Living with hormone therapy

A guide for men with prostate cancer





About this booklet

This booklet is for anyone who is about to start, or is already having, hormone therapy for prostate cancer. Partners, family and friends might also find it useful.

We explain the different types of hormone therapy and what treatment involves. We also talk about the side effects of hormone therapy and ways to manage or reduce them. You may not get all side effects that we mention, so you might want to dip into this booklet for the information that is useful for you.

If you are still deciding if hormone therapy is right for you and want to read information about the advantages and disadvantages of hormone therapy, read our fact sheet on Hormone therapy.

There's space on pages 44 to 47 to record details of your treatment and the health professionals involved in your care. If you would like to know more about anything you read in this booklet, talk to your doctor or nurse. You can also speak to our Specialist Nurses, in confidence, on 0800 074 8383, or chat to them online.

The following symbols appear throughout the booklet to guide you to sources of further information:

- Our Specialist Nurses
- Our publications
- Sections for you to fill in
- Watch online at prostatecanceruk.org



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What is hormone therapy?

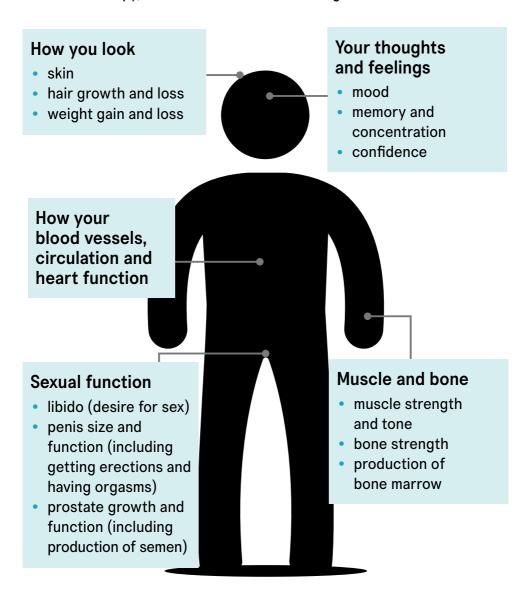
Hormone therapy is a treatment for prostate cancer. You may hear it called androgen deprivation therapy or ADT. It works by stopping the hormone testosterone from reaching the prostate cancer cells. Hormone therapy on its own won't cure your prostate cancer, but it will aim to keep it under control and delay or manage any symptoms. It can also be used with other treatments, such as radiotherapy, to make them more effective.

What happens when testosterone is taken away?

Testosterone is a hormone that affects many parts of a man's body. Testosterone can help prostate cancer cells grow. If testosterone is taken away or blocked by hormone therapy, the cancer will usually shrink, even if it has spread to other parts of your body. But reducing or blocking testosterone can cause other things to change in your body too (see diagram on page 5).

How normal levels of testosterone affect your body

This is how testosterone normally affects a man's body. If you have hormone therapy, it can affect all of these things.



Who can have hormone therapy?

Hormone therapy is an option for many men with prostate cancer, but it's used in different ways depending on the stage of your cancer. Speak to your doctor or nurse about the treatment options that are suitable for you.

If you would like to know more about hormone therapy, including information about who can have it and the different types of hormone therapy, read our fact sheet, **Hormone therapy**.

If you have localised (early) prostate cancer

If your cancer hasn't spread outside the prostate (localised prostate cancer), you might have hormone therapy alongside your main treatment, such as external beam radiotherapy.

Hormone therapy is not usually given to men having surgery to remove their prostate (radical prostatectomy) for localised prostate cancer.

Read more about localised prostate cancer, including possible treatment options, in our fact sheet, **Localised prostate cancer**.

If you have locally advanced prostate cancer

If your cancer has spread to the area just outside the prostate (locally advanced prostate cancer), you may have hormone therapy before, during and after radiotherapy. And some men might have hormone therapy on its own if radiotherapy or surgery aren't suitable for them.

Read more about locally advanced prostate cancer, including possible treatment options, in our fact sheet, **Locally advanced prostate cancer**.

If you have advanced (metastatic) prostate cancer

Hormone therapy will be a life-long treatment for most men with prostate cancer that has spread to other parts of the body (advanced prostate cancer). The hormone therapy will shrink the cancer and slow down its growth, wherever it is in the body. It can't cure the cancer, but it can keep it under control, often for years. It can also help manage the symptoms of advanced cancer, such as bone pain.

How long it will control the cancer for varies from person to person. It may depend on how sensitive your cancer is to the hormone therapy, how aggressive your cancer is, and how far it has spread. It's difficult for doctors to know exactly how long it will keep your cancer under control. Speak to your doctor or nurse about your own situation.

Read more about advanced prostate cancer, including possible treatment options, in our fact sheet, **Advanced prostate cancer**.

If your cancer has come back after treatment (recurrent prostate cancer)

If your cancer has come back after treatment for localised or locally advanced prostate cancer, hormone therapy may be one of the treatments available to you.

Read more in our booklet, If your prostate cancer comes back:

A guide to treatment and support.

What types of hormone therapy are there?

There are three main ways to have hormone therapy for prostate cancer. These are:

- · injections or implants
- tablets
- surgery to remove the testicles (orchidectomy).

The type of hormone therapy you have will depend on the stage of your cancer, the other treatments you are having and your own personal preferences – for example, whether you would prefer to have drugs, or surgery to remove the testicles.

Injections or implants

These stop your body from making testosterone. They work by blocking the message from the brain that tells your testicles to make testosterone. Injections or implants are as good at controlling prostate cancer as surgery to remove the testicles.

LHRH agonists

LHRH agonists (luteinizing hormone-releasing hormone agonists) are the most common type of injection or implant. Examples of LHRH agonists include goserelin (Zoladex®), leuprorelin acetate (Prostap®), and triptorelin (Decapeptyl® or Gonapeptyl Depot®).

They're given by an injection into your arm, stomach area (abdomen), thigh or bottom (buttock). Some LHRH agonists are available as a small pellet (implant) which is injected under your skin and slowly releases the drug.

