

Living with hormone therapy

A guide for men
with prostate cancer

This booklet is for men who are having hormone therapy for prostate cancer. It describes the different types of hormone therapy, how they work and what the treatment involves. It includes information on the possible side effects you may experience and suggests ways that you may be able to manage these. This booklet can be used as a personal guide to your treatment and has space for you to record details of your care. We hope that this booklet will also be useful to share with your partner or family to help them understand more about living with hormone therapy.

This booklet does not give information on individual drugs. You can find information on individual drugs in our **Hormone drug** fact sheets. Our **Tool Kit** information pack has information about other treatments for prostate cancer. If you have recently been diagnosed with prostate cancer you may like to read our booklet **Prostate Cancer: a guide for newly diagnosed men**.

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

-  The Prostate Cancer Charity Helpline
-  The Prostate Cancer Charity publications

If you would like to know more about anything you read in this booklet, you can call our specialist Helpline nurses on

 0800 074 8383.

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What is hormone therapy?

Hormone therapy is a way of treating cancer by changing the hormone balance in the body. Hormones are natural substances found in the body that help control some of the body's functions. For men with prostate cancer, hormone therapy can be used to control the balance of the male hormone testosterone. Testosterone controls the development of the sexual organs, including the prostate gland, and many male characteristics such as a deeper voice or muscle strength.

How does hormone therapy treat prostate cancer?

Hormone therapy for prostate cancer works by stopping testosterone reaching the prostate cancer cells. If there are cancer cells in the prostate gland, or if the prostate cancer cells have spread to other parts of the body, testosterone can make them grow faster. In other words, testosterone 'feeds' the prostate cancer. If testosterone is taken away, it is possible to shrink the cancer, wherever the cancer cells are in the body.

Most of the testosterone in your body (90-95 per cent) is produced by the testicles and a small amount comes from the adrenal glands, which sit above your kidneys. To stop testosterone reaching the prostate cancer cells, cancer specialists may offer you:

- Surgery to remove the testicles, where most testosterone is produced
- Injections to stop the production of testosterone
- Tablets to block the effect of testosterone

Hormone therapy will not cure prostate cancer but it can keep the cancer under control for many months or years, and can be used with other treatments to help make them more effective.

Who can have hormone therapy?

Hormone therapy can be given as a treatment option for men with prostate cancer, but it is used in different ways depending on the stage of your cancer.

Localised prostate cancer

Cancer that has not spread outside the prostate gland is called 'localised prostate cancer'. This may be monitored (active surveillance) or treated with radical prostatectomy, radiotherapy or brachytherapy. Your doctor may also offer you hormone therapy in the following situations:

- If you are having radiotherapy or brachytherapy, you may have hormone therapy for around three months before your treatment starts. This shrinks the prostate gland and the tumour and makes the cancer easier to treat.
- If you are having radiotherapy, you may have hormone therapy at the same time. If there is an increased risk of the cancer spreading, you may continue to have hormone therapy for between six months and three years afterwards.
- If your first treatment is no longer controlling the cancer, hormone therapy may be used.

Hormone therapy does not benefit men with localised disease who are having a radical prostatectomy.

Locally advanced prostate cancer

Prostate cancer that has spread to the area just outside the gland, but has not spread to other parts of the body, is described as 'locally advanced'. Hormone therapy treats prostate cancer wherever it is in the body and is the standard treatment for locally advanced prostate cancer. Some men may benefit from radiotherapy alongside the standard hormone treatment, depending on the stage of their cancer. Speak to your specialist team about your treatment options.

Advanced prostate cancer

Prostate cancer that has spread (metastasised) to other parts of the body, such as the bone, is called advanced or metastatic disease. Hormone therapy treats prostate cancer wherever it is in the body. It cannot cure the cancer but it can keep it under control for many months or years, by shrinking the cancer, delaying its growth and reducing symptoms. For many men hormone therapy will be a life long treatment.

You will usually be offered a type of hormone therapy that works by stopping the body from producing testosterone, either an LHRH (luteinizing hormone-releasing hormone) agonist or an orchidectomy to begin with. Some specialists may also offer a type of hormone therapy which works by blocking testosterone. This is called an anti-androgen. See page 7 for more information on the different types of hormone therapy.

What types of hormone therapy are there?

There are three main types of hormone therapy treatment for prostate cancer. These are:

- Surgery to remove the testicles (orchidectomy)
- Injections to stop the production of testosterone
- Tablets to block the effects of testosterone

This section describes the different types of hormone therapy and gives space to record details of the hormone therapy you receive. Ask your doctor or nurse to tick the boxes that apply to you.

Surgery to remove the testicles (orchidectomy)

This type of hormone therapy involves an operation, called an orchidectomy, to remove testicles, or just the parts of the testicles that make the testosterone. This stops the body from producing testosterone. Without testosterone the prostate cancer cells are not able to grow. Tick the box below if you have had this type of hormone therapy.

