

Prostate cancer

A guide for men who've
just been diagnosed



**PROSTATE
CANCER UK**

About this booklet

This booklet is for men who've recently been diagnosed with prostate cancer. Your partner, family or friends might also find it helpful. We explain what prostate cancer is, the tests you may have to diagnose it, and the treatment options available. There's also information about where you can get support if you need it.

You can use this booklet as your personal guide and write down any information that might be helpful to you in the blue shaded areas towards the back.

Each hospital will do things slightly differently. Use this booklet as a general guide to what to expect and ask your doctor or nurse for more details about your care and the support available to you. You can also speak to our Specialist Nurses, in confidence, on 0800 074 8383 or chat to them online.

This booklet is also available in large print.

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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If you've just been diagnosed with prostate cancer

If you've just been diagnosed with prostate cancer, you might feel scared, worried, stressed or even angry. There's no right way that you're supposed to feel and everyone reacts in their own way.

When you're told you have cancer, it can be a shock and you might find it difficult to take everything in. You may have lots of questions about your cancer and treatment.

You may feel anxious about the future and how having prostate cancer will affect your life and your loved ones. It can also be difficult and stressful trying to think about treatment.

There are people who are there to support you and there are also things you can do to help yourself. Families can also find this a difficult time and they may need support too.

You might find it helpful to read about prostate cancer and treatment options. And you can read more about getting support on page 41. Or you can call our Specialist Nurses.



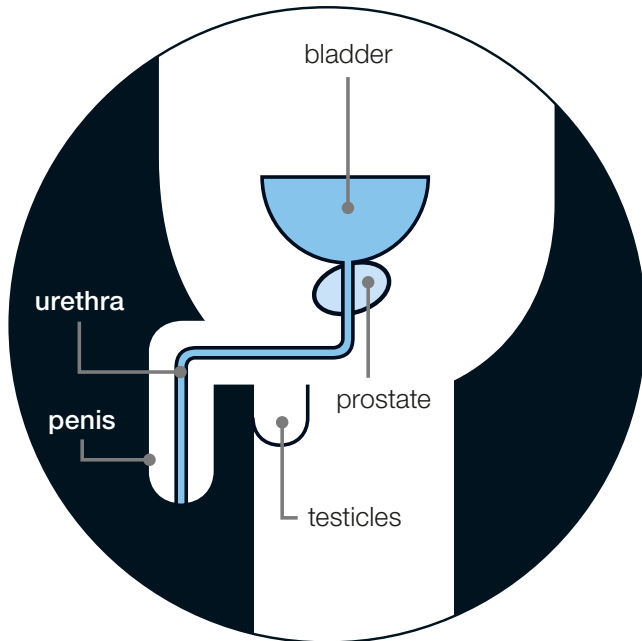
The Specialist Nurses were there for me on the day I was diagnosed. They talked me through the scenarios and possible treatments.

A personal experience

What is the prostate?

Only men have a prostate. The prostate is usually the size and shape of a walnut. It sits underneath the bladder and surrounds the urethra, which is the tube men urinate (pee) and ejaculate through.

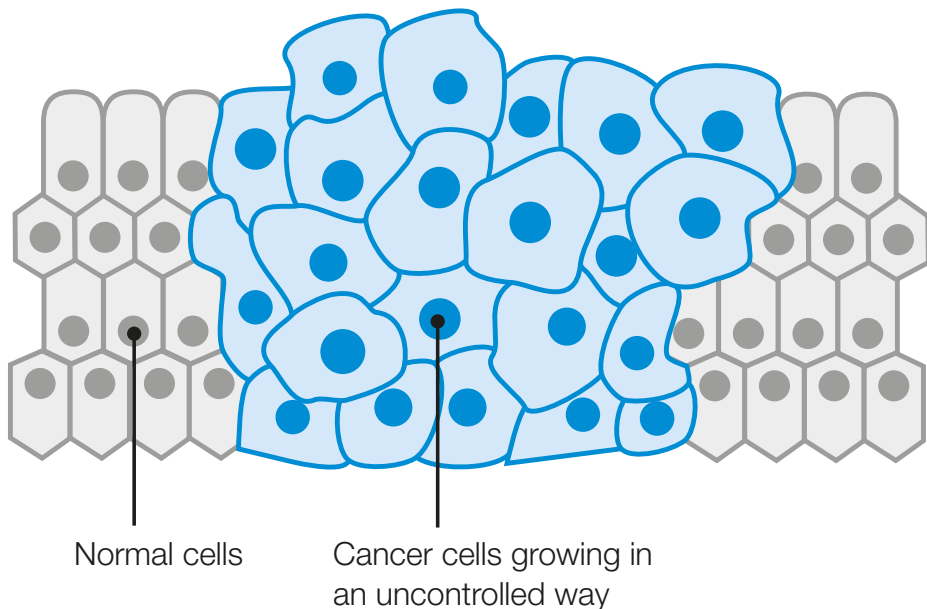
The prostate is a gland. Its main job is to help make semen – the fluid that carries sperm.



What is prostate cancer?

Normally the growth of all cells is carefully controlled in the body. As cells grow old and die, new cells take their place. Cancer can develop when cells start to grow in an uncontrolled way. If this happens in your prostate, you have prostate cancer.

How cancer develops



Prostate cancer is the most common cancer in men in the UK.

Most prostate cancer grows slowly or doesn't grow at all. It may never cause any problems or shorten a man's life. But some prostate cancer grows quickly and is more likely to spread to other parts of the body and cause problems. This needs treatment to help prevent it spreading outside the prostate.

Most men with early prostate cancer don't have any symptoms. Some men have had tests for prostate cancer because they had urinary problems. But urinary problems are usually caused by other things that aren't cancer.

In the UK, about 1 in 8 men will be diagnosed with prostate cancer at some point in their lives. And you're more likely to get prostate cancer if you're aged 50 or over, you are black, or your father or brother has had it.

Find out more about prostate cancer by watching our online video, **Understanding your prostate cancer** at prostatecanceruk.org/just-diagnosed-video

How is prostate cancer diagnosed?

Prostate cancer is diagnosed using a number of tests, which we describe on the following pages. You might have already had some of these, but you may need further tests to find out whether the cancer has spread and how aggressive it is. You may not need to have all of these tests, and you might not have them in this order.



Read more about these tests in our fact sheet, **How prostate cancer is diagnosed**.

