Living with hormone therapy
A guide for men with prostate cancer
About this booklet

This booklet is for you if you are about to start, or are 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 these side effects. You may not get all these side effects, so you might want to dip into this booklet for the information that is useful for you.

There’s space on pages 58-64 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 at prostatecanceruk.org

The following symbols appear throughout the booklet:

- Our Specialist Nurses
- Our publications
- Sections for you to fill in
- Watch online at prostatecanceruk.org
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Living with hormone therapy
What is hormone therapy?

Hormone therapy is a treatment for prostate cancer. It works by stopping testosterone from reaching the prostate cancer cells.

Testosterone is a hormone that controls the development and growth of the sexual organs, including the prostate gland. It also controls other male characteristics, such as erections and muscle strength. Most of the testosterone in your body is produced by the testicles, but a small amount comes from the adrenal glands which sit above your kidneys.

Testosterone doesn’t usually cause problems, but if you have prostate cancer it can make the cancer cells grow faster. In other words, testosterone feeds the prostate cancer. If testosterone is taken away, the prostate cancer cells shrink, wherever they are in the body.

Hormone therapy on its own won’t cure your prostate cancer. But it can keep it under control for many months or years before you need further treatment. It can also be used with other treatments, such as radiotherapy, to make them more effective.

Hormone therapy has been an effective way of keeping my prostate cancer under control for seven years now.

A personal experience
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 your own treatment options.

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, for example, radiotherapy. Hormone therapy can make the prostate smaller, making the cancer easier to treat.

- You might have hormone therapy for six months before, during or after treatment with external beam radiotherapy.
- If there is a risk of the cancer spreading outside the prostate, you might continue to have hormone therapy for up to three years after external beam radiotherapy.
- You might have hormone therapy for a few months before starting brachytherapy.

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

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.
Advanced prostate cancer
Hormone therapy will be a life-long treatment for many men with prostate cancer that has spread to other parts of the body (advanced or metastatic prostate cancer).

Hormone therapy treats prostate cancer wherever it is in the body. It can’t cure the cancer, but it can keep it under control, sometimes for several years. It can also help manage the symptoms of advanced cancer, such as bone pain.

Hormone therapy shrinks the cancer and slows down its growth, even if it has spread to other parts of the body. How long it will control the cancer for varies from man to man. It may depend on how aggressive your cancer is and how far it had spread before you started treatment. It’s difficult for doctors to predict exactly how long it will keep your cancer under control. Speak to your doctor or nurse about your own situation.

More information
Read more about the different stages of prostate cancer and treatment options in our fact sheets:
- Localised prostate cancer
- Locally advanced prostate cancer
- Advanced prostate cancer.

If your cancer comes back after treatment for localised or locally advanced prostate cancer, hormone therapy will be one of the treatment options available to you. Read our booklet, If your prostate cancer comes back: A guide to treatment and support, for more information.
I was diagnosed with locally advanced prostate cancer. I’ve had eight weeks of radiotherapy. I have a hormone implant every twelve weeks and I’m doing fine.

A personal experience
What types of hormone therapy are there?

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

- **injections or implants** to stop your testicles making testosterone
- **surgery**, called an orchidectomy, to remove the testicles or the parts of the testicles that make testosterone
- **tablets** to block the effects of testosterone.

The table on page 15 gives an overview of the different drugs available.

There are also two new types of hormone therapy, **abiraterone** and **enzalutamide**, that can be used if your prostate cancer stops responding as well to the first hormone therapy you had. We talk about these on page 16.

**Injections or implants**

These work by blocking the message from the brain that tells the testicles to make testosterone.

Injections or implants are as good at controlling prostate cancer as surgery to remove the testicles.

**LHRH agonists**

You might also hear these called GnRH agonists (not the same as GnRH antagonists – see page 11).
LHRH agonists are the most common type of injection used. There are several different LHRH agonists available and they all work in the same way.

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 which is injected under your skin.

You will have the injections at your GP surgery or local hospital either once a month, once every three months, or once every six months, depending on the dose.

Some of the common LHRH agonist drugs include:
- goserelin (Zoladex®, Novgos®)
- leuprorelin acetate (Prostap® or Lutrate®)
- buserelin acetate (Suprefact®)
- triptorelin (Decapeptyl®, Gonapeptyl Depot®).

Before you have your first injection of an LHRH agonist, you may have a short course of anti-androgen tablets (see page 13). This is to stop your body’s normal response to the first injection, which is to produce more testosterone.

If you have advanced prostate cancer, this temporary increase in testosterone could make any symptoms you have worse for a short time – this is known as a flare. The anti-androgen tablets help to stop this flare from happening.
**GnRH antagonists**
You may also hear these called GnRH blockers, or LHRH antagonists (not the same as LHRH agonists).