You will have the injections at your GP surgery or local hospital. How often you have them will vary, depending on the type you are having. Some men have an injection once a month, while others may have an injection every three or six months. Your skin where the injection is given may feel a little sore or bruised afterwards. Some men also get a small lump where the needle enters the skin. This is normal and should get better by itself. But tell your doctor or nurse if it feels very sore or painful.

LHRH agonists cause the body to produce more testosterone for a short time after the first injection. This usually happens about two or three days after you have the first injection. This temporary surge in testosterone could cause the cancer to grow more quickly for a short time, which might make any symptoms you have worse for about a week – this is known as a flare.

If you're having an LHRH agonist, you'll be given a short course of anti-androgen tablets such as bicalutamide to take before your first injection or implant. You'll continue taking these for a few weeks (see page 10). This should stop any problems caused by this temporary rise in testosterone.

GnRH antagonists

GnRH antagonists (gonadotrophin-releasing hormone antagonists) are used less often than LHRH agonists.

One type of GnRH is called degarelix (Firmagon®). Degarelix may be used to treat some men with advanced prostate cancer.

If you have degarelix, you will have injections just under the skin of your stomach area (abdomen). Your first dose will be two injections on the same day. You'll then have one injection each month, or switch to an

LHRH agonist. Degarelix can sometimes cause a reaction on the skin where the injection is given, but this isn't usually serious. Your doctor or nurse can suggest ways you can manage this, such as using an ice pack on the skin.

Unlike LHRH agonists, degarelix doesn't cause a temporary rise in testosterone with the first treatment, so you won't need to take anti-androgen tablets. Instead, your testosterone levels will start to drop straight away, usually on the first day of having treatment. Symptoms such as bone pain should start to improve quite quickly.

Tablets

There are several types of hormone therapy tablets that can be used to treat prostate cancer. They work in different ways.

Anti-androgens

Anti-androgen tablets stop testosterone from reaching the prostate cancer cells. They can be used:

- on their own
- before having injections or implants
- together with injections or implants
- after surgery to remove the testicles (orchidectomy).

There are several different anti-androgen tablets that you might have as a first treatment for prostate cancer. These include bicalutamide (Casodex®), cyproterone acetate (Cyprostat®) or flutamide (Drogenil®).

Ask your doctor how long you will need to take anti-androgens for, what type you'll have, and whether you're having them with another treatment or on their own.

Anti-androgens taken on their own are less likely to cause sexual problems and bone thinning than other types of hormone therapy. But they may be more likely to cause breast swelling and tenderness. You also have a higher risk of liver problems if you take anti-androgens. Before you start taking them, you may have some tests to check your liver. Or if you've had liver problems before, anti-androgen tablets might not be suitable for you.

If your cancer has spread to other parts of your body (advanced prostate cancer), anti-androgens will be less effective at controlling the cancer than other types of hormone therapy. So, if you have advanced prostate cancer, your doctor will usually recommend an LHRH agonist instead.

"I took anti-androgen tablets for a couple of weeks before starting injections. Hormone therapy brought my PSA right down."

A personal experience

Combined hormone therapy

Your doctor at the hospital may suggest using an LHRH agonist and an anti-androgen together to treat your prostate cancer. You may hear this called combined androgen blockade. It may be slightly more effective than using an LHRH agonist on its own when cancer has spread to other parts of the body.

Combined hormone therapy isn't usually used as a first treatment for prostate cancer because it can increase the risk of side effects. Read about side effects on page 15.

GnRH antagonist - relugolix (Orgovyx[®])

Relugolix is a new type of hormone therapy used to treat some men with prostate cancer. Unlike other GnRH antagonists, such as degarelix (see page 9), relugolix is given as a tablet. To find out more, visit prostatecanceruk.org/relugolix

Androgen receptor pathway inhibitors (ARPIs)

There are newer types of hormone therapy that can be used to treat some men with prostate cancer. You may hear them called new or second-generation hormone therapy. They may be used in combination with first-line hormone therapy treatment, or when your prostate cancer has stopped responding to other types of hormone therapy. They include abiraterone (Zytiga®), enzalutamide (Xtandi®), apalutamide (Erleada®) and darolutamide (Nubega®).

Oestrogens and steroids

Oestrogens and steroids are other types of hormone therapy that can be used to treat prostate cancer that is no longer responding to other types of hormone therapy. But they are used less often than other treatments.

Surgery to remove the testicles (orchidectomy)

An orchidectomy (or orchiectomy) is an operation to remove the testicles, or the parts of the testicles that make testosterone. It's not used as often as other types of hormone therapy. Surgery can't be reversed, so it's usually only offered to men who need long-term hormone therapy. Surgery is very effective at reducing testosterone levels, which should drop to their lowest level very quickly - usually in less than 12 hours. It also means you won't need regular injections, and there's no risk that you'll miss an injection.

Short-term side effects of an orchidectomy include swelling and bruising of the scrotum (the skin containing the testicles). The long-term side effects of an orchidectomy are similar to other hormone therapies. See page 15 for information about long-term side effects.

Some men feel down before having an orchidectomy. Others may find the thought of having an orchidectomy upsetting, and worry about how they'll feel once their testicles are removed. Some men may struggle with feelings of loss, shame or negative body image. However, it is important to know you are not alone. It is beneficial to talk to those close to you about how you feel and be supported by those you care about you and your wellbeing.

If you're thinking about having an orchidectomy, speak to your doctor about any concerns you might have. If you don't want an orchidectomy, you can usually have a different type of hormone therapy instead.

For more information about types of hormone therapy that can be used as, or together with, your first treatment for prostate cancer, read our as fact sheet, **Hormone therapy**.

To find out more about treatments that can be used if your cancer is no longer responding so well to your first hormone therapy, read our fact sheet, **Treatment options after your first hormone therapy**.



What are the side effects?

Like all treatments, hormone therapy can cause side effects. Many of the side effects occur due to the lower testosterone levels in your body rather than the medicines themselves. Speak to your doctor or nurse if you are worried about or experiencing side effects. You can also talk to our Specialist Nurses.

Hormone therapy affects men in different ways and you may not get all the side effects we've listed. Hormone therapy can also affect your mood and the way you feel (see page 35). Some men have fewer side effects than others. This doesn't mean that the treatment is any less effective.