PSA test

This is a blood test that measures the amount of prostate specific antigen (PSA) in your blood. PSA is a protein produced by normal cells in your prostate and also by prostate cancer cells. It's normal to have a small amount of PSA in your blood, and the amount rises as you get older.



Read more in our booklet, **Understanding the PSA test: A guide for men concerned about prostate cancer**.

Digital rectal examination (DRE)

This is where the doctor feels your prostate through the wall of the back passage (rectum). They'll wear gloves and put some gel onto their finger to make it more comfortable. They'll feel your prostate for any hard or lumpy areas and to get an idea of its size.

MRI scan

An MRI (magnetic resonance imaging) scan uses magnets to create a detailed picture of your prostate and the surrounding tissues.

In some hospitals you might have a special type of MRI scan, called a multi-parametric MRI (mpMRI) scan, before having a biopsy (see below). This can help your doctor see if there is any cancer inside your prostate, and how quickly any cancer is likely to grow. In other hospitals, you may have a biopsy first, followed by an MRI scan to see if any cancer found inside the prostate has spread.

Prostate biopsy

This involves using thin needles to take small pieces of tissue from the prostate. The tissue is then looked at under a microscope to check for cancer.

There are two main types of biopsy.

- A trans-rectal ultrasound (TRUS) guided biopsy is where the needle goes through the wall of the back passage. You will have a local anaesthetic, which numbs the area around your prostate.
- A template (transperineal) biopsy is where the needle goes through the skin between the testicles and the back passage. You will have a general anaesthetic, so you will be asleep and won't feel anything.

CT scan

A CT (computerised tomography) scan can also show whether the cancer has spread outside the prostate, for instance to the lymph nodes or nearby bones. Lymph nodes are part of your immune system and are found throughout your body.

Bone scan

A bone scan can show whether any cancer cells have spread to your bones. A small amount of a safe radioactive dye is injected into a vein in your arm before you have the scan. If there is any cancer in the bones, the dye will collect in these areas and show up on the scan.

PET scan

At some hospitals, you may be offered a PET (positron emission tomography) scan. This shows how well different parts of your body are working. It can be used to check if cancer has spread outside the prostate. It is normally used to see if your cancer has come back after treatment.

What do my test results mean?

Your doctor will use the results of all your tests to find out if the cancer has spread outside the prostate and how quickly it is growing. Ask your doctor or nurse to explain your test results if you don't understand them.

PSA level

It's normal to have a small amount of PSA in your blood, and the amount rises as you get older. Prostate cancer can raise your PSA level. But other things can raise your PSA level too – including a urine infection, an enlarged prostate and vigorous exercise, especially cycling. And some men with a normal PSA level can have prostate cancer.

You may have had a PSA test that showed your PSA was raised, and then had other tests to diagnose your prostate cancer.

Biopsy results

Your biopsy samples will be looked at under a microscope to check for any cancer cells. Your doctor will be sent a report, called a pathology report, with the results. The results will show:

- whether any cancer was found
- how many biopsy samples contained cancer
- how much cancer was present.

You might be sent a copy of the pathology report. And you can ask to see copies of letters between the hospital and your GP. If you have trouble understanding any of the information, ask your doctor to explain it. Or you could call our Specialist Nurses.



Your biopsy results will show how aggressive the cancer is – in other words, how likely it is to grow and spread outside the prostate. You might hear this called your Gleason grade, Gleason score or grade group.

Gleason grade

When cells are seen under the microscope, they have different patterns, depending on how quickly they're likely to grow. The pattern is given a grade from 1 to 5 – this is called the Gleason grade. Grades 1 and 2 are not cancer, and grades 3, 4 and 5 are cancer. If you have cancer, the higher your grade, the more likely the cancer is to grow and spread outside the prostate.

Gleason score

There may be more than one grade of cancer in your biopsy samples. Your Gleason score is worked out by adding together two Gleason grades.

The first is the most common grade in all the samples. The second is the highest grade of what's left. When these two grades are added together, the total is called the Gleason score.

Gleason score = the most common grade + the highest other grade in the samples

For example, if the biopsy samples show that:

- most of the cancer seen is grade 3, and
- the highest grade of any other cancer seen is grade 4, then
- the Gleason score will be 7 (3 + 4).

Your Gleason score will be between 6 (3 + 3) and 10 (5 + 5).

Some men will only be told their total Gleason score and not their Gleason grades.

Grade group

Your doctor might also talk about your 'grade group'. This is a newer system for showing how aggressive your prostate cancer is likely to be. Your grade group will be a number between 1 and 5.

Ask your doctor or nurse for more information about your grade group, or speak to our Specialist Nurses.



What does the Gleason score or grade group mean?

The higher the Gleason score or grade group, the more aggressive the cancer and the more likely it is to spread. The table on page 14 describes the different Gleason scores and grade groups that can be given after a prostate biopsy. This is just a guide. Your doctor or nurse will talk you through what your results mean.

Gleason score	Description	Grade group
6 (3 + 3)	All of the cancer cells found in the biopsy look likely to grow slowly.	1
7 (3 + 4)	Most of the cancer cells found in the biopsy look likely to grow slowly. There are some cancer cells that look likely to grow at a moderate rate.	2
7 (4 + 3)	Most of the cancer cells found in the biopsy look likely to grow at a moderate rate. There are some cancer cells that look likely to grow slowly.	3
8 (3 + 5)	Most of the cancer cells found in the biopsy look likely to grow slowly. There are some cancer cells that look likely to grow quickly.	4
8 (4 + 4)	All of the cancer cells found in the biopsy look likely to grow at a moderate rate.	
8 (5 + 3)	Most of the cancer cells found in the biopsy look likely to grow quickly. There are some cancer cells that look likely to grow slowly.	
9 (4 + 5)	Most of the cancer cells found in the biopsy look likely to grow at a moderate rate. There are some cancer cells that are likely to grow quickly.	5
9 (5 + 4)	Most of the cancer cells found in the biopsy look likely to grow quickly. There are some cancer cells that look likely to grow at a moderate rate.	
10 (5 + 5)	All of the cancer cells found in the biopsy look likely to grow quickly.	

What stage is my cancer?