GnRH antagonists aren’t used as often as LHRH agonists. There’s currently only one kind of GnRH antagonist available in the UK, called degarelix (Firmagon®). It may not be available in every hospital.

Degarelix can be used as a first treatment for advanced prostate cancer that has spread to the bones. It may help to prevent metastatic spinal cord compression (MSCC), which can happen if cancer cells grow in or near the spine and press on the spinal cord.

If you have degarelix you will have injections just under the skin of your stomach area (abdomen). Your first dose will be two injections and after that you’ll have one injection once a month.

Unlike LHRH agonists, degarelix does not cause a temporary rise in testosterone with the first treatment so you won’t need to take anti-androgen tablets. It starts to lower testosterone levels on the first day of treatment.
Surgery to remove the testicles (orchidectomy)

An orchidectomy 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 is as good at controlling prostate cancer as injections or implants. Your testosterone levels will drop very quickly – usually in less than 12 hours. It also means that you won’t need to have regular injections, and there’s no risk that you’ll miss an injection.

Surgery can’t be reversed so it’s usually only offered to men who need long-term hormone therapy. If you’re thinking about having an orchidectomy, your doctor may suggest trying injections or implants (see page 9) for a while first to see how you deal with the side effects of lowered testosterone levels.

Short-term side effects of surgery include swelling and bruising of the scrotum (the skin containing the testicles). See page 23 for information about longer-term side effects.

Some men find the thought of having an orchidectomy upsetting, and worry about how they’ll feel about themselves afterwards. If you don’t want to have an orchidectomy, you can usually have a different type of hormone therapy instead. If you’re thinking about having an orchidectomy, speak to your doctor about any concerns you might have.
## Tablets to block the effects of testosterone

There are two types of tablets used to block the effects of testosterone: anti-androgens and oestrogens. They work in different ways.

### Anti-androgens

Anti-androgens stop testosterone reaching the prostate cancer cells. They’re taken as a tablet. They can be used:

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

Ask your doctor how long you will need to take anti-androgens for 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, tenderness and weakness.

If your prostate cancer has spread to other parts of your body (advanced prostate cancer) anti-androgens are less effective at controlling the cancer than other types of hormone therapy. Because of this, if you have advanced prostate cancer, your doctor will usually recommend an LHRH agonist rather than taking an anti-androgen on its own.
There are several different anti-androgens, including:

- bicalutamide (for example Casodex®)
- flutamide (for example Drogenil®)
- cyproterone acetate (for example Cyprostat®).

Read more about LHRH agonists, GnRH antagonists, surgery and anti-androgens in our fact sheet, Hormone therapy.

**Oestrogens**

Oestrogens are a type of hormone that can be used to treat your cancer if it’s no longer responding to other types of hormone therapy. Oestrogen is found in both men and women, but women usually produce more.

It is used less often than other treatments. Oestrogens can be given as a tablet called diethylstilbestrol (Stilboestrol®).

Like all treatments, oestrogens can cause side effects. These can be similar to the side effects of other types of hormone therapy, and can include breast swelling and tenderness.

Diethylstilbestrol can also increase your risk of circulation problems, such as blood clots. You will usually take drugs such as aspirin or warfarin to make this less likely. You may not be able to take diethylstilbestrol if you have a history of high blood pressure, heart disease or strokes.
The table below gives an overview of the different types of hormone therapy.

<table>
<thead>
<tr>
<th>Type of hormone therapy</th>
<th>How it is given</th>
<th>Names of commonly used drugs</th>
</tr>
</thead>
<tbody>
<tr>
<td>LHRH agonists</td>
<td>injection (with or without anti-androgen tablets)</td>
<td>goserelin (Zoladex®, Novgos®) leuprolelin acetate (Prostap®, Lutrate®) buserelin acetate (Suprefact®) triptorelin (Decapeptyl®, Gonapeptyl Depot®)</td>
</tr>
<tr>
<td>GnRH antagonists</td>
<td>injection</td>
<td>degarelix (Firmagon®)</td>
</tr>
<tr>
<td>Anti-androgens</td>
<td>tablet</td>
<td>bicalutamide (Casodex®, flutamide (Drogenil®, cyproterone acetate (Cyprostat®,)</td>
</tr>
<tr>
<td>Oestrogens</td>
<td>tablet</td>
<td>diethylstilbestrol (Stilboestrol®)</td>
</tr>
</tbody>
</table>
New types of hormone therapy

**Abiraterone (Zytiga®)**
Abiraterone is a new type of hormone therapy, which is taken as a tablet. It stops testosterone being produced by the testicles and adrenal glands.

Abiraterone is suitable for men with advanced prostate cancer that has stopped responding to other types of hormone therapy. This means you won’t be offered it as your first hormone therapy.

