Urologist, Oncologist or GP if you're having trouble sleeping.

Some people may be tempted to try and escape it all by drinking too much alcohol or using drugs. This is never a good idea. Alcohol and unprescribed drugs may make how you're feeling worse and might affect the treatment that you are on.

Look out for our 'Living well with prostate cancer' 6 week course run in partnership with some Maggies Centres. https://www.prostatescotland.org.uk/help-and-support-for-you/living-well-with-prostate-cancer-course

This website is well a worth a look as it is dedicated to giving support at every stage of your journey. They offer a range of workshops and classes providing advice and guidance around the physical changes you may experience while undergoing treatment.

https://lookgoodfeelbetter.co.uk/support/men/ https://lookgoodfeelbetter.co.uk/workshops/

Getting active

Speak to your CNS, Urologist, Oncologist or GP first, but research has shown that exercising when you have prostate cancer can make a difference:

- It might relieve some of the side-effects of treatment.
- It may help slow the risk of progression of prostate cancer.
- It might improve prostate cancer survival.
- Overall, it may improve your mood and relieve some stress, tension and anxiety.

If you've been used to regular exercise and so you might be keen to get going again. If exercising is completely new to you then doing a small amount of exercise is better than not doing anything so don't feel daunted about getting started.

Try going for a walk, playing golf or going bowling, washing the car, doing the weeding, walking up the stair – all these things and more count towards having some exercise.

Prostate Scotland have an exercise video on our website specifically designed for men with prostate cancer so grab your trainers and give it a go!

https://www.prostatescotland.org.uk/news/prostate-cancer-exercise-video

In some areas we also offer Prostate FFIT 12 week exercise courses for men living with prostate cancer https://www.prostatescotland.org.uk/help-and-support-for-you/prostate-ffit

Above all if you're struggling to cope then please talk to someone. Your CNS, Urologist, Oncologist and GP are great sources of help along with the many voluntary organisations out there.

COMPASS

Prostate Scotland is currently developing a range of support and wellbeing services to help people across Scotland navigate prostate cancer. It's called our COMPASS project and in time it will cover information, courses, exercise programmes, workshops and support services for people with prostate cancer and disease. Visit www.prostatescotland.org.uk/help-and-support-foryou to see what's available.

We currently offer:

- Prostate Scotland Cancer Navigator App available and free to download from the Apple Store or Google play. This includes information on treatment decision making, the ability to record your consultation (with permission), appointment and medication diaries, monitor side-effects and much more.
- 'Living Well with Prostate Cancer' This is a 6 week course for those undergoing treatment or when treatment has finished. We take a look at fatigue, urinary problems, side-effects and how to minimise them, erectile dysfunction and relationships, eating well and the practicalities of living with prostate cancer.
- The opportunity to speak to a Cancer Support Specialist through a joint initiative with Maggie's in some areas of Scotland. The Cancer Support Specialists have expert knowledge of prostate cancer, and you can speak to them face-to-face at a Maggie's centre, on the phone or by video call. Whether it's talking through being diagnosed with prostate cancer, chatting about your treatment options, speaking about your symptoms and side-effects or the impact it's had on your life, this service can help.
- Our special online exercise programmes for those living with prostate cancer are particularly relevant for those on hormone therapy. Please check with your CNS, oncologist, urologist or GP that these programmes are suitable for you before starting to exercise.

Available on our website https://www.prostatescotland.org.uk/help-and-support-for-you/exercise-video

- In some areas of Scotland, we have a 12 week programme for men diagnosed with prostate cancer to participate in a specially designed exercise course, as well as building your knowledge on diet and nutrition and healthier lifestyles. We ran 2 pilot programmes earlier in 2023. These were so successful that other football clubs are now offering the Prostate FFIT (Football Fans in Training) 12 week programme. For more details, please go to our website https://www.prostatescotland.org.uk/help-and-support-for-you/prostate-ffit
- There will shortly be a 'Treatment decision making' workshop. Check our website as to when this will be available.

For more information visit

prostatescotland.org.uk/help-and-support-for-you

Other useful websites

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

Prostate Cancer Foundation NZ

Had a very informative and frank webinar in July 2020 on the topic of 'Let's Talk about Erectile Dysfunction and Prostate Cancer', and you can view it on the Events page of their website. Please note the health service is different in New Zealand and products and treatments mentioned may not be available in Scotland. https://prostate.org.nz/webinars/

British Association of Urological Surgeons

Has information about erectile dysfunction on their website. https://www.baus.org.uk/patients/ conditions/3/erectile_dysfunction_impotence

Frank Talk

An American charity offering an online community for men to talk about erectile dysfunction. https://www.franktalk.org/

Relate

Provides relationship counselling and a range of relationship support services. https://www.relate.org.uk/

The Sexual Advice Association

Has information about erectile dysfunction.
https://sexualadviceassociation.co.uk/

Other Prostate Scotland booklets that you might find helpful include :

- Advanced prostate cancer explained:

https://www.prostatescotland.org.uk/wp-content/uploads/resources/Introduction-to-Advanced-Prostate-Cancer.pdf

- Prostate conditions and erectile dysfunction:

https://www.prostatescotland.org.uk/wp-content/uploads/resources/Prostate-conditions-and-erectile-dysfunction.pdf

For more information...

If you have any questions, then you can speak to your CNS, oncologist, urologist 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.

There may be a prostate cancer support group in your area where you can talk to other men (and often their family) who have been diagnosed with prostate cancer. Often these men share their experiences when they were diagnosed with prostate cancer, how they decided on treatment and about

Organisation	**Website**	**Contact number**	**Helpline available**
Prostate Scotland (includes support group details	www.prostatescotland.org.uk	0131 603 8660	Information line not a helpline
NHS 24	www.nhs24.scot	111	Yes
NHS Inform	www.nhsinform.scot		
Prostate Cancer UK (includes some support group details)	www.prostatecancer.org.uk	0141 314 0050	0800 074 8383
Macmillan Cancer Support Support nurses	www.macmillan.org.uk	020 7840 7840 0808 808 0000	Yes
Cancer Research UK Cancer Information Nurses	www.cancerresearchuk.org	020 7242 0200 0808 800 4040	Yes
UCAN Care Centre Ward 209, Aberdeen Royal Infirmary	www.ucanaberdeen.com	01224 550333 (voicemail)	
Patient UK	www.patient.co.uk		

Maggies centres in Scotland

Maggies centres provide support for anyone diagnosed with cancer and also for their family. To find a Maggies centre near you visit www.maggies.org/our-centres/

Prostate Scotland works in partnership with some Maggies centres to run the Prostate Scotland COMPASS service providing the one-to-one support service or the 'Living well with prostate cancer' course.

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

Our work

All our awareness materials, introductory guides, explanatory guides and ‘Spotlight on’ guides such as this booklet are available free of charge to men and their families and all healthcare settings.

If you found the booklet helpful, you can help us reach many more men with awareness and information about prostate disease and prostate cancer by:

- Obtaining and wearing a Prostate Scotland badge
- Volunteering some of your time
- Taking part in or organising a fundraising event or making a donation.

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