This section has information on the most common side effects of hormone therapy and how to manage or reduce them, including:

- hot flushes (see page 16)
- extreme tiredness (fatigue) (see page 21)
- changes to your sex life (see page 23)
- weight gain (see page 26)
- strength and muscle loss (see page 26)
- changes to your memory and concentration (see page 28)
- changes to your mood (see page 35)
- breast swelling and tenderness (see page 29)
- loss of body hair (see page 31)
- bone thinning (see page 31)
- risk of other health problems (such as heart disease, stroke and type-2 diabetes) (see page 33).

There are treatments and support to help manage side effects. And some men find that their side effects get better or become easier to deal with over time. The risk of getting each side effect depends on your type of hormone therapy and how long you take it for. If you have hormone therapy alongside another treatment, you may get side effects from both treatments.

How long will side effects last?

The side effects of hormone therapy are caused by lowered testosterone levels. Side effects will usually last for as long as you are on hormone therapy. If you stop hormone therapy, your testosterone levels should gradually rise again and some of the side effects will reduce. Your side effects won't stop as soon as you finish hormone therapy - it may take from several months to several years.

Surgery to remove the testicles (orchidectomy) can't be reversed, so the side effects are permanent. But there are treatments that can help reduce or manage some of the side effects.

Hot flushes

Hot flushes are a common side effect of hormone therapy. You might feel very hot in your face, neck, chest or back. They can vary from a few seconds of feeling very hot to a few hours of sweating, which can be uncomfortable.

Some men find that their hot flushes get milder and happen less often over time, but other men continue to have hot flushes for as long as they have hormone therapy or longer.

Hot flushes can vary from a few seconds of feeling overheated to a few hours of sweating, which can be uncomfortable. You might feel very hot in your face, neck, chest or back. They are sometimes described as being mild, moderate or severe.

- A mild hot flush could last for less than three minutes and may make you feel warmer than usual and a little uncomfortable.
- A moderate hot flush can cause you to feel too hot. You might sweat and find you need to take off some layers of clothes.

A severe hot flush can make you feel very hot and sweaty and you
may need to change your clothes or bedding. Some men can feel
irritable, uncomfortable, or even sick (nauseous).

Hot flushes might happen suddenly without warning, or they may be triggered by things such as stress, a hot drink or a change in the temperature. You may find you feel cold, shivery or exhausted after having a hot flush. You might also sweat at night, which can disrupt your sleep and cause tiredness.

If your hot flushes are mild or don't bother you, you may not need or want treatment. But speak to your doctor or nurse if you find them disruptive or difficult to deal with.

What can help?

There are a number of things you can do to help manage hot flushes.

Lifestyle changes

There are some lifestyle changes that may help.

- If you smoke, try to stop. Speak to your GP for help stopping, or visit the NHS website.
- Try to stay a healthy weight. Read more in our fact sheet, <u>Diet and</u>
 physical activity for men with prostate cancer.
 - Make sure you drink enough. Aim for around six to eight glasses of water a day. Try to cut down on alcohol and drinks that contain caffeine, like tea and coffee.
 - Reduce the amount of spicy food you eat.
 - Keep your room at a cool temperature and use a fan.
 - Keep a handheld fan in your bag or pocket for when you're out and about.

- Wear cotton, linen or bamboo clothes, especially at night.
- Use light cotton, linen or bamboo bed sheets. If you sweat a lot at night, try using a cotton towel on top of your sheets that you can change easily.
- Try having lukewarm baths and showers rather than hot ones.
- Find ways to help reduce stress, such as using calming breathing techniques, practising meditation or yoga.

It can be helpful to keep a diary of your hot flushes. This can help you work out if there are any situations, drinks or foods that bring on a hot flush. Keeping a diary can also help you and your doctor understand how hot flushes are affecting your life. You can write down how they make you feel, both physically and mentally. Download our hot flush diary at prostatecanceruk.org/hot-flush-diary

Medicines

There are medicines that may help relieve the symptoms of hot flushes and reduce how often you get them. Your doctor or nurse may suggest a medicine called medroxyprogesterone or cyproterone acetate. Examples of other medicines that are sometimes used include gabapentin, venlafaxine and paroxetine.

As with any drug, you may get side effects from these medicines. Talk to your doctor or nurse about these before starting any treatment for hot flushes. Some medicines may not be suitable for men who have a history of high blood pressure, heart disease, strokes or problems with their liver. Your doctor or nurse will discuss this with you.

Complementary therapies

Complementary therapies are used alongside standard treatments (often called conventional treatments), rather than instead of them. There are many different complementary therapies available that might help with hot flushes. These include acupuncture, hypnotherapy, cognitive behavioural therapy (CBT), herbal remedies and homeopathy. But the evidence for most complementary therapies isn't very strong and we need more research to understand the possible risks and benefits.

It is important to tell your doctor about any complementary therapy you use or are thinking about using. Some complementary therapies have side effects or may interfere with your cancer treatment. You should also tell your complementary therapist about any cancer treatments you are having.

When you choose a therapist, make sure they are properly trained and belong to a professional body. The Complementary and Natural Healthcare Council can give you advice about finding a therapist. Some complementary therapies are available on the NHS. Ask your hospital doctor, nurse or GP about this. Many hospices offer complementary therapies too.

Some men find that acupuncture and hypnotherapy help them deal with hot flushes.

- Acupuncture involves inserting very thin, sterile needles just below the skin. This shouldn't hurt, but you might get a tingling feeling.
- Hypnotherapy is where a therapist talks to you and helps you go into a trance-like state where you feel very relaxed and calm. They then suggest things that might help.

Cognitive behavioural therapy (CBT) can help some men on hormone therapy deal with their hot flushes and night sweats. CBT helps you deal with hot flushes by changing negative thought patterns to help create new, healthier ways of thinking and develop strategies to better manage.

Herbal remedies use plants or plant extracts. Some men like to use herbal remedies, such as sage tea, evening primrose oil and red clover, to help with their hot flushes. But there's no evidence that these work, and it's important to check with your doctor that these are safe for you. For example, there is a small chance that a herbal supplement called black cohosh may cause liver damage. This is rare, but you shouldn't take it if you've ever had liver or kidney disease.

Not all herbal remedies in the UK are licensed, and the quality varies a lot. Be very careful when buying herbal remedies over the internet. Many are made outside the UK and may not be high-quality.