If you’ve already had a type of hormone therapy called enzalutamide (see below), you may not be able to have abiraterone. To find out if you can have abiraterone, speak to your doctor or nurse or call our Specialist Nurses. Read more about abiraterone on our website at prostatecanceruk.org/abiraterone

**Enzalutamide (Xtandi®)**
Enzalutamide is a new type of hormone therapy for men with advanced prostate cancer that has stopped responding to other types of hormone therapy.

Enzalutamide may not be an option if you’ve already had abiraterone. Read more about this at prostatecanceruk.org/enzalutamide

For more information about treatments that can be used if your cancer is not responding as well to your first hormone therapy (including non-hormone treatments) read our fact sheet, **Treatment options after your first hormone therapy.**
The hormone therapy I’m having is called Zoladex®. It’s implanted every 12 weeks. They put it in just above the groin area – I call it a big injection. It’s a little pellet which they pop under the skin.

A personal experience
Which hormone therapy will I have?

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 prefer to have drugs or surgery to remove the testicles.

Talk to your doctor or nurse if you have any questions about which treatments are right for you or about the treatment you’re already having. If you’re unsure about anything, ask them to explain it and make notes if it helps.

Combined hormone therapy

Your specialist may suggest using both an LHRH agonist and an anti-androgen (see page 13) to treat the cancer. Some health professionals call this 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 is not commonly used as a first treatment for prostate cancer because it can increase the risk of side effects. Read about side effects on page 23.

Intermittent hormone therapy

You might be able to stop hormone treatment when your PSA level is low and steady, and start it again when your PSA starts to rise. This is called intermittent hormone therapy. It may help to give you a break from the side effects, but it can take several months before you may notice an improvement.
For some men intermittent hormone therapy can be just as effective at treating prostate cancer as continuous treatment. But it is not 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. This will normally be when your PSA rises to 10 ng/ml.

“I took anti-androgen tablets for a couple of weeks before starting injections. Hormone therapy brought my PSA right down. Since then, I’ve either been on hormone therapy, or on a holiday from it.”

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.

A personal experience
What are the advantages and disadvantages of hormone therapy?

Advantages

- It’s an effective treatment for controlling prostate cancer.
- It can treat prostate cancer wherever it is in the body.
- It can be used alongside other treatments to make them more effective.
- It can help to reduce some of the symptoms caused by advanced prostate cancer, such as urinary symptoms.

Disadvantages

- It can cause side effects that might have a big impact on your daily life (see page 23).
- Used by itself, hormone therapy cannot cure the cancer completely, but it can keep it under control for many months or years.

You can read more about the advantages and disadvantages of each type of hormone therapy in our fact sheet, Hormone therapy.
What are the side effects?

Like all treatments, hormone therapy can cause side effects. Make sure you discuss these with your doctor or nurse before you start treatment. You can also talk to our Specialist Nurses.

We’ve included the most common side effects and how to manage or reduce them. Hormone therapy affects men in different ways and you may not get all of the side effects we’ve listed. Some men have fewer side effects than others. This doesn’t mean that the treatment is any less effective.

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 your hormone therapy, your testosterone levels will gradually rise again and some of the side effects will reduce. This may take several months. Your side effects won’t stop as soon as you finish your hormone therapy.

Surgery to remove the testicles (orchidectomy) can’t be reversed, so the side effects can’t be reversed. 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 and can affect men on LHRH agonists or anti-androgens. They are similar to the hot flushes women get when they’re going through the menopause.

Up to eight out of ten men on LHRH agonists (80 per cent) get hot flushes. Some men find that their hot flushes get milder and happen less often over time, but other men find that they continue to have hot flushes for as long as they have hormone therapy. Hot flushes can vary from a few seconds of feeling overheated to a few hours of sweating which can be uncomfortable. 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. They can make some men feel irritable, uncomfortable and sometimes 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 washed out after having a hot flush. You might also find that you sweat at night, which can disrupt your sleep and cause tiredness.

If your symptoms are mild or not bothering you then you may not need treatment. But speak to your doctor or nurse if you find your symptoms 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. NHS Choices also provides advice.

- Try to stay a healthy weight. You can read more about this in our fact sheet, Diet and physical activity for men with prostate cancer.

- Make sure you drink enough. Aim for around six to eight glasses 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.

- Use light cotton bed sheets. If you sweat a lot at night, try using a cotton towel on top of your sheets that you can change easily.

- Wear cotton clothes, especially at night.

- Try having lukewarm baths and showers rather than hot ones.

You might find it helpful to keep a diary of your symptoms for a few weeks. This can help you work out if there are any situations, or particular drinks or foods that bring on a hot flush. The diary might also help you to decide whether to have treatment for your hot flushes.
As a keen do-it-yourself person, I love making and repairing things, but for the past few years this has been difficult due to sweating. As soon as I start a physical activity I break out in a heavy sweat and have to stop to cool down.