Orchidectomy

Injections (LHRH agonists)

Some hormone therapy drugs work by stopping the brain from telling your body to make testosterone. Without testosterone the prostate cancer cells are not able to grow. This family of drugs are called LHRH agonists and are given by an injection into your arm or buttock, or a small implant, usually into your abdomen.

You may have the injections at your GP surgery or local hospital once a month or once every three months, depending on the dose you are having. There are several different LHRH agonist drugs made by different drug companies. Some of the common ones are listed below. Ask your doctor or nurse to tick the name of the drug that you have from the list below:

- Goserelin (Brand name: Zoladex)
- Leuprorelin acetate (Brand name: Prostag)
- Buserelin acetate (Brand name: Suprefact)
- Triptorelin (Brand name: Decapeptyl)
- Other (please specify)

i Read our **Hormone drug** fact sheets for more information on each of these drugs.

Before you have your first injection, you will be given a short course of anti-androgen tablets (see opposite). This is to prevent the body's normal response to the first injection, which is to produce more testosterone. This rise in testosterone, known as a flare, could cause the cancer to grow more quickly for a short time. The anti-androgen tablets help to prevent this flare from happening. You will start taking the tablets a week or so before the first injection and continue taking them for a week or two afterwards. It is important that you take all of the tablets you have been given.

Surgery and injections both use hormone therapy to treat prostate cancer by stopping your body from making testosterone and both treatments are equally effective.

Tablets

There are two different types of tablets that work in two different ways. These are anti-androgens and oestrogens.

Anti-androgens

Anti-androgens are drugs that work by stopping testosterone from reaching the cancer cells. Without testosterone the prostate cancer cells are not able to grow. This type of hormone therapy is taken as a tablet at least once a day. Anti-androgens can be used on their own, before having injections or together with an orchidectomy or LHRH agonists. You can ask your doctor how long you will need to take tablets for. Ask your doctor or nurse to tick the drug that you have from the list below:

- Bicalutamide (Brand name: Casodex)
- Flutamide (Brand name: Drogenil or Chimax)
- Cyproterone acetate (Brand name: Cyprostat)
- Other (please specify)

i Read our **Hormone drug** fact sheets for more information on each of these drugs.

Oestrogens

The oestrogen drug diethylstilbestrol (previously called stilboestrol) can treat prostate cancer in two ways:

- It stops the brain from telling the testicles to release testosterone.
- It acts directly on cancer cells, slowing their growth and causing some cancer cells to die.


Tick the box below if you have had this type of hormone therapy.

Diethylstilbestrol

Taking diethylstilbestrol tablets can increase your risk of circulation problems. Because of this, diethylstilbestrol is usually only used to treat advanced prostate cancer which is no longer responding to anti-androgens or LHRH agonists. You may not be able to take diethylstilbestrol if you have a history of high blood pressure, heart disease or stroke. Your doctor will advise you about this and can explain the potential risks and benefits. You will usually be given aspirin at the same time to reduce the risk of circulation problems.

What does the treatment involve?

Depending on which type of hormone therapy you have, you may visit the hospital or your GP surgery for treatment. You will have regular Prostate Specific Antigen (PSA) tests which will help to check how well your treatment is working. PSA is a protein produced by some of the cells in your prostate gland. The PSA test is a simple blood test that can measure the amount of PSA in your blood. You may like to ask your specialist how often you will have your PSA level checked. We have included a space at the back of this booklet for you to record the results of your PSA tests.

 Your specialist will also monitor any side effects you have from your treatment. Our **Hormone drug** fact sheets have details of individual LHRH agonist and anti-androgen treatments.

Your specialist team may suggest different ways of using hormone therapy, such as ‘maximal androgen blockade’ and ‘intermittent hormone therapy’.

Maximal androgen blockade

In some cases your specialist may suggest a way of using hormone therapy called ‘maximal androgen blockade’, also known as ‘combined androgen blockade’. This uses both an LHRH agonist and an anti-androgen to treat the cancer. Some specialists think that maximal androgen blockade slightly improves survival in men whose cancer has spread to other parts of the body (advanced prostate cancer). However, it may also increase the risk of side effects, so it is usually only used if single hormone therapies stop being effective.

Intermittent hormone therapy

Intermittent hormone therapy involves stopping treatment when your PSA level is low and steady and starting treatment again when your PSA starts to rise. Your doctor will advise you when you will start and stop treatment. The advantage of this method is that you may be able to avoid side effects during the time that you are not having treatment. However it can take six to nine months or sometimes longer for the side effects to wear off.

Researchers think that intermittent hormone therapy is just as effective at treating prostate cancer as continuous treatment, but this is still being tested in clinical trials. We do not yet fully understand all of the benefits and risks of this treatment method and it may not be suitable for all men.

What are the advantages and disadvantages of hormone therapy?

Advantages

- Hormone therapy is an effective treatment for prostate cancer.
- Hormone therapy can treat prostate cancer wherever the cancer cells are in the body.
- Hormone therapy can be used alongside other treatments to make them more effective.
- Hormone therapy can help to reduce some of the symptoms caused by prostate cancer, for example urinary symptoms.