Many companies also make claims that aren't based on proper research. There may be no real evidence that their products work, and some may even be harmful. Remember that even if a product is 'natural', this doesn't mean it is safe. Some herbal remedies may also affect your prostate specific antigen (PSA) level, making the PSA test unreliable.

Macmillan Cancer Support and Cancer Research UK have more information on available complementary therapies, and important safety issues to consider when choosing a therapy. For more information about using herbal remedies safely, visit the MHRA website.

"I always carry a flask of iced water to drink. It cools you down for a while. The thing about hot flushes is that they disappear just as quickly as they come." A personal experience

Extreme tiredness (fatigue)

Having hormone therapy for prostate cancer can cause extreme tiredness. For some men, this can affect their everyday life. Fatigue can affect your energy levels, your motivation and your emotions. Some men find that tiredness can come on quite suddenly. This means that you need to be careful in certain situations – for example, when you are driving.

Fatigue can also have other causes such as the cancer itself or other conditions, such as a drop in the number of red blood cells (anaemia) or depression. Talk to your doctor or nurse about how tiredness is affecting you. There are ways to help manage it.

What can help?

You might find that your tiredness improves over time. But if it doesn't get better, there are changes you can make to your lifestyle that could help, including:

- organising your day and prioritising the important tasks, like going to medical appointments
- planning activities for when you know you'll have more energy maybe first thing in the morning, or in the afternoon after you've had a rest
- being as physically active as you can be, but take things at your own pace
- dealing with any problems sleeping try to relax before bed by reading or listening to music. It may also help to avoid drinks with caffeine, such as tea and coffee, as these can keep you awake
- eating a well-balanced diet
- complementary therapies, such as mediation, yoga or acupuncture.

Some of these changes may be difficult to make, so take things slowly. Speak to your doctor or nurse before you start any kind of exercise routine.

We also have a fatigue diary available on our website that can help you plan your day-to-day activities. Download one for free at prostatecanceruk.org/fatique-diary

Fatigue can affect how you feel about yourself and take a toll on you emotionally and mentally. If you're struggling with these changes, you're not alone. You can find helpful information on looking after your emotional, mental, and physical wellbeing on our website. visit prostatecanceruk.org/wellbeing

There's also more information on ways to manage fatigue in our fact sheet, Fatique and prostate cancer.

Support for fatigue

Our **Specialist Nurses** are here to support you. They can talk to you about your experience of fatigue and the impact it is having on your day-to-day life. They can discuss ways to better manage your tiredness. Speak to them, in confidence, on 0800 074 8383. or visit prostatecanceruk.org/fatique

"I found exercise was a good way to manage my fatigue. It motivated me and helped keep my spirits up."

A personal experience

Changes to your sex life

Having hormone therapy affects your sex life in different ways. In most cases, these changes last for as long as you are on hormone therapy. It can take up to a year or longer for sexual function to gradually return to normal after stopping hormone therapy. But some men don't see an improvement after stopping hormone therapy. If you've had surgery to remove the testicles (orchidectomy), these side effects can't be reversed.

Not everyone will have all the same side effects, but possible changes to your sex life may include the following.

- Less desire for sex (low libido). Hormone therapy will change your sex drive and may mean that you have less interest in sex. This is because hormone therapy lowers your level of testosterone, which is what gives you your sex drive. If you're on long-term hormone therapy, you could ask your doctor or nurse about intermittent hormone therapy (see page 42).
- Erection problems. Hormone therapy can cause problems getting or keeping an erection, although this is less likely if you're taking anti-androgen tablets on their own. You may hear erection problems called erectile dysfunction (ED). Your GP or doctor or nurse at the hospital can talk to you about treatment options.
- Changes to ejaculation and orgasm. You may notice that you produce less or no semen while you are on hormone therapy. You should still be able to have an orgasm, but it might feel different to before treatment. Some men have less intense orgasms when they are having hormone therapy.
- Changes in penis and testicle size. Hormone therapy can make your penis shorter and change the size of your testicles. If you put on weight because of your hormone therapy, you might also find it harder to see your penis. This could mean that you don't aim so well

when urinating. We don't yet know if these changes improve if you stop having hormone therapy, but early research suggests that your penis length might recover a little. Using a vacuum pump can help reduce the risk of your penis getting shorter and keep your penis healthy. Ask your doctor or nurse about accessing a vacuum pump while you're having hormone therapy.

Talk to your doctor or nurse about what treatments are available for you for sexual side effects. You can also read more about these side effects and treatments in our booklet, Prostate cancer and your sex life.

What can help you deal with these changes

Men deal with these side effects in different ways. Some men find changes to their sex life more difficult to come to terms with than others.

If you have a partner, talking about sex, your thoughts and feelings can help you both deal with any changes. It isn't always easy to talk about sex and relationships, even for a couple who have been together a long time. But it can bring you closer together and make you feel more confident about facing changes and challenges.

If you're single or starting to think about dating, you may worry about explaining sexual problems, such as difficulty getting erections or changes to your penis size, to someone you don't know very well. Fear of rejection or being worried about what other people think about you is normal and everyone has their own worries, whether or not they've had cancer.

Remember, having sex isn't just about erections or penetrative sex. Men can have orgasms without an erection or ejaculating, and some men get pleasure from pleasuring their partner. There isn't just one way to have sex or experience sexual pleasure - have fun and experiment.

There are also other, non-sexual ways of being close. This can be as simple as holding hands or trying new activities together.

Also, you could call our sexual support service. This is where you can speak to one of our trained **Specialist Nurses** about sexual problems after treatment for prostate cancer. Call **0800 074 8383** or find out more about the sexual support service online at **prostatecanceruk.org/sexual-support**

Are you gay or bisexual?

bisexual men.

If you're gay, bisexual, or a man who has sex with men, the side effects of hormone therapy will affect you in many of the same ways as heterosexual men. But you may find that you have some specific issues as well. There is information that may help you in our booklet, **Prostate cancer tests and treatment: A guide for gay and**

Are you the partner of a man with prostate cancer?