A personal experience

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. This is a man-made hormone which may help.

Other medicines that may help are a hormone called megestrol or an anti-androgen called cyproterone acetate. These are usually given if medroxyprogesterone doesn’t improve your hot flushes. A drug called gabapentin may also be helpful.

As with any drug, there is a risk of 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 or strokes, or problems with their liver. Your doctor or nurse will discuss this with you.
Complementary therapies
Complementary therapies are used alongside conventional treatments, rather than instead of them. There are many different complementary therapies available which might help with hot flushes. These include acupuncture, hypnotherapy, cognitive behavioural therapy, herbal remedies and homeopathy.

It is important that you tell your doctor about any complementary therapy you are having or are thinking about having. 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 will be able to 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, although we need more research to show whether these treatments work for all men.

- Acupuncture involves inserting fine sterile needles just below the skin. This shouldn’t hurt, but you might feel a tingling sensation.
- 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.
A small research study found that cognitive behavioural therapy (CBT) helped women cope with hot flushes. Another small study is now looking at whether this approach could help men on hormone therapy deal with their hot flushes. CBT is a therapy that helps you manage problems by helping you to think in a positive way. You can find more information at www.nhs.uk

Some men have found that herbal remedies can help. Herbal remedies use plants or plant extracts. However, there is no scientific evidence that these are effective. Check with your doctor that these are safe for you.

- Sage tea, evening primrose oil and red clover are all herbal remedies.
- Black cohosh is a herb which can be bought as a supplement. There is a small possibility that it may cause liver damage. This is rare, but you should not take it if you have ever had liver or kidney disease.

Not all herbal remedies in the UK are licensed, and the quality varies greatly. Be particularly careful about buying herbal remedies over the internet. Many are manufactured outside the UK and may not be regulated.

Many companies make claims that are not based on proper research, and there may be no real evidence to show they work. Remember that a product is not necessarily safe because it is called ‘natural’. Some herbal remedies may artificially reduce your PSA level, making the PSA test unreliable.
Macmillan Cancer Support and Cancer Research UK have more information on complementary therapies available, and important safety issues to consider when choosing a therapy.

"One of the major side effects of the treatment is the hot flushes. 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

Changes to your sex life

Having hormone therapy affects your sex life in different ways.

- It changes your desire for sex (libido) and may mean you have much less interest in sex.

- It can cause problems getting or keeping an erection (erectile dysfunction).

In most cases, these effects last for as long as you are on hormone therapy. It can take up to a year for sexual function to gradually return to normal after stopping hormone therapy. Very occasionally, 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.
**Desire for sex (libido)**

All types of hormone therapy will change your sex drive and may mean you have less interest in sex. This is because hormone therapy lowers your level of testosterone, which is what gives you your sex drive.

Testosterone is not the only thing that can affect your sex drive. Other physical and emotional factors can also affect how you feel about sex.

- Some men describe feeling like they have lost their self-esteem and confidence, particularly around their masculinity.
- If you are feeling depressed or anxious then you may be less interested in sex.
- Treatment can cause tiredness and mean you have no energy for sex.
- You might feel worried or embarrassed about physical changes after hormone therapy – such as putting on weight (see page 39), changes to the size of your penis (see page 33), or breast swelling (see page 41).

If you have a partner, their desire for sex might also change after your diagnosis and during treatment. If they are feeling anxious, they may have less interest in sex. Dealing with a cancer diagnosis and treatment can also put a strain on relationships. This can affect how you and your partner feel about sex.
Your desire to have sex wanes, it disappears and I am more conscious now of, ‘do I want to have sex?’ But it doesn’t mean that I can’t have an interesting sex life.

A personal experience

Erection problems
All types of hormone therapy can cause problems getting or keeping an erection (erectile dysfunction or ED). Having less interest in sex can also play a part.

Anti-androgen tablets are less likely to cause erection problems than other types of hormone therapy. But if you have advanced prostate cancer, anti-androgens taken on their own are not as effective at controlling the cancer as other types of hormone therapy.

What can help?
Men with prostate cancer can get free medical treatment for problems with erections or other sexual problems on the NHS. Your GP or doctor or nurse at the hospital can prescribe treatment. Treatments are available to you whether you’re single or in a relationship. You can also be referred to a specialist service such as an erectile dysfunction (ED) clinic.
There are different treatments for erection problems available. Your doctor may first suggest you try tablets that belong to a group of medicines called PDE5 inhibitors, for example sildenafil (Viagra®). Tablets such as sildenafil might not work for everyone, especially if your hormone therapy is affecting your desire for sex. But there are many other treatments that can help give you an erection without sexual desire.

For more information about treatments to help with getting an erection read our booklet, *Prostate cancer and your sex life*.