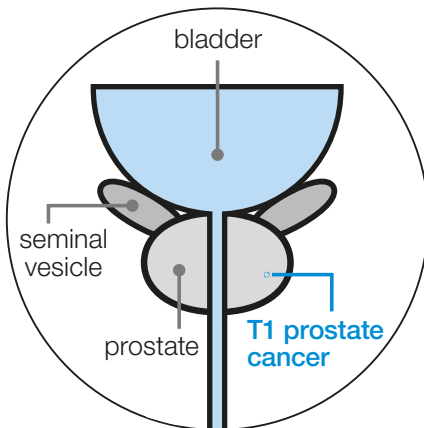
You might need scans to find out the stage of your cancer – in other words, how far it has spread. You might have an MRI, CT or bone scan. The results should help you and your doctor decide which treatments might be suitable for you.

You might not need a CT or bone scan if your PSA is low and your biopsy results suggest that the cancer is unlikely to have spread.

The most common way to record the stage of your cancer is the TNM (Tumour-Nodes-Metastases) system.

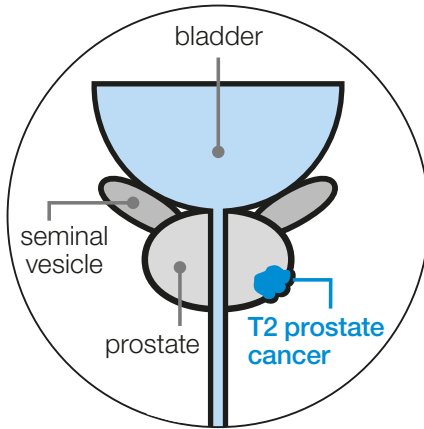
T stage

The T stage shows how far the cancer has spread in and around the prostate. A digital rectal examination (DRE) or MRI scan is usually used to find out the T stage, and sometimes a CT scan.

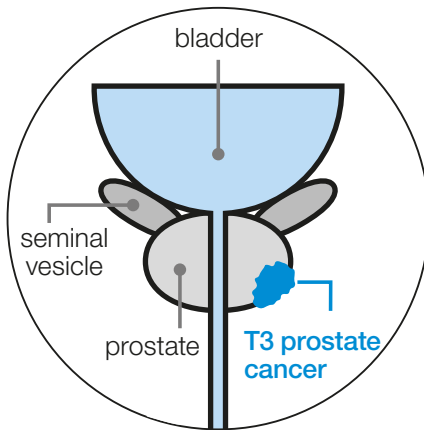


T1

The cancer can't be felt during a DRE or seen on scans, and can only be seen under a microscope.

**T2**

The cancer can be felt during a DRE or seen on scans, but is still contained inside the prostate.

**T3**

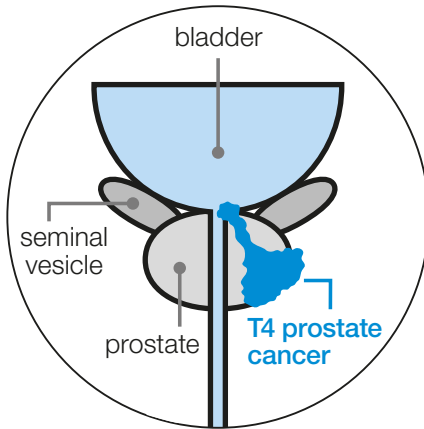
The cancer can be felt during a DRE or seen breaking through the outer layer (capsule) of the prostate.

T3a

The cancer has broken through the outer layer of the prostate, but has not spread to the seminal vesicles (which produce some of the fluid in semen).

T3b

The cancer has spread to the seminal vesicles.



T4

The cancer has spread to nearby organs, such as the bladder, back passage, pelvic wall or lymph nodes.

N stage

The N stage shows whether the cancer has spread to the lymph nodes near the prostate. Lymph nodes are part of your immune system and are found throughout your body. The lymph nodes near your prostate are a common place for prostate cancer to spread to. An MRI or CT scan is used to find out your N stage.

The possible N stages are:

- NX** The lymph nodes were not looked at, or the scans were unclear.
- N0** No cancer can be seen in the lymph nodes.
- N1** The lymph nodes contain cancer.

M stage

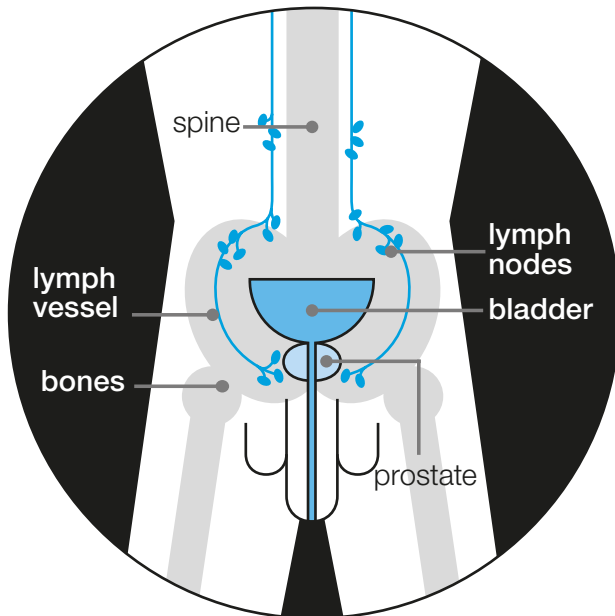
The M stage shows whether the cancer has spread (metastasised) to other parts of the body, such as the bones. A bone scan is usually used to find out your M stage. Your doctor may offer you a bone scan if they think your cancer may have spread. Cancer that has spread to other parts of the body is called advanced prostate cancer.

The possible M stages are:

- MX** The spread of the cancer wasn't looked at, or the scans were unclear.
- M0** The cancer hasn't spread to other parts of the body.
- M1** The cancer has spread to other parts of the body.

How prostate cancer spreads

Prostate cancer cells can move from the prostate to other parts of the body through the blood stream. Or they can spread to the lymph nodes near the prostate and then travel through the lymph vessels to other parts of your body. Lymph nodes and lymph vessels are part of your lymphatic system, and are found throughout your body.



What does my stage mean?

Your TNM stage is used to work out if your cancer is localised, locally advanced or advanced.