A personal experience

‘An unexpected benefit was that my flow has become that of a youth. It is wonderful to fully empty my bladder quickly and without any dribbles.’

Disadvantages

- Hormone therapy cannot remove the cancer completely, but can keep it under control for many months or years.
- Hormone therapy can cause undesirable side effects. For more information about possible side effects, please see the following section on ‘Managing the side effects of hormone therapy’.

You can read more about the advantages and disadvantages of each type of hormone therapy in our Tool Kit fact sheet called

i **Hormone Therapy.**

Managing the side effects of hormone therapy

Like all drugs and treatments, hormone therapy carries a risk of side effects and it is important to discuss these with your specialist team before you start any treatment. If you know what side effects to expect, it can make it easier to cope with them. Hormone therapy affects different men in different ways. There is no way of knowing in advance which side effects you will get and how bad they will be. **The risk of getting each side effect depends on which treatment you are having as well as how long you take it for. Read our Hormone Drug fact sheets for information on individual treatments.**

The side effects of hormone therapy, caused by lowered testosterone levels, can be upsetting for some men. If you stop or change your treatment, your testosterone levels will rise again and some of the side effects may reduce slowly over time. Orchiectomy cannot be reversed but there are treatments that can help to reduce some of the side effects.

Some men who are having hormone therapy may have few side effects or may not have any side effects at all. This does not mean that the treatment is any less effective.

If you have any concerns about your side effects or if you get any new symptoms while you are having treatment, speak to your doctor or nurse or call our confidential Helpline on 0800 074 8383 to speak to a Prostate Cancer Charity Specialist nurse.

The following pages describe the most common side effects of hormone therapy and include information about how you and

your specialist team may be able to manage or reduce the side effects.

Loss of sex drive and erectile dysfunction

Hormone therapy has a big impact on sexual function. It can affect your sex life in two different ways: your desire for sex (libido) and your ability to get and keep an erection (erectile dysfunction). In most cases this will last for as long as you are on hormone therapy and may take a while to return if you stop treatment.

Desire for sex (libido)

All types of hormone therapy are likely to reduce, or cause you to lose your desire for sex. This is because of the decrease in testosterone, which is the hormone responsible for giving you your sex drive. One study suggested that about one in two men (50 per cent) taking LHRH agonists or who have had an orchidectomy will lose their interest in sex.

Testosterone is not the only factor that can affect your sex drive. Both physical and psychological factors can affect how you feel about sex. Some men describe feeling like they have lost their role within the partnership or family. This can sometimes affect a man's self esteem and confidence. For others, the treatment may lead to tiredness and a lack of energy. Physical changes after hormone therapy such as putting on weight, or breast swelling, can also affect the way you feel about your body and appearance. All of these factors may result in a lack of interest in sex.

Erectile dysfunction (ED)

All types of hormone therapy can cause problems getting or keeping erections. However, anti-androgens are less likely to cause erectile dysfunction than other types of hormone therapy, but do have risks of other side effects such as breast swelling. One study found that seven out of ten men (70 per cent) taking LHRH agonists or who had an orchidectomy experienced problems getting or keeping an erection strong enough for sexual intercourse. It is thought that reducing the levels of testosterone can cause physical changes to some of the erectile tissue needed to produce an erection.

Another possible side effect of treatment for prostate cancer, including hormone therapy, is a reduced amount of semen. When you ejaculate you may experience what is sometimes called a 'dry ejaculation', where you feel the sensations of orgasm, but do not release any semen from the tip of the penis. This may feel a little different to the orgasms you are used to. Occasionally, some men will find that a small amount of liquid comes out from the tip of the penis during orgasm, which may be fluid from glands lining the urethra.

A personal experience

'The main side effect has been dry orgasms and a reduced, though working, libido. I have not had any hot flushes or tiredness so far. I was informed from the outset by the urologist that my sex life may be over, but that has been far from the case. In fact it has increased (probably due to worries that it would end soon). I have no problems with erections and do not require chemical assistance at the moment.'

Coping with changes to your sexual function

Different men deal with changes to their sexual function in different ways. Some men find that because they no longer have a desire for sex, it is easier for them to come to terms with problems getting an erection. Having problems with erections or losing your desire for sex is a problem that many men have at some point in their lives. For some men the ability to have sex or get an erection is an extremely important part of how they see themselves as men. But it is important to remember that there is more to being a man than this.

A personal experience

'It has been hard to live with the total loss of my sex drive. I am 64 and have been living with these treatments now for seven years and in general I feel fine. I go to the gym a couple of nights a week and my body is in good shape. I eat healthy food and I don't get any more tired now than before I was diagnosed.'

If you have a partner, or are starting a new relationship, it is important to talk to them about any changes to your sex life. You may find that talking helps to reduce any worry about what your partner thinks. Talking may help them to understand more about the changes your treatment has caused or may cause. Talking may also help you to come to terms with any side effects you are experiencing.