Try not to be embarrassed to go and talk to your doctor or nurse. Remember that they will have talked about these problems 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.

If you are finding it difficult to deal with losing your desire for sex or problems with erections, intermittent hormone therapy might be an option (see page 18). Your sexual function may improve during your break from treatment. Speak to your doctor about this.

**Changes to ejaculation and orgasm**
You may notice that you produce less semen while you are on hormone therapy. You will still have feeling in your penis and 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.
The main side effect has been dry orgasms and a reduced libido. No hot flushes or tiredness so far. I was informed from the outset that my sex life may be over but that hasn’t been the case. I have no problems with erections and don’t require chemical assistance.

A personal experience

Changes in penis and testicle size
Hormone therapy can make your penis shorter. It can also make your testicles smaller. Treatments for erection problems, such as using a vacuum pump, might help to keep the penis tissue healthy and in good working order.

If you put on weight because of your hormone therapy, you might find it harder to see your penis. This could mean that you don’t aim so well when urinating. Problems with aim, or a smaller penis, mean that some men prefer to sit rather than stand when they urinate.

Dealing with these changes
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’s easier for them to come to terms with problems getting an erection. But for others, these changes can be a big loss.
Yes we still have sex, but in different ways and with a little bit of medical intervention. It’s more about thinking, ‘okay, maybe we don’t want to have sex, maybe we want to go and have a curry, maybe we want to go to the pictures, maybe we just want to lie on the bed and cuddle’.

A personal experience

What can help?
If you have a partner, talking about sex, your thoughts and feelings can help you both deal with any changes. It is not 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 finding it difficult to talk about sex, it might help to see a sex therapist (a psycho-sexual counsellor). They help people who are having sexual problems or experiencing difficulties in their sexual relationship. Your GP, doctor or nurse may be able to refer you to a sex therapist, but this type of therapy is not always available on the NHS. You can find a therapist yourself by contacting the College of Sexual and Relationship Therapists. The organisation Relate provides relationship counselling and other support services.
Remember, having sex is not 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’s no 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.

Read our booklet, **Prostate cancer and your sex life** for more information and support. It offers practical tips to help with sex and relationships.

**Watch Bruce’s story**
Find out more about how hormone therapy can affect your sex life.

**Are you gay or bisexual?**
If you are gay or bisexual, the side effects of hormone therapy will affect you in many of the same ways as straight men, but you may find that you have some specific issues as well.

**Watch Martin’s story**
For one gay man’s experience of how hormone therapy affected his sex life.

There is information to help you in our booklet, **Prostate cancer and your sex life** – whether you are gay, bisexual, straight or transgender.
At first I was concerned when they told me my sex drive and performance would be affected. However, a loss of drive alongside reduced performance is not a problem for me. A reduced performance with continued strong drive would be.

A personal experience

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 come to terms with changes in their body image or their ability to perform sexually. They might avoid intimate situations where they may feel under pressure to have sex. Some men might distance themselves from close relationships. But this doesn’t mean that they no longer care for their partner or loved ones.

It is also important to get some support for yourself. All of Prostate Cancer UK’s services are also open to you. And the Sexual Advice Association offers information and support for partners.
I don’t ejaculate anymore, although I can orgasm. There is a whole list of things that affect me but they can all be treated pretty successfully.

A personal experience
Extreme tiredness (fatigue)

Hormone therapy for prostate cancer can cause extreme tiredness. Some men experience tiredness that affects their everyday life. Fatigue can affect your energy levels, your motivation and your emotions. Some men find that tiredness can come on quite suddenly, which means that you need to be careful in certain situations – for example, when you are driving. Talk to your doctor or nurse about how tiredness is affecting you. There are ways to help manage it.

Fatigue can also have other causes such as the cancer itself or other conditions, such as a reduced number of red blood cells (anaemia) or depression.

What can help?

You might find that your tiredness improves over time. And there are changes you can make to your lifestyle that could help, including:

• being as physically active as you’re able
• organising your day
• planning activities for when you know you will have more energy
• dealing with any problems sleeping
• eating healthily
• complementary therapies.

Some of these changes may be difficult to make, so take things gradually.

Ask your doctor or nurse about help to start a regular exercise routine. Research shows that doing exercises such as swimming or fast walking at least twice a week for 12 weeks can help men on hormone therapy to reduce their fatigue.
Our fatigue support service

Our fatigue support service is a 10-week telephone service delivered by our Specialist Nurses. It can help if you have problems with extreme tiredness (fatigue). The fatigue support service can help you make positive changes to your behaviour and lifestyle, which can improve your fatigue over time. Visit prostatecanceruk.org/fatigue

There is also more information on ways to manage fatigue in our fact sheet, **Fatigue and prostate cancer.**

"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."