If your partner has prostate cancer, it might help to learn about the possible effects of hormone therapy. Some men struggle to accept the changes to their body image or their ability to have sex. They might avoid intimate situations or distance themselves from close relationships. But this doesn't mean that they no longer care for their partner or loved ones. It's also important to have support yourself. All Prostate Cancer UK services are open to partners too, and you may find our booklet, When you're close to someone with prostate cancer: A guide for partners and family, helpful.

Weight gain

Some men put on weight while they are on hormone therapy, particularly around the waist. You may start to put on weight soon after starting hormone therapy. Some men find this physical change difficult, particularly if they've never had any problems with their weight in the past.

What can help?

Physical activity and a healthy diet can help you stay a healthy weight. But it can take a long time to lose any weight that you put on during hormone therapy. If you are finding it difficult to lose weight, ask your doctor to refer you to a dietitian or weight loss programme. Or you could join a local weight loss group - spending time with other people who also want to lose weight can be motivating. The NHS website has lots of tips on how physical activity and a healthy diet can help you to lose weight. Visit www.nhs.uk/better-health

Read more about healthy eating and physical activity in our fact sheet, Diet and physical activity for men with prostate cancer.

Strength and muscle loss

Testosterone plays an important role in the physical make up of men's bodies. Compared with women, men usually have more muscle and less body fat. Hormone therapy can cause a decrease in muscle tissue and an increase in body fat. This can change the way your body looks and how physically strong you feel.

Some men also experience muscle aches or joint pain while they're on hormone therapy. This can happen when you lose muscle. Talk to your doctor or nurse if you have any pain in your muscles or joints. They can talk to you about ways to manage it.

What can help?

Regular gentle resistance exercise, such as lifting light weights or using elastic resistance bands, can help to prevent muscle loss and keep your muscles strong. Speak to your doctor before you start any exercise. They may be able to refer you to a physiotherapist or a local exercise programme. If you can't move about easily, a physiotherapist can give you some gentle exercises to do at home. Some areas also have walking groups that you could join, which could help you improve your strength and meet new people.

Read more about physical activity in our fact sheet, **Diet and physical** activity for men with prostate cancer.



Memory and concentration

If you're having hormone therapy, you may find it difficult to concentrate or focus on certain tasks. Some men also say they struggle to remember things as well as they did before having hormone therapy. You may hear this called brain fog. But we don't know for sure whether any changes are caused by the hormone therapy or by something else, because the evidence isn't very strong. For example, feeling tired, stressed, anxious or depressed can all affect your memory and ability to concentrate. Problems with memory and concentration can also happen naturally as you get older.

Whatever the cause, you may find problems with memory or concentration very frustrating. If you're having problems with your memory, talk to your doctor or nurse. They will be able to suggest things that may help.

What can help?

You might find some of these tips helpful.

- Try keeping lists or reminder notes.
- Try to concentrate on doing just one thing at a time.
- Avoid things that distract you when you need to concentrate on something.
- Try keeping your mind active for example, by doing crosswords or other puzzles.
- Make sure you eat a well-balanced diet. Gentle physical activity might also help.
- Make sure you get plenty of rest.

"My wife gives me some leeway because she knows I forget things. She just gently reminds me, and then tomorrow she will remind again. And eventually I get around to doing it."

A personal experience

Breast swelling and tenderness

Hormone therapy may cause swelling (gynaecomastia) and tenderness in the chest or breast area. This is caused when levels of oestrogen and testosterone change because of hormone therapy. The amount of swelling can vary from a small amount of swelling to noticeably larger breasts. Tenderness can affect one or both sides of the chest and can range from mild sensitivity to long-lasting pain.

For men taking anti-androgen tablets (such as bicalutamide) on their own, breast swelling and tenderness is the most common side effect. If you take oestrogen tablets, you may also get breast swelling. It's less common if you are having an LHRH agonist or GnRH antagonist, have had surgery to remove the testicles, or are having combined hormone therapy (see page 11). Most men taking a high dose of the anti-androgen bicalutamide for more than six months will get breast swelling.

If you put on weight while you're on hormone therapy, this can also lead to larger breasts.

What can help?

Breast swelling and tenderness can make men feel uncomfortable or embarrassed about their bodies. But there are treatments available which can help prevent or reduce these side effects. These include:

- tablets called tamoxifen
- surgery to remove some of the breast tissue
- treating the breast area with a single dose of radiotherapy.

If you've put on weight while having hormone therapy, a balanced diet and regular exercise may help you lose weight, including from your chest area.

Tamoxifen

Tamoxifen tablets can be taken once a week to help prevent or treat breast swelling and tenderness in men taking anti-androgen tablets. They work by stopping the hormone oestrogen from reaching the breast tissue. Tamoxifen may be an option if radiotherapy hasn't helped to prevent breast swelling.

You might not be able to have tamoxifen if you are taking oestrogen tablets because it may stop the oestrogens from working properly. We don't know how tamoxifen affects other hormone treatments in the long term. If you have hot flushes, some men find that taking tamoxifen tablets can make hot flushes worse.

Surgery

Surgery may also be used to treat breast swelling by removing painful or swollen areas of the breast. This treatment carries a risk of damage to the nipple and a loss of feeling. It's usually only offered if other treatments haven't helped to reduce the breast swelling. It's not available at all hospitals, so talk to your doctor or nurse about whether surgery is an option for you.

Radiotherapy

If you are about to start long-term anti-androgens, your doctor may suggest treating the breast area with a low dose of radiotherapy, but this isn't common. Speak to your doctor about if this is an option for you.

Loss of body hair

Some men lose their body hair while they are on hormone therapy. This is because testosterone plays a role in hair growth. So when testosterone is reduced, you might lose some of it. It's less common to lose hair from your head, but if you do, any hair loss caused by hormone therapy treatment usually grows back if you stop hormone therapy. We need more research to show how common this side effect is.

Bone thinning

Testosterone helps to keep bones strong. Long-term hormone therapy may cause your bones to gradually lose their bulk. LHRH agonists, GnRH antagonists and surgery to remove the testicles (orchidectomy) can all have this effect. This can happen in the first 12 months of beginning treatment and the amount of bone loss may increase the longer you are on treatment. Anti-androgen and oestrogen tablets are less likely to cause bone thinning. Some research suggests the use of newer hormone therapies such as abiraterone or enzalutamide may increase the risk of bone fractures when used alongside other types of hormone therapy.