Loss of interest in sex does not mean you lose interest in a loving and supportive relationship. There are ways to remain physically intimate without having sexual intercourse. If you are used to a close physical relationship, it is important to remember that physical contact - through cuddles and kissing - maintains intimacy, provides support and does not have to lead to intercourse. Some men find they become closer to their partner after starting treatment.

A personal experience

'At first I was concerned when they told me that my sex drive and performance would be affected. However a loss of drive alongside reduced performance is not a problem for me, but a reduced performance with continued strong drive would be.'

If you are a partner, it can be helpful to understand how hormone therapy may change a man's sexual function. It is important to be patient and to help him to understand that there is no pressure to perform. Some men will struggle to come to terms with changes in their body image or their ability to perform sexually. This can result in avoiding intimate situations where they may feel under pressure to make love. Sometimes men may distance themselves from close relationships, but this does not mean that they no longer care for their partner or loved ones.

Couples occasionally worry that cancer can be passed on when they are intimate together. It is not possible to pass cancer on to your partner through intercourse. Having sexual intercourse will not affect your cancer or the success of your treatment.

The Sexual Dysfunction Association has further information written for partners. If you or your partner are finding it difficult to approach the issue of sex, you may find it helps to see a psycho-sexual counsellor.

Treatment for erectile dysfunction (ED)

For some men and their partners the loss of erectile function is not a problem and they may choose not to have treatment. Others are less happy about losing what may be a very important part of their lives and may choose to seek treatment.

If you are worried about the way hormone therapy is affecting your sex life, do not be embarrassed to talk to your doctor or nurse. It may help to remember that they will have talked about these difficulties with their patients many times before. As well as discussing the treatments available, they can also let you know about local support groups or counselling services available in your area. There is a list of useful organisations that may be able to help on page 42 of this booklet.

Many treatment centres have an ED clinic. You can ask your doctor or nurse for a referral. It may be helpful to bring your partner along to the appointment. There are a number of different types of treatment available, but these work best when sexual desire (libido) is still present. Treatment options include:

- Tablets
- Injections
- Pellets
- Vacuum pumps
- Implants

If you do not have success with one treatment you may find that a different treatment is more effective. For more information about treatments for erectile dysfunction read our Tool Kit

i fact sheet on **Sexuality and prostate cancer**.

If loss of desire for sex is a big problem for you, you may wish to discuss the option of intermittent hormone therapy with your doctor. Intermittent hormone therapy involves having hormone therapy for a set period of time, stopping treatment and then re-starting it again. This may help to improve sexual function in the 'off-treatment' period. You can read more about this approach on page 12 of this booklet. For some men, sexual function may gradually return to normal after hormone treatment is stopped, but it can take up to a year.

Hot flushes

Hot flushes are a common side effect of hormone therapy. Between five and eight out of every ten men (50 to 80 per cent) taking hormone therapy will get hot flushes. They may happen within about three months of starting treatment. Hot flushes give you a sudden feeling of warmth in the upper body and can be similar to those experienced by women going through the menopause.

Hot flushes may happen suddenly without warning or they may be triggered by stress, a hot drink or a change in the temperature around you. Hot flushes can vary from a few seconds of feeling overheated to a few hours of sweating that can stop you from sleeping or cause discomfort. Although exact definitions vary, hot flushes are sometimes described as being mild, moderate or severe.

- A mild hot flush may 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 may 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. They can make some men feel irritable, uncomfortable and sometimes nauseous.

How long the hot flush lasts is not always as important as whether it affects your everyday life. Some men may not be worried by the symptoms, but for other men they can be very disruptive and difficult to cope with. If your hot flushes are affecting your everyday life, speak to your doctor or nurse. Mild symptoms may not need any treatment and some men find that their hot flushes get better with time.

A personal experience

‘As a keen do-it-yourself person I love making, repairing and maintaining things but for the past two and a half years this has been difficult due to sweating. I no sooner start a physical activity than I break out in a heavy sweat and have to stop to cool down.’

What can I do to manage hot flushes?

There are a number of different options to help you manage hot flushes, including lifestyle changes, drug treatments and complementary therapies.

Some basic lifestyle changes that may help to prevent or reduce hot flushes include:

- Stop smoking
- 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
- Use light cotton bed sheets or use a cotton towel on top of your sheets that you can change easily
- Wear cotton clothes, especially at night

Recent reports have suggested that eating soy may help to reduce hot flushes. If you would like to include soy in your diet, try naturally occurring kinds such as soy beans, miso, tempeh, tofu and soy milk.

You may find it helpful to talk to your doctor or nurse about keeping a diary of your symptoms for a few weeks. This can help you and your doctor or nurse to decide whether or not to start treatment for your hot flushes.

There are number of drug treatments which can help to relieve hot flushes. Some men find that a course of man-made hormones called progestogens can help. The most commonly used one is called megestrol acetate. Other drug treatments that may help with hot flushes include an anti-androgen called cyproterone acetate, oestrogen patches and the oestrogen drug diethylstilbestrol. As all drug treatments carry a risk of side

effects, talk to your doctor or nurse about these before starting any treatment for hot flushes.