Stage	Description	T stage	N stage	M stage
Localised	Cancer that's contained inside the prostate.	T1 or T2	N0 or NX	M0 or MX
Locally advanced	Cancer that's started to break out of the prostate, or has spread to the area just outside it.	T1 or T2	N1	M0
		T3 or T4	N0 or N1	M0
Advanced	Cancer that's spread from the prostate to other parts of the body. Also known as metastatic prostate cancer.	Any T stage	Any N stage	M1

Localised prostate cancer

Localised prostate cancer is cancer that's contained inside the prostate. You may also hear it called early prostate cancer. Many localised cancers are not aggressive and grow slowly or not at all. They may not cause any problems or shorten your life. Slow-growing localised prostate cancer may not need to be treated and can often be monitored instead. But some localised cancers may grow more quickly and spread to other parts of the body. These cancers are more likely to cause problems and need to be treated. Treatments for localised prostate cancer usually aim to get rid of the cancer. There are a number of treatments for localised prostate cancer (see page 23). Read more in our fact sheet,



Localised prostate cancer.

Locally advanced prostate cancer

Locally advanced prostate cancer is cancer that's started to break out of the prostate, or has spread to the area just outside it. It can spread to the seminal vesicles, the bladder, back passage, pelvic wall or lymph nodes near your prostate. You might have treatment to get rid of the cancer or to keep it under control. Your treatment options will depend on how far the cancer has spread. Read more



in our fact sheet, **Locally advanced prostate cancer.**

Advanced prostate cancer

Advanced prostate cancer is cancer that has spread from the prostate to other parts of the body. It's also called metastatic prostate cancer. Prostate cancer can spread to any part of the body, but it most commonly spreads to the bones and lymph nodes.

It's not possible to cure advanced prostate cancer, but treatments can keep it under control, sometimes for several years.

Advanced prostate cancer can cause symptoms, such as fatigue (extreme tiredness), pain in the back, hips or pelvis, and problems urinating. There are treatments available to help manage these symptoms. Read more in our fact sheet,



Advanced prostate cancer.

What are my treatment options?

Your treatment options will depend on whether your prostate cancer is localised, locally advanced or advanced (see page 20). We've included a summary of the main treatments for prostate cancer below. Some of these treatments may not be suitable for you, so talk to your doctor or nurse about your own situation. There's more information about choosing a treatment on page 33.



I'm pretty sure that I would have had this treatment anyway, but I think I would have benefited from learning more about the options available.

A personal experience



Ask your doctor or nurse to mark which treatments might be suitable for you. Read more about all of the available treatments on the following pages.

Treatment options

- Localised prostate cancer**
- Active surveillance
 - Watchful waiting
 - Surgery (radical prostatectomy)
 - External beam radiotherapy
 - Brachytherapy (either permanent seed or high dose-rate)
 - High-intensity focused ultrasound
 - Cryotherapy
-

- Locally advanced prostate cancer**
- External beam radiotherapy with hormone therapy (and sometimes with high dose-rate brachytherapy)
 - Hormone therapy
 - Watchful waiting
 - Less commonly, surgery (radical prostatectomy) with hormone therapy and/or external beam radiotherapy
 - Less commonly, high-intensity focused ultrasound
 - Less commonly, cryotherapy
-

- Advanced prostate cancer**
- Hormone therapy (sometimes with chemotherapy)
 - Chemotherapy
 - Further treatments to control advanced prostate cancer
 - Treatments to manage the symptoms of advanced prostate cancer

Active surveillance

Active surveillance is a way of monitoring slow-growing prostate cancer. The aim is to avoid or delay unnecessary treatment in men who have localised prostate cancer that is unlikely to spread. This means you can avoid or delay the side effects of treatment.

Active surveillance involves monitoring your cancer with regular tests, rather than treating it straight away. You might have PSA tests, biopsies and scans (see page 8). Ask your doctor or nurse what to expect. The tests aim to find any changes that suggest the cancer is growing. If any changes are found, you will be offered treatment that aims to get rid of the cancer completely, such as surgery (radical prostatectomy), external beam radiotherapy or brachytherapy.



Read more in our fact sheet, **Active surveillance**.

Watchful waiting

Watchful waiting is a different way of monitoring prostate cancer that isn't causing any problems. The aim is to monitor the cancer over the long term. This means you can avoid or delay treatment and its side effects.

If your cancer starts to grow more quickly than expected and you start to get symptoms, such as problems urinating or bone pain, you'll be offered hormone therapy to control the cancer and help manage your symptoms, rather than treatment to get rid of the cancer.

Watchful waiting involves having tests less regularly than active surveillance. And you might have fewer tests. Ask your doctor or nurse what to expect. It's generally suitable for men with other health problems who are not fit enough for treatments such as

surgery or radiotherapy. It might also be suitable if your prostate cancer isn't likely to cause problems during your lifetime.



Read more in our fact sheet, **Watchful waiting**.

Monitoring your cancer

If you're offered active surveillance or watchful waiting, make sure you know which one your doctor is talking about. There are key differences between them. These terms aren't always used in the same way, and some doctors use different terms such as 'active monitoring' and 'wait and see'. Ask your doctor to explain exactly what they mean.

Surgery (radical prostatectomy)

This is an operation to remove the prostate and the cancer inside it. Your surgeon will also remove the seminal vesicles – two glands that lie behind the prostate and produce some of the fluid in semen. Your surgeon may also remove nearby lymph nodes if there is a risk that the cancer has spread there.

There are several types of operation:

- keyhole (laparoscopic) surgery
- robot-assisted keyhole surgery
- open surgery.

Surgery is usually only suitable for men with localised prostate cancer who are generally fit and healthy. It may also be an option for some men with locally advanced prostate cancer if your surgeon thinks it's possible to remove all the cancer that has spread outside the prostate. If this happens, you may also need to have external beam radiotherapy after your surgery.

Side effects can include leaking urine and erection problems. Side effects may improve over time but some men have side effects for longer. There are treatments available to help manage them.

After surgery, you won't be able to ejaculate any semen. But you can still feel the sensation of orgasm. Surgery will affect your ability to have children (fertility). If you're planning on having children, you may be able to store your sperm before the operation for use in fertility treatment.



Read more about surgery, including the side effects, in our fact sheet, **Surgery: radical prostatectomy**.

External beam radiotherapy

This uses high-energy X-ray beams to destroy the cancer cells from outside the body. These beams damage the cells and stop them from dividing and growing. External beam radiotherapy treats the whole prostate, and sometimes the area around it.

Radiotherapy is suitable for men with localised prostate cancer, who will often have it with hormone therapy. Radiotherapy with hormone therapy is also the standard treatment for men with locally advanced prostate cancer.