A personal experience

**Weight gain**

Some men put on weight while they are on hormone therapy, particularly around the waist. You may find that you 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 weight that you may have 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.

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 the amount of body fat. This can change the way your body looks and how physically strong you feel.

What can help?
Regular gentle resistance exercise, such as lifting light weights or using elastic resistance bands, can help to reduce 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 who can give advice and suggest a specific exercise programme for your needs. If you can’t move about easily, a physiotherapist can give you some gentle exercises to do at home.

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

Hormone therapy may cause swelling (gynaecomastia) and tenderness in the chest area. This is caused by the effect that hormone therapy has on the balance of the hormones oestrogen and testosterone in the body. The amount of swelling can vary from a small amount of swelling to a more noticeably enlarged breast. Tenderness can affect one or both sides of the chest and can range from mild sensitivity to ongoing 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 taking an LHRH agonist or GnRH antagonist, have had surgery to remove the testicles, or are having combined hormone therapy (see page 18). Most men taking a high dose of the anti-androgen bicalutamide for more than six months will get breast swelling.

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:

- treating the breast area with a single dose of radiotherapy
- tablets called tamoxifen
- surgery to remove some of the breast tissue.
If you are about to start anti-androgens, your doctor will suggest treating the breast area with a low dose of radiotherapy. This can reduce the risk of breast swelling and tenderness. It has to be done within a month of starting hormone therapy because it won’t work once swelling has already happened. Side effects include the skin becoming red, darker or irritated, but this usually clears up in three to five weeks. You may also lose your chest hair in the area that is treated. Sometimes chest hair doesn’t grow back.

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.

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 aren’t able to reduce the breast swelling.

Watch Bruce’s story for his experience of breast swelling.
Loss of body hair

Some men find that they 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. The hair should grow 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 within 6 to 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.

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

Your doctor may suggest you have a type of X-ray called a DEXA scan, before you start hormone therapy. This checks for any signs of bone thinning. Some men may also need to have scans regularly during hormone therapy treatment. You can talk to your doctor about whether you might need a scan.

What can help?

Lifestyle changes
There are a number of lifestyle changes that may help to reduce your risk of bone thinning and of developing osteoporosis.
Make sure you get enough calcium and vitamin D in your diet. Calcium and vitamin D are important for strong bones. You should aim for 1200-1500mg of calcium each day. You can get calcium from dairy foods (cheese, milk and yoghurt) and non-dairy foods (like tinned sardines with the bones, tofu and kale).

The main source of vitamin D is exposure to sunlight. About 15 minutes of sun exposure around the middle of the day, two or three times a week between April and September, should provide enough vitamin D for the year. You can also get it from eating oily fish such as sardines, pilchards, mackerel and salmon, as well as foods fortified with vitamin D such as breakfast cereals. You may need to take calcium and vitamin D supplements – speak to your doctor about this.

Cut down on alcohol. Drinking too much can increase your risk of osteoporosis. Government 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 stopping. NHS Choices also has advice.

Exercise regularly. Regular exercise may help to keep you strong and prevent falls which could lead to bone fractures. Walking, swimming and gentle resistance exercise, such as lifting light weights, can 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.**
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 National Osteoporosis Society has more information.

**Treatments to manage bone thinning**
Bisphosphonates are drugs that are used to treat bone pain in men with advanced prostate cancer. They are also used to treat osteoporosis in men on hormone therapy.

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

Denosumab (Xgeva®) is a new drug for treating bone problems. It’s usually only available on the NHS for men on hormone therapy who have osteoporosis but who are not able to have bisphosphonates.

If you live in England and your doctor thinks it is suitable for you, they may be able to apply to get it for you. If you live in Scotland, Wales or Northern Ireland, your doctor may be able to apply for it for you, but there is no guarantee that they’ll be able to get it.
Risk of heart disease, stroke and Type 2 diabetes

Evidence suggests that having hormone therapy might increase the chance of developing heart disease, stroke and Type 2 diabetes. More research is needed to help us understand the link between these conditions. Research shows that hormone therapy can cause:
- an increase in weight, particularly around the tummy (see page 39)
- an increase in cholesterol levels
- changes in insulin.

Talk to your hospital doctor and GP about how often you should have regular health checks.

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.

While the risk of getting these conditions may be worrying, it’s important to remember that hormone therapy helps men to live longer by controlling your cancer.

What can help?

A healthy lifestyle can help reduce your risk of heart disease, stroke and diabetes. This includes:
- eating a healthy diet
- being physically active
- limiting the amount of salt you eat
- stopping smoking
- cutting down on alcohol.

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.
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 67). An unusual side effect is one that isn’t mentioned in the leaflet that comes with your medicine or herbal remedy.

“I have put on weight, which I can get rid of – that is up to me – but the treatment does enhance it, it does make it worse.”