A small number of trials have shown that antidepressants may help to relieve hot flushes, but more research is needed before we can say for sure.

Complementary therapies may also help you cope with hot flushes. A small number of studies have found that acupuncture reduces hot flushes in some men and the results so far are promising. Acupuncture involves inserting fine sterile needles just below the skin. It aims to help balance the body's energy.

Although there is no scientific evidence, some men have found that sage tea and evening primrose oil help them to cope with hot flushes. Other complementary medicines that may help include red clover and black cohosh.

Your specialist team or GP may be able to give you details about receiving complementary therapies on the NHS. If you would prefer to find your own therapist or treatment centre, make sure that they are registered and qualified. The British Complementary Medical Association has lists of registered practitioners throughout the UK.

Always tell your specialist team if you are thinking of taking herbal or complementary medicines because some of them cannot be taken alongside other medicines. Your pharmacist can also give you advice on this.

Bone thinning

LHRH agonists and orchidectomy treat prostate cancer by reducing the levels of testosterone in the body. However, because testosterone helps to keep the bones strong, long term treatment with these types of hormone therapy may cause the bones to gradually lose their bulk. This can happen within 6 to 12 months of beginning treatment and the degree of bone loss may increase the longer you are on treatment. Long term treatment with LHRH agonists or orchidectomy can cause thinning of the bones that, if severe, can lead to the condition known as osteoporosis. This can result in an increased risk of bone fractures. Anti-androgens and oestrogens do not have this effect.

How can I reduce my risk of osteoporosis?

There are a number of lifestyle changes such as exercise and changes to your diet that may help to reduce your risk of osteoporosis. You can help to reduce your risk by:

- Making sure you have enough vitamin D and calcium in your diet. You can increase your intake of calcium by eating more spinach, some breakfast cereals, beans, spring greens and fish with soft bones such as sardines. You can get vitamin D from eating oily fish and from exposure to sunlight. If you are not sure if you are getting enough vitamin D or calcium in your diet, speak to your doctor about suitable doses of supplements. Aim for between 1000mg and 1500mg of calcium each day and between 400 to 800 units (10 to 20 micrograms) of vitamin D to keep your bones strong. You may also like to read our Tool Kit fact sheet on **Diet and prostate cancer**.



- Cutting down on alcohol. Government guidelines recommend that men should not regularly drink more than three to four units of alcohol a day. This is about two standard size glasses of red wine or one and a half pints of lager.
- Stopping smoking.
- Exercising regularly, especially resistance exercises such as swimming, pilates, fast walking or using weights. These types of exercises, also called weight bearing exercises can help to keep your bones strong and prevent any falls which could result in a bone fracture. Aim for 30 minutes to an hour of exercise two or three times a week.
- Keeping a healthy weight. Men who are underweight have a higher risk of bone thinning.

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 treatment with LHRH agonists or orchidectomy. You should also tell your doctor if you are taking any other medicines which might increase your risk of osteoporosis. More information about osteoporosis is available from the National Osteoporosis Society. Please see the More Information section on page 42 of this booklet.

Breast swelling and tenderness

Treatment for prostate cancer with anti-androgens and oestrogens may cause swelling (gynaecomastia) and tenderness in the breast area. This can affect one or both breasts and can range from mild sensitivity to ongoing pain. The amount of swelling can also vary from a small amount to a more noticeable enlarged breast area. It is caused by the effect that hormone therapy has on the balance of the hormones oestrogen and testosterone in the body.

Around half (50 per cent) of men taking an anti-androgen will get some swelling and between a quarter and three quarters (25 to 75 per cent) will get some degree of tenderness. Most men taking a high dose of the anti-androgen bicalutamide for more than six months will get breast swelling. However, it is less common in men who have had an orchidectomy or who are having maximal androgen blockage.

Breast swelling and tenderness can make some men feel uncomfortable about their bodies. You may like to talk to your doctor about the treatments available to help prevent or reduce this side effect.

How can I reduce my risk of breast swelling and tenderness?

There are a number of options available that can help to reduce your risk of breast swelling and tenderness or help to treat the problem. These include:

- Treating the breast area with a single dose of radiotherapy
- Tablets
- Surgery

If you are about to start taking anti-androgens or oestrogens, your doctor may recommend treating the breast area with radiotherapy. A single low dose of radiation can reduce the risk of breast swelling and tenderness. It must be used within the first month of hormone treatment because it has no effect once swelling has already happened. Side effects include reddening of the skin and irritation but this usually clears up in three to five weeks.

Tamoxifen tablets can be used both to prevent and treat breast swelling in men taking anti-androgens. They are commonly used to treat breast cancer and work by stopping the hormone oestrogen from reaching the breast tissue. You may not be able to have tamoxifen if you are taking oestrogens because it may stop your treatment from working properly. We do not know how tamoxifen affects other hormone treatments in the long term.

Surgery may be a suitable option for men who have been treated with either anti-androgens or oestrogens. Surgery removes painful or swollen areas of the breast. However, this treatment carries a risk of damage to the nipple and a loss of feeling and is usually only offered if other treatments are not suitable.