Side effects can include problems urinating, bowel problems such as passing loose or watery bowel movements (diarrhoea), erection problems, and extreme tiredness (fatigue). Side effects can develop during treatment and may get better with time. But for some men they can be long-term. And some men may develop side effects several months or years after having radiotherapy. There are treatments available to help manage side effects.



Read more about external beam radiotherapy, including the side effects, in our fact sheet, **External beam radiotherapy**.



Once I'd found out about the different treatments, and then experienced the wonderful care of my medical team, things did not look nearly so bad.

A personal experience

Brachytherapy

This is a type of internal radiotherapy. There are two types of brachytherapy – permanent seed brachytherapy and high dose-rate brachytherapy.

- Permanent seed brachytherapy, also called low dose-rate brachytherapy, involves putting tiny radioactive seeds into the prostate. The seeds release radiation for 8 to 10 months but stay in the prostate forever. This may be an option for men with localised prostate cancer that is unlikely to have spread outside the prostate.
- High dose-rate brachytherapy, also called temporary brachytherapy, is where a source of radiation is put into the prostate for a few minutes at a time and then removed. It can be used to treat localised prostate cancer that is likely to grow quickly, and sometimes locally advanced prostate cancer.

Brachytherapy can be used together with external beam radiotherapy to give higher doses of radiation to the whole prostate, as well as the area just outside it.

You might have hormone therapy to shrink the prostate for a few months before starting brachytherapy.

Side effects can include problems urinating, erection problems, and extreme tiredness (fatigue). Men who have permanent seed brachytherapy may also get bowel problems, although these tend to be mild. There are treatments available to help manage these side effects.



Read more about brachytherapy, including the side effects, in our fact sheets, **Permanent seed brachytherapy** and **High dose-rate brachytherapy**.

High-intensity focused ultrasound (HIFU)

HIFU uses high-frequency ultrasound energy to heat and destroy cancer cells in the prostate. It is newer than some of the other treatments for prostate cancer, so we don't know as much about the risk of side effects or how well it works in the long term (after 10 years). Because of this, it's only available in specialist centres in the UK or as part of a clinical trial.

HIFU can be used to treat localised prostate cancer, and less commonly locally advanced prostate cancer. It can also be used to treat cancer that has come back after external beam radiotherapy.

Side effects can include urinary problems and erection problems. These side effects may improve over time, and there are ways to manage them.

 Read more about HIFU, including the side effects, in our fact sheet,

High-intensity focused ultrasound (HIFU).


Cryotherapy

Cryotherapy uses extreme cold to freeze and destroy cancer cells. It's newer than some of the other treatments for prostate cancer, so we don't know as much about the risk of side effects and how well it works in the long term. Because of this, it's only available in specialist centres in the UK or as part of a clinical trial.

Cryotherapy is usually used to treat prostate cancer that has come back after treatment with external beam radiotherapy or brachytherapy.

Cryotherapy can also be used to treat localised prostate cancer, and less commonly locally advanced prostate cancer.

Side effects can include urinary problems and erection problems. These side effects may improve over time, and there are ways to manage them.

 Read more about cryotherapy, including the side effects, in our fact sheet, **Cryotherapy.**

Hormone therapy

Prostate cancer needs the male hormone testosterone to grow. Hormone therapy works by either stopping your body from making testosterone, or by stopping testosterone from reaching the cancer cells.

It will treat all prostate cancer cells, wherever they are in the body. Hormone therapy won't get rid of your prostate cancer, but it can keep the cancer under control, sometimes for several years.

Hormone therapy is often used with external beam radiotherapy to treat localised prostate cancer. It can also be used with external beam radiotherapy to treat locally advanced prostate cancer. Hormone therapy is the standard treatment for advanced prostate cancer. If you have advanced prostate cancer, you may be offered chemotherapy at the same time as your hormone therapy.

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

- injections or implants to stop your testicles making testosterone
- tablets to block the effects of testosterone
- surgery to remove the testicles or the parts of the testicles that make testosterone (orchidectomy).

The side effects of hormone therapy are usually caused by low testosterone levels. They can include:

- hot flushes
- loss of desire for sex
- problems getting or keeping an erection
- extreme tiredness (fatigue)
- breast swelling or tenderness (gynaecomastia)
- weight gain.

The chances of getting each side effect depend on the type of hormone therapy you're having and how long you have it for. There are ways to manage side effects.



Read more about hormone therapy, including the side effects, in our publications, **Hormone therapy** and **Living with hormone therapy: A guide for men with prostate cancer**.

Chemotherapy

Chemotherapy uses anti-cancer drugs to kill prostate cancer cells, wherever they are in the body. It doesn't get rid of prostate cancer, but it aims to shrink it and slow down its growth.

Chemotherapy is usually only used to treat advanced prostate cancer. It can be used at the same time as hormone therapy in men who have just been diagnosed with advanced prostate cancer. It can also be given to men whose cancer has stopped responding to hormone therapy (see page 29).

You need to be quite fit to have chemotherapy because the side effects can be harder to deal with if you have other health problems.

Side effects include extreme tiredness (fatigue), feeling and being sick, loss of appetite, hair loss, bowel problems, a sore mouth, and being less able to fight off infections. These side effects usually gradually improve after you finish treatment.



Read more about chemotherapy, including the side effects, in our fact sheet, **Chemotherapy**.

Treatments to control advanced prostate cancer

Hormone therapy, sometimes alongside chemotherapy, is the standard first treatment for advanced prostate cancer. Over time, it may become less effective, but there are other treatments available that can help control the cancer and help men live longer.

- **More hormone therapy** can help control your cancer. You might be offered new treatments called abiraterone (Zytiga®) or enzalutamide (Xtandi®).
- **More chemotherapy** might be an option if your hormone therapy is no longer working so well.
- **Radium-223 (Xofigo®)** is a new type of internal radiotherapy that helps some men live longer. It can also delay some symptoms, such as bone pain and bone fractures.
- **Steroids** can stop the body from producing as much testosterone. They may also help improve your appetite and energy levels, and can treat pain.




Read more in our fact sheet, **Treatment options after your first hormone therapy**.

Treatments to manage the symptoms of advanced prostate cancer

If you've been diagnosed with advanced prostate cancer and have symptoms such as bone pain, there are treatments to manage these.

- **Pain-relieving drugs** can help manage any pain.
- **Radiotherapy** can slow down the growth of the cancer and control symptoms.