If bone thinning is severe, it can lead to a condition called osteoporosis. This can increase your risk of broken bones (fractures).

Your doctor may suggest you have a type of X-ray before you start hormone therapy to check if any areas of bone tissue are already weak. You may hear this called a DEXA (dual energy X-ray absorptiometry) scan or a bone density scan. Some men may also need to have regular scans while they are having hormone therapy. You can talk to your doctor about whether you might need a scan.

What can help?

If you already have osteoporosis, have a family history of osteoporosis or have had fractures in the past, talk to your doctor before you start hormone therapy. You should also tell your doctor about any other medicines you are taking, in case they might increase your risk of osteoporosis. The Royal Osteoporosis Society has more information on their website.

Lifestyle changes

There are a number of lifestyle changes that may help to reduce your risk of bone thinning and osteoporosis.

- Eat plenty of calcium and vitamin D. Calcium and vitamin D are important for strong bones. You can get calcium from dairy foods (cheese, milk and yoghurt) and non-dairy foods, non-dairy (tofu and green leafy vegetables). Most of your vitamin D is made inside the body when your skin is exposed to sunlight. But it can be difficult for your body to make enough vitamin D, especially in winter. You can also get it from eating oily fish such as sardines, mackerel and salmon, as well as foods with added vitamin D, such as margarine and some breakfast cereals. You may need to take calcium and vitamin D supplements - speak to your doctor before taking any supplements.
- Cut down on alcohol. Drinking too much alcohol can increase your risk of osteoporosis. Guidelines recommend that men should not regularly drink more than 14 units of alcohol a week.

- Stop smoking. Smoking can increase your risk of osteoporosis. Speak to your GP for help to stop, or visit the NHS website.
- Be as active as you can. We don't yet know whether exercise can help to prevent bone thinning in men who are on hormone therapy. But regular exercise may help to keep you strong and prevent falls that could lead to broken bones. Walking, swimming and gentle resistance exercise, such as lifting light weights or using elastic resistance bands, may be particularly good.
- Keep a healthy weight. Men who are underweight have a higher risk of bone thinning.

Read more about a healthy lifestyle in our fact sheet, **Diet and physical** activity for men with prostate cancer.

Treatments to manage bone thinning

Bisphosphonates are drugs that can be used to treat osteoporosis caused by hormone therapy. They can also be used to treat bone weakness caused by cancer that has spread to the bones (advanced prostate cancer). Denosumab (Xgeva®) is a drug that can help manage bone thinning caused by hormone therapy. It might be an option if bisphosphonates aren't suitable for you.

Read more about bisphosphonates and denosumab in our fact sheet, **Bisphosphonates for advanced prostate cancer**.

Risk of other health problems

Evidence suggests that having hormone therapy might increase the chance of developing heart disease, stroke and type-2 diabetes. There is also some research that suggests having hormone therapy can increase your risk of getting blood clots and anaemia.

But more research is needed to help us understand the links between these conditions. While the risk of getting these conditions may be worrying, not every man on hormone therapy will get these side effects. It's important to remember that hormone therapy helps men to live longer by controlling your cancer.

Research shows that hormone therapy can cause:

- an increase in weight, particularly around the waist (see page 26)
- · an increase in cholesterol levels
- · changes in insulin.

Talk to your hospital doctor and GP about how often you should have general health checks. You may be weighed and have your blood pressure checked regularly. You may also have blood tests to check for diabetes and to measure your cholesterol levels. Your GP may suggest you have these checks about every six months. Or you can ask for them yourself at your GP surgery.

If you already have heart problems or diabetes, talk to your doctor before you start hormone therapy. They will work with you to manage these conditions.

What can help?

A healthy lifestyle can help reduce your risk of heart disease, stroke and type-2 diabetes. This includes:

- · eating a well-balanced diet
- being physically active
- · limiting the amount of salt you eat
- stopping smoking
- cutting down on alcohol.

Reporting unusual side effects

If you get any unusual side effects from your treatment, speak to your doctor or nurse, or visit the Medicines and Healthcare products Regulatory Agency (MHRA) website (see page 50). An unusual side effect is one that isn't mentioned in the leaflet that comes with your medicine or herbal remedy.

Read more about a healthy lifestyle in our fact sheet, **Diet and physical** activity for men with prostate cancer. You can find out more about heart disease from the British Heart Foundation at www.bhf.org.uk

How might hormone therapy make me feel?

Hormone therapy can affect your mood. You may find that you feel more emotional than usual or 'different' to how you felt before. You may find that you cry more easily or have mood swings, such as getting tearful and then angry. Just knowing that these feelings are caused by hormone therapy can help.

But everyone's experience is different, you may not get side effects of hormone therapy that impacts emotional wellbeing and how you feel.

Some of the side effects of hormone therapy are hard to come to terms with. Physical changes, such as putting on weight or changes to your sex life, might make you feel very different about yourself. Some men say they feel less masculine because of their diagnosis and treatment.

Things in your day-to-day life can change because of having hormone therapy. Your relationships with your partner, family and friends might change. Or you might be too tired to do some of the things you used to do.

You may experience low moods, anxiety or depression. This could be directly caused by the hormone therapy itself, or because you've been diagnosed with prostate cancer. It could also be due to the impact that treatment is having on you and your family.

If your mood is often very low, you are losing interest in things, or your sleep pattern or appetite has changed a lot, speak to your GP or doctor at the hospital. These can be signs of depression and there are treatments available that can help.

It's important to try and take care of your emotional and mental health during this time. The shock of being diagnosed with prostate cancer and the impact of hormone therapy side effects can be hard to process. It can take some time to come to terms with these big changes in your life. However, there are ways to help you process these tough emotions and these changes to help you take care of your wellbeing.

What can help?

Some men find their own way to cope and might not need or want any outside help or support. Other men may try to cope on their own because they don't want to talk about things or are afraid of worrying their loved ones. However, it's important to remember you don't have to go through this alone. Go easy on yourself and give yourself time to process your feelings.

Talking about it

Talking to people you trust, like family or friends, or joining a support group can help you feel more understood and less alone as you deal with your feelings. Or talking to your doctor or nurse might help.