A personal experience
With hormone therapy, it does make you quite down, it does make you quite tearful. But you learn to recognise when it’s coming on and you can do things to deal with it.

A personal experience
How might hormone therapy make me feel?

Hormone therapy itself can affect your mood. You may find that you feel more emotional than usual or just different to how you felt before. Some men find that they cry a lot. You may also find that you get mood swings, such as getting tearful and then angry. Just knowing that these feelings are caused by hormone therapy can help.

Everyone’s different – some men are surprised by the side effects and how upsetting they find them. Others have fewer symptoms or are not as worried by them.

Some of the other 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. Sometimes men describe feeling less masculine as a result of their diagnosis and treatment.

If you’re starting hormone therapy very soon after being diagnosed with prostate cancer, you might still feel upset, shocked, frightened or angry about having cancer.

Things in your day-to-day life can change because of the hormone therapy. Your role in 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.

Some men experience low moods, anxiety or depression. This could be as a direct result of hormone therapy, a response to being diagnosed with prostate cancer, or the impact of treatment and the cancer on your life.
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 or nurse at the hospital. These can be signs of depression and there are treatments available for depression.

Watch Bruce’s story
Find out how hormone therapy has affected him emotionally.

What can help?
Some men find their own way to cope and might not want any outside help. Others try to cope on their own because they don’t want to talk about things or are afraid of worrying loved ones. It’s good to talk but go easy on yourself, and give yourself time to deal with your feelings.

Talking about it
Sometimes talking about how you feel can help. You might be able to get support from talking to family or friends. Or talking to your doctor or nurse might help. You could also speak in confidence to our Specialist Nurses.

You might find it helps to talk to someone who’s been there. The volunteers on our one-to-one 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. Call our Specialist Nurses to be put in touch with a support volunteer.
There are also support groups across the country where you and your family can meet others affected by prostate cancer. You can find details of support groups at prostatecanceruk.org/support-groups or ask your nurse.

If you have access to the internet, you could join our online community where you can talk to other people with prostate cancer and their families. You can join the online community at prostatecanceruk.org

There is nothing like talking to someone who has been there.
A personal experience

Counselling
It’s sometimes difficult to talk to people close to you. Some people find it easier to talk to someone they don’t know. Counsellors are trained to listen and can help you understand your feelings and find your own answers. Your GP may be able to refer you to a counsellor or you can pay to see one yourself. There are different types of counselling available. To find out more contact the British Association for Counselling & Psychotherapy.
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 or meditation
• regular physical activity
• trying to keep up with your usual hobbies and social activities or trying some new ones – some men say that 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 Centres, Self Management UK and Penny Brohn UK run free courses for people living with cancer. Ask your nurse, GP or support group if they run training days or if they invite health professionals to give talks.

Read our booklet, Living with and after prostate cancer: A guide to physical, emotional and practical issues, for more information.

Treatments for depression
If you are feeling depressed or anxious, anti-depressant medicines are one of the treatment options that may help. Let your GP know if you think you are depressed so that they can help find the right treatment for you. 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 are taking.
You and your partner

If you have a partner, they may feel worried, anxious or upset about your cancer. They might feel isolated and find it difficult to tell you how they are feeling for fear of worrying you. You can get support together. Sometimes it can also be useful to get separate support as well.

Doctors and nurses are always happy for you to bring your partner along to your appointments, and they might be able to direct you to the type of support that would suit you both. Many support groups also welcome partners. The charity Relate provides relationship counselling and other support services.

Your partner might find our booklet, When you’re close to a man with prostate cancer: A guide for partners and family, helpful.
If you’ve got issues, if you’ve got concerns, if you’ve got worries, talk about them. My wife is very good at comforting me when I’m feeling down.

A personal experience
How will my treatment be monitored?

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 as it will depend on the stage of your treatment.

If your PSA level falls, this usually suggests your treatment is working. How quickly your PSA level falls, and how low, will vary from man to man.

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 grow more quickly.

Your doctor or nurse will also keep an eye on your side effects or symptoms. Let them know if there are any changes while you are on hormone therapy.

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.
I’d got to the point of wanting to stop the hormone treatment but I took a look at the things I’m not happy about and made some small changes that are making a difference.

A personal experience
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. They will explain how this will affect your cancer and discuss any other possible treatments or options.

You might be able to have intermittent hormone therapy (see page 18), although this isn’t suitable for all men.

The side effects won’t stop as soon as you stop hormone therapy. It may take several months for the side effects to improve.
My team members

Use this space to record names and contact details of the team of health professionals involved in your care. You may hear this called your multi-disciplinary team (MDT). We’ve listed the health professionals you are most likely to see, but you might not see all of them.

Main contact
Your main point of contact might be called your key worker. This could be your specialist nurse or another health professional. They will help to co-ordinate your care, guide you to the appropriate team member and tell you where you can get information.