- **Drugs called bisphosphonates** can strengthen the bones and help to prevent broken bones in men whose cancer has caused bone thinning. Bisphosphonates can also be used to treat pain caused by cancer that has spread to the bones.

 Read more about these in our fact sheets, **Managing pain in advanced prostate cancer**, **Radiotherapy for advanced prostate cancer** and **Bisphosphonates for advanced prostate cancer**.

Clinical trials

A clinical trial is a type of medical research. Clinical trials aim to find new and improved ways of preventing, diagnosing, treating and managing illnesses. You can ask your doctor or nurse if there are any clinical trials you could take part in, or speak to our  Specialist Nurses. You can also find details of some clinical trials happening now in the UK in Cancer Research UK's database at www.cancerresearchuk.org/trials

 Read more in our fact sheet, **A guide to prostate cancer clinical trials**.

Choosing a treatment

Your treatment options and which treatment you choose may depend on several things, including:

- how far your cancer has spread (its stage)
- how quickly your cancer may be growing
- the advantages and disadvantages of each treatment
- what each treatment involves
- the possible side effects of each treatment
- practical things, such as how often you would need to go to hospital, or how far away your nearest hospital is
- your own thoughts about different treatments

- how the treatment you choose now could affect your treatment options later if your cancer comes back or spreads (see page 35)
- your general health
- how long you're expected to live for.

Side effects from treatments affect each man differently, and you might not get all the possible side effects. It's important to think about the side effects and how you would cope with them when deciding on a treatment.

The different treatment options can be a lot to take in, especially when you've just been diagnosed with prostate cancer. Make sure you have all the information you need, and give yourself time to think about which treatment is right for you.

It can be a good idea to write down any questions you might want to ask at your next appointment. And you might find it useful to have someone with you at the appointment, or to make notes to help you remember what is said.

If you need further treatment

If your cancer comes back after treatment that aimed to get rid of it, the first treatment you have had may affect which treatments you can have in the future.

Some of these treatments may not be suitable for you, so speak to your doctor or nurse about your own situation.

The table on the next page shows you which treatments may be possible after your first treatment.

First treatment for prostate cancer	Second-line treatments that may be available
Surgery (radical prostatectomy)	<ul style="list-style-type: none"> • Radiotherapy to the prostate bed (with or without hormone therapy) • Hormone therapy alone
External beam radiotherapy	<ul style="list-style-type: none"> • High-intensity focused ultrasound (HIFU) • Cryotherapy • Hormone therapy • Brachytherapy • Surgery
Permanent seed brachytherapy or high dose-rate (HDR) brachytherapy	<ul style="list-style-type: none"> • Cryotherapy • Hormone therapy • Rarely, HIFU • Surgery
High-intensity focused ultrasound (HIFU)	<ul style="list-style-type: none"> • More HIFU • External beam radiotherapy • Cryotherapy • Hormone therapy • Rarely, surgery
Cryotherapy	<ul style="list-style-type: none"> • More cryotherapy • External beam radiotherapy • Hormone therapy • Very rarely, surgery



Read more about this in our booklet, **If your prostate cancer comes back: A guide to treatment and support.**



I think the most confusing bit was being given a choice of treatments. You sort of expect to be told what the treatment will be, not have to decide yourself. It's a lot to take in.

A personal experience.

Dealing with prostate cancer

Some men say being diagnosed with prostate cancer changes the way they think and feel about life. If you've just been diagnosed with prostate cancer you might feel scared, worried, stressed, helpless or even angry.

At times, lots of men with prostate cancer get these kinds of thoughts and feelings. But there's no 'right' way that you're supposed to feel and everyone reacts in their own way.

There are things you can do to help yourself and people who can help. Families can also find this a difficult time and they may need support too. This section might also be helpful for them.



Everyone's experience of cancer, whether you are the patient or the carer, is very, very unique and I don't think anybody can tell you how you should behave.

A personal experience

Am I going to die?

You might want to know how prostate cancer will affect you and whether you are likely to die from prostate cancer. This is sometimes called your outlook or prognosis. Most prostate cancer grows slowly and may never cause any problems or shorten a man's life. So having prostate cancer doesn't necessarily mean that you'll die from it.

No one can tell you exactly what will happen. How prostate cancer affects you will depend on many things.

- **Your stage.** If you are diagnosed with localised prostate cancer, you may not need treatment or you will have treatment that aims to get rid of the cancer. If you are diagnosed with locally advanced prostate cancer, you may have treatment that aims to get rid of the cancer or keep it under control. If you are diagnosed with advanced prostate cancer, the treatment won't cure your cancer but it can help to keep it under control.
- **Your Gleason score or grade group.** The higher your Gleason score or grade group, the more aggressive the cancer, and the more likely it is to spread (see page 12).
- **Your PSA level.** After you've been diagnosed, PSA tests are a good way of monitoring your prostate cancer and seeing how you're responding to treatment.
- **Your treatment options.** You may be able to have treatment aimed at getting rid of the cancer. Or you may be able to have treatment to keep the cancer under control.
- **How successful your treatment is.** Your treatment may be successful at getting rid of your cancer or keeping it under control. But for some men, treatment may not work as well as expected.
- **Your health.** If you have other health problems, you may have fewer treatment options. And other health conditions may cause more problems than your prostate cancer.

For more information about the outlook for men with prostate cancer, visit the Cancer Research UK website. The figures they provide are a general guide and they cannot tell you exactly what will happen to you. Speak to your doctor or nurse about your own situation.

Talking to your family

You might be worried about telling your friends and family that you have cancer. You might be concerned about how they'll react or if you'll upset them.

It can be difficult to know how to start a conversation. Try to find a quiet place and explain to them that you have prostate cancer. You might find it helpful to show them this booklet.

Ask them if they have any questions. If you don't know the answers, you could write down their questions and ask your doctor or nurse at your next appointment.

If you don't feel able to tell your friends and family, you could ask someone you trust to tell people for you.

Macmillan Cancer Support produce information that can help you figure out where to start and make these conversations a bit easier. It includes information about talking to children.

If you have brothers or sons, you might want to talk to them about their own risk of prostate cancer. This is because men are two and a half times more likely to get prostate cancer if their father or brother has had it, compared to someone who doesn't have any relatives who have been diagnosed with prostate cancer. They might want to talk to their doctor or nurse about their situation, particularly if they



are 45 or over. Read more about this in our booklet, **Know your prostate: A guide to common prostate problems.**

How can I help myself?