O You could also speak in confidence to our **Specialist Nurses**.

You might find it helps to talk to someone who's been through something similar. The volunteers on our one-to-one peer support service have all been affected by prostate cancer. They are trained to listen and offer support over the phone. We have volunteers who have had hormone therapy and can understand what you're going through. Visit **prostatecanceruk.org/one-to-one** to find out more.

There are also support groups across the country where you can meet others affected by prostate cancer. Most support groups also welcome partners and family members. Most support groups also invite health professionals to give talks at group meetings. You can find details of local support groups at www.tackleprostate.org/supportgroups or ask your nurse.

You could also join our online community where you can talk to other people with prostate cancer and their families, or simply read previous conversations. Find it on our website at **prostatecanceruk.org/online-community**



"It's important to look after your mental wellbeing as much as your physical recovery." A personal experience

Counselling

It can be difficult to talk to people close to you, especially about cancer. Some people find it easier to talk to someone they don't know. Counsellors are trained to listen and can help you find your own ways to manage things. Many hospitals have counsellors or psychologists who specialise in helping people with cancer - ask your doctor or nurse if this is available. You can also refer yourself for counselling on the NHS, or you could see a private counsellor. To find out more, visit www.nhs.uk/counselling or contact the British Association for Counselling & Psychotherapy at www.bacp.co.uk

Changes to your lifestyle

There are several lifestyle changes that might help improve your mood and ease feelings of depression and anxiety. These include:

- learning ways to relax such as yoga, mindfulness, or listening to music
- doing regular physical activity start slowly and pace yourself, maybe just start off by having a short walk
- · carrying on with your usual work, hobbies and social activities that you enjoy, or trying something new - some men say this helps them stay happy and relaxed.

You might also find it helpful to go on a course to learn ways to manage side effects, feelings and relationships. Macmillan Cancer Support, Maggie's and Penny Brohn UK run free courses for people living with cancer. Ask your doctor or nurse if there are any courses or education

sessions for patients in your local area. Some hospitals have support and information services that may run these types of activities for people with cancer.

Read more in our booklet, Living with and after prostate cancer:

A guide to physical, emotional and practical issues.

Watch Bruno's story

Find out more about how prostate cancer treatment can impact your mental and physical wellbeing and ways to help improve your mood.

Watch our videos with Bruno at prostatecanceruk.org/bruno

Treatments for depression

If you are feeling depressed or anxious, talk to your GP so they can help find the right treatment for you. Treatment options may include guided self-help, talking therapies (counselling) or anti-depressants. Before you start taking any anti-depressants, make sure you tell your GP, doctor or nurse at the hospital about any other medicines or complementary therapies you're taking. Anti-depressant medicines can sometimes take a few weeks to start working. Until you start feeling better, you may want to try other things as well, such as counselling or meditation.

Our Wellbeing Hub

Visit our online wellbeing hub to find information on the mental and emotional impact of a prostate cancer diagnosis and its treatments. You'll find information on how to manage stress and anxiety and where to get support. Find out more at prostatecanceruk.org/wellbeing

You and your partner

Prostate cancer not only affects you but also those close to you. They may also be feeling worried, anxious or upset about your cancer. They might feel isolated and find it difficult to tell you how they are feeling in case they worry you. It's important to speak to each other about how you are both feeling and you can get support together. Or sometimes it can be useful to get support separately as well.

Doctors and nurses are always happy for you to bring your partner along to your appointments, and they might be able to tell you about types of support that would suit you both. The charity Relate provides relationship counselling and other support services for couples.

If Your partner might want to read our booklet, When you're close to someone with prostate cancer: A guide for partners and family.

What will happen while I'm having hormone therapy?

You will have regular check-ups to monitor how well your treatment is working, including regular PSA tests. The PSA test is a simple blood test and is an effective way of monitoring your cancer. Your doctor or nurse will tell you how often you'll have check-ups. This will depend on the stage of your prostate cancer and any other treatments you are having.

If you're having treatment to get rid of your cancer

If your PSA level falls and stays low, this usually suggests your treatment has been successful at getting rid of your cancer. How quickly your PSA level falls, and how low, will depend on the treatment you've had and will vary from man to man.

Your doctor or nurse will want to know if you experience any side effects from your treatment. Let them know if there are any changes while you are on hormone therapy, or if you get any new symptoms.

If there is a continuous rise in your PSA level, this may be a sign that your cancer has come back. If this happens, there are further treatments available. Read more in our booklet, If your prostate cancer comes back: A guide to treatment and support.

If you're having treatment to control your cancer

If you have advanced prostate cancer and your PSA level falls, this usually suggests your treatment is working. How quickly your PSA level falls, and how low, will vary from person to person.

You'll generally keep having the hormone therapy, even after your PSA has fallen. This is because the hormone therapy is controlling the cancer and if you stop having it, the cancer might start to grow.

As well as regular PSA tests, you'll have other blood tests to see whether the cancer is affecting other parts of your body, such as your liver, kidneys or bones. You may also have scans to monitor how well your cancer is responding to treatment. Your doctor or nurse will want to know if you experience any side effects or symptoms. Let them know if you notice any changes to your health.

If there is a continuous rise in your PSA level, this may be a sign that your hormone therapy is no longer controlling your cancer so well. There are further treatments available, including other types of hormone therapy or a combination of other treatments. Read more in our fact sheet, **Treatment options after your first hormone therapy**.

What if I'm struggling with side effects?

There are treatments and support available to help manage side effects. But you may find that side effects continue to affect your daily life. If this happens, speak to your doctor or nurse. It might be possible to try a different treatment, or to take a break from hormone therapy.

Intermittent hormone therapy

If you're on life-long hormone therapy and having problems with side effects, you might be able to have intermittent hormone therapy. This is where you stop hormone therapy when your PSA level is low and steady, and start it again if your symptoms get worse or your PSA starts to rise. It may help to give you a break from some of the side effects, such as hot flushes and sexual problems, and you may feel better in yourself. But it can take several months for side effects to improve, and some men never notice any improvement.

For some men, intermittent hormone therapy can be just as effective at treating prostate cancer as continuous treatment. But it isn't suitable for everyone. And it isn't an option if you choose surgery (orchidectomy).