Tiredness (fatigue)

Hormone therapy for prostate cancer can cause extreme tiredness. While some men may not feel tired at all, other men may experience tiredness that affects their everyday life. Fatigue can affect areas such as your energy levels, your motivation and your emotions. It is important to let your doctor know how you feel and how tiredness is affecting you so that they can help you. Fatigue may be due to your treatment but it can also have other causes such as the cancer itself or other conditions such as anaemia.

You may find that your tiredness improves over time but many men find that regular resistance exercise gives them more energy and helps them to cope with treatment. Try swimming or walking up and down stairs, or if you are not able to move about easily, ask your doctor or nurse for a referral to a physiotherapist at your hospital who can give you some gentle exercises to do at home.

Macmillan Cancer Support provides more information about coping with fatigue including what to do if fatigue is affecting your ability to work. To order a copy of 'Coping with fatigue' call 0800 500 800.

A personal experience

"I found exercise is the best thing to combat tiredness and it also motivates you in general and keeps your spirits up and stress levels down."

Weight gain

You may notice that you start to put on weight, particularly around the waist. Some men find this physical change difficult to cope with particularly if they have never had any problems with their weight in the past.

Exercise and a healthy diet can help you stay a healthy weight. It can take a long time to lose any weight that you may have put on during hormone therapy. If you are finding it difficult to lose weight, ask to be referred to a state registered dietitian.

You can read more about healthy eating in our Tool Kit fact sheet on **Diet and 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 a small amount of body fat and a greater amount of muscle and muscle strength. Hormone therapy reduces the amount of testosterone and can cause a decrease in muscle tissue and an increase in the amount of body fat.

This can change the way your body looks and how physically strong you feel. Regular resistance exercise such as gentle weight lifting, fast walking or swimming may help to reduce muscle loss and keep your muscles strong.

Memory and concentration

Testosterone is thought to be linked to cognitive function in men. This includes things such as memory and the ability to concentrate. Some studies have shown that hormone therapy can affect cognitive function but we do not know for sure whether this is caused by the hormone therapy or whether other factors, such as hot flushes and fatigue, may play a part.

Risk of heart disease and diabetes

Some studies have found that men receiving hormone therapy may have an increased risk of heart disease and diabetes. You may be able to help reduce your risk by:

- Eating a healthy diet
- Taking regular exercise
- Limiting the amount of salt you eat
- Avoiding smoking
- Cutting down on alcohol

You can find out more about healthy eating in our Tool Kit fact sheet on **Diet and prostate cancer**.



How will hormone therapy affect how I feel?

You may be starting hormone therapy very soon after being diagnosed with cancer. This can have a significant effect on your emotions and you may still feel shocked, frightened or angry as a result of your diagnosis.

Hormone therapy affects different men in different ways and it can be hard to know before starting treatment how the side effects will make you feel. Even if you have been told about the possible side effects before starting treatment, they can be difficult to cope with. Some men are surprised by the side effects and shocked at how upsetting they find them. Other men experience fewer symptoms or are not as worried by them.

It can be hard to come to terms with some of the changes that hormone therapy causes. Some men find that the physical change to their bodies, such as putting on weight, or changes to their sexual function, can make them feel very different about their bodies and cause a sense of loss. Sometimes men describe feeling less masculine as a result of their diagnosis and treatment. Talking about the changes in your body with your doctor, specialist nurse or counsellor may help you. Open communication with your partner or close friends and family may also help you to come to terms with any changes.

Hormone therapy treatment itself may also affect your mood. You may find that you feel more emotional than usual. Some men have told us that just knowing that these feelings were caused by hormone therapy helped them to cope.

Some men may also experience low moods or depression. This can be as a direct result of hormone therapy, a response to the shock of diagnosis or the impact that treatment can have on your life. If you are finding that your mood is often very low, that you are losing interest in things or that your sleep pattern or appetite has changed significantly, then this may indicate that you are depressed.

Some men try to cope with this on their own because they may be too embarrassed to talk about it or afraid of worrying loved ones. However, often sharing these things can help men to cope with them. A recent study found that men who talked about their emotions experienced a greater sense of wellbeing.

If you think you might be depressed, try to get help early on as this will help you cope better with treatment. Your doctor or nurse can answer any questions you may have and can be a good source of support. Talking to family and friends can also help, and may take some of the pressure off you. Anti-depressants are often successfully used to treat hormone therapy-related depression.

A small study has shown that intermittent hormone therapy may help to relieve depression and anxiety. This is a fairly new treatment approach, and we do not yet fully understand all the benefits and risks. Talk to your specialist team if you think this may help you.

For more information about available support, read the section 'What support is available to me?' on page 34 of this booklet.

You and your partner

It is important to remember that your partner or family members may feel more anxious or depressed about your diagnosis than you do. They may feel isolated and may find it difficult to tell you how they are feeling for fear of making you feel anxious. It is important to work out the best way of making those close to you feel supported. Open communication with him or her may help you both. Doctors and nurses are always happy for you to

bring your partner along to your appointments and may be able to direct you to the type of support that most suits your needs. Many support groups also welcome partners and can be helpful for both of you.