Everyone has their own way of dealing with prostate cancer, but you may find some of the following suggestions helpful.

Look into your treatment options

Find out about the different treatments that are available to you. Bring a list of questions to your doctor or nurse. And ask about any side effects so you know what to expect and how to manage them. This will help you decide what's right for you.

Talk to someone

Share what you're thinking – find someone you can talk to. It could be someone close or someone trained to listen, like a counsellor or your doctor or nurse. Your GP, nurse or other health professionals involved in your care should be able to answer any questions or concerns you might have.

Set yourself some goals

Set yourself goals and things to look forward to – even if they're just for the next few weeks or months.

Look after yourself

Take time out to look after yourself. When you feel up to it, learn some techniques to manage stress and to relax – like breathing exercises or listening to music.

Eat a healthy, balanced diet

Eating well is good for your general health. There is some evidence that certain foods may help slow down the growth of prostate cancer or lower the risk of it coming back after treatment. Eating a healthy diet can also help with some side effects of treatment.



For more information, read our fact sheet, **Diet and physical activity for men with prostate cancer**.

Be as active as you can

Keeping active can improve your physical strength and fitness, and can lift your mood. Some research suggests that physical activity may help slow down the growth of prostate cancer. It can also help you stay a healthy weight, which may help to lower your risk of advanced prostate cancer. Physical activity can also help with some side effects of treatment, such as anxiety, depression and extreme tiredness (fatigue). Even a small amount of physical activity can help. Take things at your own pace. For more information, read our fact



sheet, **Diet and physical activity for men with prostate cancer**.

Get more ideas about how to look after yourself from Macmillan Cancer Support, Maggie's Centres, Penny Brohn UK or your nearest cancer support centre. You can also find more ideas in our booklet,



Living with and after prostate cancer: A guide to physical, emotional and practical issues.

Who else can help?

Your medical team

It could be useful to speak to your nurse, doctor, GP or someone else in your medical team. They can explain your diagnosis, treatment and side effects, listen to your concerns, and put you in touch with others who can help.



Our Specialist Nurses

Our Specialist Nurses can answer your questions and explain your diagnosis and treatment options. They've got time to listen, in confidence, to any concerns you or those close to you have.



I found talking on the phone to an experienced Prostate Cancer UK nurse very helpful.

A personal experience.

Trained counsellors

Counsellors are trained to listen and can help you find your own ways to deal with things. Many hospitals have counsellors or psychologists who specialise in helping people with cancer – ask your doctor or nurse at the hospital if this is available. Your GP may also be able to refer you to a counsellor, or you can see a private counsellor. To find out more, contact the British Association for Counselling & Psychotherapy.

Our one-to-one support service

Our one-to-one support service is a chance to speak to someone who's been there and understands what you're going through. They can share their experiences and listen to yours. You can discuss whatever's important to you. Our Specialist Nurses will try to match you with someone with similar experiences.



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

A personal experience

Our online community

Our free online community is a place to talk about whatever's on your mind – your questions, your ups and your downs. Anyone can ask a question or share an experience.



I wish I had known about the online community when my other half was diagnosed. Until you start using it you don't appreciate its worth.

A personal experience.

Local support groups

At local support groups, men get together to share their experiences of living with prostate cancer. You can ask questions, share worries and know that someone understands what you're going through. Some groups have been set up by local health professionals, others by men themselves. Many also welcome partners, friends and relatives.

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), which is a common symptom of prostate cancer. Fatigue can also be a side effect of some treatments for prostate cancer. The fatigue support service can help you make positive changes to your behaviour and lifestyle, which can improve your fatigue over time.

To find out more about any of these services, visit prostatecanceruk.org/get-support or call our Specialist Nurses on 0800 074 8383.

Spiritual support

You might begin to think more about spiritual beliefs as a result of having prostate cancer. It's important that you get spiritual support if you need it. This could be from your friends or family, or from your religious leader or faith community.

Practical issues



You might need to make decisions about things like work and money. Read more about this in our booklet, **Living with and after prostate cancer: A guide to physical, emotional and practical issues**.

If you live in England and are having treatment for cancer, including treatments for symptoms or side effects, you are entitled to free prescriptions. You'll need to apply for a medical exemption certificate. Ask your doctor for a FP92A form. Once you have filled out the form, your doctor will need to sign it, and the certificate will be sent to you. You can find out more about free prescriptions from NHS Choices. Anyone over 60 in England also gets free prescriptions.

If you live in Scotland, Wales or Northern Ireland, all prescriptions are free.

List of medical words



Our fact sheet, **A to Z of medical words**, explains more words that you may hear or read when you are finding out about prostate cancer.

Gleason grade

When cells are seen under the microscope, they have different patterns, depending on how quickly they're likely to grow. The pattern is given a grade from 1 to 5 – this is called the Gleason grade. Grades 1 and 2 are not cancer, and grades 3, 4 and 5 are cancer (see page 12).

Gleason score

Your Gleason score is worked out by adding together two Gleason grades. The first is the most common grade in all the samples. The second is the highest grade of what's left. If you have cancer, the higher the Gleason score, the more likely the cancer is to grow and spread outside the prostate (see page 12).

Lymph nodes

These are part of your immune system and are found throughout your body. Lymph nodes are sometimes called lymph glands. The lymph nodes near the prostate are a common place for prostate cancer to spread to.

Metastasis

Metastasis is the spread of prostate cancer cells from the prostate to other parts of the body. Cancers that have spread may be called advanced cancer, metastases, mets, secondary cancers, or secondaries. A cancer that has spread is said to have metastasised.

Oncology department

The hospital department that deals with the diagnosis and treatment of cancer. An oncologist is a doctor who specialises in cancer treatments other than surgery, such as radiotherapy or chemotherapy. There will usually be an oncologist in your team of health professionals.

Prostate specific antigen (PSA)

A protein produced by normal cells in the prostate, and also by prostate cancer cells. It's normal for all men to have a small amount of PSA in their blood. A raised PSA level can be caused by a number of things including age, a urine infection, an enlarged prostate and prostate cancer.

Seminal vesicles

Two glands located behind the prostate and bladder that produce some of the fluid in semen.