Name

Telephone no.

Out of hours contact details

Notes

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

Name

Telephone no.

Out of hours contact details

Notes
**Consultant oncologist**
This type of doctor specialises in treating cancer with treatments other than surgery.

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**Consultant urologist**
This type of doctor is a surgeon who specialises in the urinary system, which includes the prostate.

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**GP (general practitioner)**
Your GP and your practice or district nurse will help to co-ordinate your care and can offer you support through diagnosis and treatment. They will keep in touch with your MDT 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.

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**Out of hours doctor’s surgery contact details**

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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, dietitian, sexual dysfunction clinician, continence nurse or physiotherapist.

Name
Telephone no.
Notes

Name
Telephone no.
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Name
Telephone no.
Notes

Prostate Cancer UK Specialist Nurses 0800 074 8383.
# 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.

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# Appointments

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

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### PSA levels

You can 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.

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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 pack.

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

Call 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

* 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 883300
Information about counselling and details of therapists in your area.

British Heart Foundation
www.bhf.org.uk
Telephone 0300 330 3311
Information about heart disease and eating for a healthy heart.

Cancer Research UK
www.cancerresearchuk.org
Telephone: 0808 800 4040
Patient information from Cancer Research UK.

Carers UK
www.carersuk.org
Telephone: 0808 808 7777
Information and advice for carers, and details of local support groups.

College of Sexual and Relationship Therapists (COSRT)
www.cosrt.org.uk
Telephone: 020 8543 2707
Information about sexual and relationship therapy, and details of therapists who meet national standards.

Complementary and Natural Healthcare Council (CNHC)
www.cnhc.org.uk
Telephone: 020 3668 0406
Details of complementary therapists who meet national standards.
Diabetes UK
www.diabetes.org.uk
Telephone: 0345 123 2399
Information about diabetes.

Macmillan Cancer Support
www.macmillan.org.uk
Telephone: 0808 808 00 00
Practical, financial and emotional support for people with cancer, their family and friends.

Maggie’s Centres
www.maggiescentres.org
Telephone: 0300 123 1801
A network of drop-in centres for cancer information and support. Includes an online support group.

Medicines and Healthcare products Regulatory Agency (MHRA)
www.mhra.gov.uk
Telephone: 020 3080 6000
Advice about how to use herbal remedies safely. Also runs the Yellow Card Scheme, a system for reporting unusual side effects from any treatment, including herbal remedies.

National Osteoporosis Society
www.nos.org.uk
Telephone: 0808 800 0035
Information and support for people with weak bones.

NHS Choices
www.nhs.uk
Information about treatments, conditions and lifestyle. Support for carers and a directory of health services in England.
Penny Brohn UK
www.pennybrohn.org.uk
Telephone: 0303 3000 118
Runs courses and offers physical, emotional and spiritual support for people with cancer and those close to them.

Relate
www.relate.org.uk
Telephone: 0300 100 1234
Information, advice, relationship counselling and sex therapy. In Scotland, contact Relationships Scotland instead.

Relationships Scotland
www.relationships-scotland.org.uk
Telephone: 0345 119 2020
Information, advice, relationship counselling and sex therapy.

Samaritans
www.samaritans.org
Telephone: 116 123
Confidential, judgement-free emotional support, 24 hours a day.

Self Management UK
www.selfmanagementuk.org
Telephone: 03333 445 840
Free self-management courses in England (and online in parts of Wales) – to help you take control and manage your condition.

Sexual Advice Association
www.sexualadviceassociation.co.uk
Information about treatment for sexual problems including erection difficulties.
About us

Prostate Cancer UK has a simple ambition: to stop men dying from prostate cancer – by driving improvements in prevention, diagnosis, treatment and support.

At Prostate Cancer UK, we take great care to provide up-to-date, unbiased and accurate facts about prostate cancer. We hope these will add to the medical advice you have had and help you to make decisions. Our services are not intended to replace advice from your doctor.

References to sources of information used in the production of this booklet are available at prostatecanceruk.org

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- Our Specialist Nurses
- Our Volunteers.
Living with hormone therapy
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Did you find this information useful? Would you like to help others in your situation access the facts they need? Every year, 40,000 men face a prostate cancer diagnosis. Thanks to our generous supporters, we offer information free to all who need it. If you would like to help us continue this service, please consider making a donation. Your gift could fund the following services:

• £10 could buy a Tool Kit – a set of fact sheets, tailored to the needs of each man with vital information on diagnosis, treatment and lifestyle.

• £25 could give a man diagnosed with prostate cancer unlimited time to talk over treatment options with one of our specialist nurses.

To make a donation of any amount, please call us on 0800 082 1616, visit prostatecanceruk.org/donate or text PROSTATE to 70004†. There are many other ways to support us. For more details please visit 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