How will my treatment be monitored?

While you are receiving hormone therapy your doctor or nurse and you will need to check how well the treatment is working. You will need to have your PSA level checked regularly. Your doctor or nurse will tell you how often this will be as it will depend on the stage of your treatment. They will also keep an eye on your symptoms. It is important that you let them know if there are any changes to your symptoms while you are on hormone therapy.

What will happen if I decide to stop my treatment?

It can be difficult to cope with the side effects of hormone therapy and some men may feel that they want to stop their treatment. If you are thinking about stopping hormone therapy, talk to your doctor. They will explain how this will affect your cancer and any possible alternatives. You can also talk to your doctor about other options such as intermittent hormone therapy (see page 12), but this may not be suitable for all men.

What support is available to me?

There are lots of different ways of getting support, so it is important to choose options that suit you as an individual. You may find that making smaller changes to your life can help, but sometimes you may feel you need more support or expert advice. Do not be embarrassed to ask for help. There are a number of people that can offer support including:

Friends and family

It is not always easy to talk about cancer and how the side effects of treatment are affecting you. Talking to a partner, friend or relative may help you to cope with side effects and make them easier to deal with. By helping people close to you to understand the side effects of your treatment they can find a way of offering support in a way that is right for you.

Your specialist team

Let your specialist team know how your treatment is affecting you. If they know what side effects you are experiencing and how they are affecting you, they can explain what options are available to help you deal with them. There are a range of lifestyle changes and treatments available that may help to reduce the symptoms.

Support groups

Support groups can be a great way for you to meet people with similar experiences. These groups are often set up by local health professionals, or by people who have experience of prostate cancer who chose to set up their own group. Meetings are usually informal and offer an opportunity to find out about

other people's experiences as well as discussing your own thoughts and concerns. Ask your health professional for details of support groups near you. Many support groups are happy for you to bring your partner along with you. You can also find details of support groups on The Prostate Cancer Charity website www.prostate-cancer.org.uk or by calling our free and confidential Helpline on 0800 074 8383.



Counselling

It can sometimes be difficult to talk to people close to you because you do not want to upset them, or you may find it hard to show your emotions. Some people find it easier to talk to someone they do not know. Counsellors are trained to listen and can help you to understand your feelings and find your own answers. Your GP may be able to refer you to a counsellor or you can see a private counsellor. There are different types of counselling available. To find out more contact the British Association for Counselling and Psychotherapy on 0870 443 5252 or visit www.bacp.co.uk.

The Prostate Cancer Charity

If you, your partner or your family have any questions about prostate cancer, treatments, or any of the side effects described in this booklet you can call our free and confidential Helpline to speak to a specialist nurse. Call 0800 074 8383.




You can also send a query to the Helpline by using our email contact form. Visit www.prostate-cancer.org.uk and click on 'support' for details of how to contact the Helpline.

We also provide a one-to-one support service which can give you the opportunity to talk to someone who has experience of hormone therapy and understands what you are going through. Our Support Volunteers are all personally affected by prostate cancer: men with a diagnosis, wives, partners, family members or friends. They have been trained to listen and offer support.

You may also like to use our online message board. This is an internet discussion group for people affected by cancer where you can share your views and experiences www.prostate-cancer.org.uk

We have further information for men who have been diagnosed with prostate cancer including **Prostate cancer: a guide for newly diagnosed men** and our **Tool Kit** information pack which explains how prostate cancer is treated and how it may affect your lifestyle.

 To order our publications call our Helpline on 0800 074 8383 or email us at literature@prostate-cancer.org.uk. You can also download all of our publications from our website at www.prostate-cancer.org.uk

My team members

You can use this space to record names and contact details for the members of your Multi-Disciplinary Team (MDT). This is the team of health professionals who may be involved in your ongoing care. We have listed the health professionals who you are most likely to see, but you may not come into contact with all of these.

Key worker

Your key worker is your main point of contact. They help to co-ordinate your care and can guide you to the most appropriate team member or source of information. This may often be your specialist nurse.

Name	
Telephone no.	
Notes	

Specialist nurse

You may have a urology, uro-oncology or prostate cancer specialist nurse as part of your MDT. They can answer any questions you may have about your cancer and may carry out some of the tests you will have.

Name	
Telephone no.	
Notes	

Consultant oncologist

This type of doctor specialises in treating cancer.

Name	
Telephone no.	
Notes	

Consultant urologist

This type of doctor is a surgeon who specialises in the urinary system and male reproductive system.

Name	
Telephone no.	
Notes	

General practitioner (GP)

Your GP and Practice or District Nurse will help to co-ordinate your care and can offer you support through your diagnosis and treatment. They will keep in touch with your specialist team at the hospital and keep a record of your treatment. Your GP can also refer you to local health services and organisations in your area.