Urology department

The hospital department that deals with the diagnosis and treatment of diseases of the urinary system, including prostate cancer. Urologists are surgeons who operate on the prostate. There will usually be a urologist in your team of health professionals.

Uro-oncology

The diagnosis and treatment of cancers of the urinary system, including prostate cancer.

What are my test results?

You can use this section with your doctor or nurse to write down your test results and appointment dates.



PSA level at diagnosis:

Number of biopsy samples taken:

Number of biopsy samples affected:

Gleason score:

Grade group:

T stage at diagnosis (if known):

N stage at diagnosis (if known):

M stage at diagnosis (if known):

Date of MRI scan (if needed):

Results of MRI scan:

Date of CT scan (if needed):

Results of CT scan:

Date of bone scan (if needed):

Results of bone scan:

The cancer is (please tick):

- localised** – contained inside the prostate
- locally advanced** – starting to break out of the prostate or spread to the area just outside it
- advanced** – spread from the prostate to other parts of the body.

Treatment plan:

My next appointments are with my (tick those that apply):

- urologist
- specialist nurse
- oncologist
- other.

You can write down details of future appointments on page 52.

Contact your doctor or nurse at any time if you have any questions or concerns. There will usually be one person who is your main contact – you might hear them called your key worker. You can



also speak to our Specialist Nurses.

Who are my team members?

You can use this space to write down the names and contact details of the health professionals who will be involved in your care. You may hear them called your multi-disciplinary team (MDT). They will discuss your individual diagnosis and agree on which treatment options would be suitable for you.

We've listed the health professionals who are likely to be most involved in your care, but you might not see all of them. You're likely to meet more of them later on when you begin treatment or have check-ups.

Specialist nurse

You may have a urology, uro-oncology or prostate cancer specialist nurse. They can answer any questions you may have, and might carry out some of your tests, treatments and follow-up care.



Name:

Job title:

Telephone:

Notes:

Main contact (key worker)

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 help you get information.

Name:

Job title:

Telephone:

Notes:

Consultant urologist

This type of doctor specialises in the urinary and reproductive systems. Urologists are surgeons.

Name:

Job title:

Telephone:

Notes:

Consultant oncologist

This type of doctor specialises in cancer treatments other than surgery, such as radiotherapy.

Name:

Job title:

Telephone:

Notes:

Other health professionals

You can write down contact details of other health professionals in the space below.

General practitioner (GP):

Practice nurse:

Other health professionals:

Our Specialist Nurses: 0800 074 8383

Your nearest local support group:

You can find out about your nearest local support group from your nurse or on our website.



When I was first diagnosed I found it extremely helpful to fill in the details of the diagnosis. It also helped me to ask the right questions.

A personal experience

Appointment diary

You can fill in this diary before and after your appointments, to help you get the most out of them. You might want to photocopy these pages so you have enough copies to last you for a while.



Date of appointment

Fill in before your appointment

How I've been feeling – you can include physical things (for example, side effects of treatment) as well as emotional things.

Things I want to talk about at my appointment:

- | | |
|---|---|
| <input type="checkbox"/> urinary problems | <input type="checkbox"/> emotional or mood problems |
| <input type="checkbox"/> sexual problems | <input type="checkbox"/> diet |
| <input type="checkbox"/> bowel problems | <input type="checkbox"/> physical activity |
| <input type="checkbox"/> fatigue problems | <input type="checkbox"/> work and finances |

Your doctor or nurse may not have time to talk about all of these things, so think about what is most important to you. You can also call our Specialist Nurses in confidence.





Fill in during or after your appointment

My questions or concerns:

Answers to my questions or concerns:

Advice from my doctor or nurse:

PSA level:

Date and time of next appointment:

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**



**Speak to our
Specialist Nurses**

0800 074 8383*

prostatecanceruk.org

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

Other useful organisations

British Association for Counselling & Psychotherapy

www.bacp.co.uk

Telephone: 01455 88 33 00

Information about counselling and details of therapists in your area.

Cancer Research UK

www.cancerresearchuk.org

Telephone: 0808 800 4040

For some strange reason, this currently links to the url for the organisation above.

Carers UK

www.carersuk.org

Telephone: 0808 808 7777

Information and advice for carers, and details of local support groups.

Citizens Advice

www.citizensadvice.org.uk

Telephone: 03444 77 20 20 (Wales) 03444 111 444 (England)

Advice on a range of issues including financial and legal matters. Find your nearest Citizens Advice Bureau in the phonebook or online.

Healthtalk.org

www.healthtalk.org

Watch, listen to and read personal experiences of men with prostate cancer and other health problems.

Macmillan Cancer Support

www.macmillan.org.uk

Telephone: 0808 808 0000

Practical, financial and emotional support for people with cancer, their family and friends.

Maggie's Centres

www.maggiescentres.org

Telephone: 0300 123 1801

Drop-in centres for cancer information and support. Includes an online support group.

National Institute for Health and Care Excellence (NICE)

www.nice.org.uk

Telephone: 0300 323 0140

Guidelines for care and for the use of treatments and procedures on the NHS in England and Wales.

NHS Choices

www.nhs.uk

Information about conditions, treatments and lifestyle. Support for carers and a directory of health services in England.

NHS Direct Wales

www.nhsdirect.wales.nhs.uk

Telephone: 0845 46 47

Provides health advice 24 hours a day, and lists local health services in Wales.

NHS Inform

www.nhsinform.scot

Telephone: 0800 22 44 88

Health information and details of NHS and other support services in Scotland.

nidirect

www.nidirect.gov.uk

Information about government services in Northern Ireland, including health services.

Penny Brohn UK

www.pennybrohn.org.uk

Telephone: 0303 3000 118

Runs courses and offers physical, emotional and spiritual support for people affected with cancer and those close to them.

Samaritans

www.samaritans.org

Telephone: 116 123

Confidential, judgement-free emotional support, 24 hours a day, by telephone, email, letter or face-to-face.

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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- Nona Toothill, Urology Clinical Nurse Specialist, Airedale NHS Foundation Trust, West Yorkshire
- Our Specialist Nurses
- Our Volunteers.

Donate today – help others like you

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



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**Speak to our
Specialist Nurses**

0800 074 8383*

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To be reviewed October 2018

**Call our Specialist Nurses from Monday to Friday 9am - 6pm,
Wednesday 10am - 8pm**

* Calls are recorded for training purposes only.

Confidentiality is maintained between callers and Prostate Cancer UK.

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