There is a risk that having a break from treatment may mean your cancer might grow. Speak to your doctor or nurse about the advantages and disadvantages of intermittent hormone therapy and whether it might be an option for you.

You will need to have your PSA level checked every three months while you're having a break from treatment. You can have intermittent hormone therapy for as long as it continues to work. Your doctor or nurse will tell you when you need to start treatment again.

What if I decide to stop treatment?

The side effects of hormone therapy can be difficult to deal with, and some men feel that they want to stop their treatment. If you are thinking about stopping hormone therapy, talk to your doctor or nurse. They will explain how this could affect your cancer and discuss any other possible treatments with you.

If you do stop having hormone therapy, the side effects won't stop straight away. It may take several months or longer for the side effects to improve.



Name.

My main contact

Use this space to record the name and contact details of your main point of contact for example, your key worker or clinical nurse specialist (CNS). They will help to co-ordinate your care, guide you to the appropriate team member and help you get information.

Namor						
Telephone no:						
Notes:						
241 1 141 6 1 1						
Other health professionals						
Name:						
Telephone no:						
Notes:						
Name:						
Telephone no:						
Notes:						

Drug chart

Use this table to record details of the hormone drugs you are having. Your doctor or nurse can help you fill it in. The details may also be listed on your repeat prescription form.

2	Hormone drug	Dose	How often?

Appointments

Record details of your appointments at the hospital or GP surgery.

Date	Time	Location	Notes

PSA levels

Use this table to record the results of your PSA tests. If you need more space, you can order PSA record cards by calling us on 0800 074 8383. Your doctor or nurse might also be able to print out a copy of your PSA results for you to keep.

Date	PSA level	Date	PSA level

More information from us

The Tool Kit

The Tool Kit information pack contains fact sheets that explain how prostate cancer is diagnosed, how it's treated and how it may affect your lifestyle. Each treatment fact sheet also includes a list of suggested questions to ask your doctor. Call our Specialist Nurses for a personally tailored copy.

Leaflets and booklets

We have a range of other leaflets and booklets about prostate cancer and other prostate problems.

To order publications:

All our publications are free and available to order or download online. To order them:

- call us on 0800 074 8383
- visit our website at prostatecanceruk.org/publications

Chat to one of our Specialist Nurses

If you want to talk about prostate cancer or other prostate problems, call our Specialist Nurses in confidence. You can also text NURSE to 70004, or you can email or chat online with our nurses on our website. Visit prostatecanceruk.org/get-support



Chat to one of our **Specialist Nurses** 0800 074 8383* prostatecanceruk.org

^{*} Calls are recorded for training purposes only. Confidentiality is maintained between callers and Prostate Cancer UK.

Other useful organisations

British Association for Counselling & Psychotherapy

www.bacp.co.uk

Telephone: 01455 883 300

Information about counselling and details of therapists in your area.

British Heart Foundation

www.bhf.org.uk

Telephone: 0808 802 1234

Information about heart disease and eating for a healthy heart.

Cancer Research UK

www.cancerresearchuk.org Telephone: 0808 800 4040

Information about cancer, including information about hormone therapy.

Complementary and Natural Healthcare Council

www.cnhc.org.uk

Telephone: 020 3327 2720

Details of complementary therapists who meet national standards.

Macmillan Cancer Support

www.macmillan.org.uk
Telephone: 0808 808 0000

Practical, financial and emotional support for those affected by cancer.

Maggie's

www.maggies.org

Telephone: 0300 123 1801

Drop-in centres for cancer information and support, and online support groups.

Medicines and Healthcare products Regulatory Agency (MHRA)

www.mhra.gov.uk

Telephone: 020 3080 6000

Advice on medicines and herbal remedies. Runs the Yellow Card Scheme.

NHS websites

England: www.nhs.uk

Scotland: www.nhsinform.scot Wales: www.111.wales.nhs.uk

nidirect (Northern Ireland)

www.nidirect.gov.uk/health-and-wellbeing

Penny Brohn UK

www.pennybrohn.org.uk Telephone: 0303 3000 118

Courses and physical, emotional and spiritual support for people with

cancer and their loved ones.

Royal Osteoporosis Society

www.theros.org.uk

Telephone: 0808 800 0035

Information and support for people with weak bones.

Switchboard - LGBT+ helpline

www.switchboard.lgbt Telephone: 0800 0119 100

Support and information for lesbian, gay, bisexual and trans people.

About us

We're Prostate Cancer UK. We're striving for a world where no one dies from prostate cancer.

We work to give everyone the power to navigate prostate cancer, by providing up-to-date, unbiased and accurate information about prostate diseases. But we're not here to replace your doctor. Always get advice from a healthcare professional to help you make decisions that are right for you.

References used in this booklet are available at prostatecanceruk.org

This publication was written and edited by our Health Information team.

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- Philip Reynolds, Consultant Therapeutic Radiographer,
 The Clatterbridge Cancer Centre NHS Trust
- · our Specialist Nurses
- · our Health Information team.

Tell us what you think

If you have any comments about our publications, you can email: yourfeedback@prostatecanceruk.org

Donate today – help others like you

Every year over 52,000 men get the life-changing news that they have prostate cancer. But thanks to our generous supporters, we're there to help men when they need us most. You can help more men get free, unbiased, confidential support by donating to us today:

- £10 could fund a call with one of our Specialist Nurses.
- £20 could give 40 men vital information through our handy

Mow your prostate: a quick guide.

To donate, visit prostatecanceruk.org/donate or call 0800 082 1616 or text PROSTATE to 70004†. And for other ways to support us, head to prostatecanceruk.org/get-involved

† You can donate up to £10 via SMS and we will receive 100% of your donation. Texts are charged at your standard rate. For full terms and conditions and more information, please visit prostatecanceruk.org/terms





Chat to one of our **Specialist Nurses** 0800 074 8383* prostatecanceruk.org

Trusted Information Creator

Patient Information Forum







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Call our Specialist Nurses from Monday to Friday 9am - 5pm, Wednesday 10am - 5pm

* Calls are recorded for training purposes only.

Confidentiality is maintained between callers and Prostate Cancer UK.