Name	
Telephone no.	
Out-of-hours doctor's surgery contact details	
Notes	

Practice or District nurse

Name	
Telephone no.	
Notes	

Other health professionals

You can record contact details of other health professionals in the space below. For example these might include a radiographer, pharmacist, dietician, sexual dysfunction clinician, continence nurse or physiotherapist.

Name	Contact details

 **The prostate cancer Charity Support & Information Specialist Nurses: Helpline 0800 074 8383.**

Drug chart

You may like to use this space to record details of the hormone drug you are having. Your doctor or nurse can help to fill in the table below.

Hormone drug	Dose	Frequency

PSA levels

You can use this space to record the results of your PSA tests. If you need more space, you can order PSA record cards by calling



The Prostate Cancer Charity on 0800 074 8383.

Date	PSA level	Date	PSA level

More information

The following organisations may be able to offer you, your partner or your family further support and information.

British Association of Counselling and Psychotherapy (BACP)

www.bacp.co.uk

Telephone 01455 883316

BACP will help you find counsellors who work to clearly defined standards of good practice.

British Association for Sexual and Relationship Therapy (BASRT)

www.basrt.org.uk

Telephone 020 8543 2707

For information on sexual and relationship therapy, including a list of therapists.

British Complementary Medicine Association

www.bcma.co.uk

Telephone 0845 345 5977

A non-profit umbrella organisation that can provide details of practitioners in a range of complementary therapies.

Cancer Black Care

www.cancerblackcare.org

Telephone 020 8961 4151

Provides cancer information and support to people from black and minority ethnic communities.

Cancer Counselling Trust

www.cancercounselling.org.uk

Counselling service Helpline 020 7843 2292

Provides free specialist counselling for people affected by cancer, their friends and family.

Carers UK

www.carersuk.org

Carers line 0808 808 7777 10-12am & 2-4pm, Wed & Thurs

Provides information and advice for carers including signposting to support groups.

GaysCan

Email: gayscan@blotholm.org.uk

Provides a national, confidential helpline for gay men living with cancer, their partner, families and friends.

Macmillan Cancer Support

www.macmillan.org.uk

Freephone Cancerline 0808 808 2020 Mon-Fri 9am-9pm

For support and information about cancer, including financial advice.

Maggie's Centres

www.maggiescentres.org

Telephone 0131 537 2456

A network of drop-in centres across the UK for people affected by cancer.

National Osteoporosis Society

www.nos.org.uk

Helpline 0845 450 0230

Provides a nurse-led Helpline about osteoporosis.

Penny Brohn Cancer Care

www.pennybrohncancercare.org

Helpline 0845 123 23 10

Provides complementary care for people with cancer and their families.

Relate

www.relate.org.uk

Telephone 0300 100 1234

Provides relationship counselling, sex therapy and a range of other relationship support services.

Sexual Dysfunction Association

www.sda.uk.net

Helpline 0870 774 3571

For detailed information on treatments for erectile dysfunction.

Samaritans

www.samaritans.org

Helpline 0845 790 9090

A Helpline offering confidential emotional support to anyone in the UK.

UK Prostate Link

www.prostate-link.org.uk

This website guides you to reliable sources of prostate cancer information.

For a copy of our A-Z of medical words visit our website at



www.prostate-cancer.org.uk or call 0800 074 8383 for a printed copy.

References to sources of information used in the production of this booklet are available on our website at www.prostate-cancer.org.uk.

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- Andrea Harris, Acupuncturist for Urology, James Cook University Hospital, Middlesbrough
- Macmillan GP Advisory Group, Macmillan Cancer Support
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- The Prostate Cancer Charity Information Volunteers
- The Prostate Cancer Charity Support & Information Specialist Nurses

Written and edited by: The Prostate Cancer Charity Information Team

The Prostate Cancer Charity funds research into the causes of, and treatments for, prostate cancer. We also provide support and information to anyone concerned about prostate cancer. We rely on charitable donations to continue this work. If you would like to make a donation, please call us on 020 8222 7666.

The Prostate Cancer Charity makes every effort to make sure that its services provide up-to-date, unbiased and accurate facts about prostate cancer. We hope that these will add to the medical advice you have had and will help you to make any decisions you may face. Please do continue to talk to your doctor if you are worried about any medical issues.

The Prostate Cancer Charity

First Floor, Cambridge House, 100 Cambridge Grove,
London W6 0LE

Email: info@prostate-cancer.org.uk

Telephone: 020 8222 7622

Fax: 020 8222 7639

The Prostate Cancer Charity Scotland

Unit F22-24 Festival Business Centre, 150 Brand Street,
Glasgow G51 1DH

Email: scotland@prostate-cancer.org.uk

Telephone: 0141 314 0050



Free and confidential Helpline

0800 074 8383*

Mon – Fri 10am – 4pm, Wed 7pm – 9pm

Website: www.prostate-cancer.org.uk

* Calls are free of charge from UK landlines. Mobile phone charges may vary. Calls may be monitored for training purposes. Confidentiality is maintained between callers and the Prostate Cancer Charity.

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THE
PROSTATE
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