# About the prostate

- What is the prostate? .......................................................... 3
- What does the prostate do? .................................................. 3
- Do men have hormones? ..................................................... 3
- Do trans women have a prostate? ......................................... 3

# About prostate cancer

- What is prostate cancer? ...................................................... 4
- What causes prostate cancer? .............................................. 4
- What are the stages of cancer? .............................................. 4
- What do grades of cancer mean? .......................................... 6

# Risk of prostate cancer

- What increases the risk of getting prostate cancer? ............ 6

# Symptoms

- What are the symptoms of prostate cancer? ....................... 7
- How should I approach my doctor? ................................. 7

# Tests

- What checks and tests are available for prostate cancer? .. 8
- Digital rectal examination (prostate check) ....................... 8
- Prostate-specific antigen (PSA) test ................................ 8
- What happens if you are ‘at risk’ of prostate cancer? .. 8

# Common treatments

- What treatments are available for prostate cancer? .......... 12
- What are the most common side effects of prostate cancer treatments? .................................................. 12
- Monitoring cancer .......................................................... 12
- Surgery ............................................................................. 13
- Radiotherapy .................................................................... 13
- Hormone therapy ............................................................. 14
- Chemotherapy ................................................................... 16
- Other treatments ............................................................. 17

# Living with cancer

- What is it like living with prostate cancer? ....................... 18
- Practical issues ................................................................. 19
- Palliative care ................................................................. 19

# Recurrence

- What happens if the cancer comes back? ......................... 20

# My notes and questions

This information was produced by the European Association of Urology (EAU) and updated in May 2021.

This chapter contains general information about prostate cancer. If you have any specific questions about your individual medical situation you should consult your doctor or other professional healthcare provider. No website or leaflet can replace a personal conversation with your doctor.

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This information has been reviewed by a lay panel.
About the prostate

What is the prostate?
The prostate is a small gland that forms part of a man’s reproductive system. It is about the size of a golf ball and surrounds the tube that empties urine from the bladder, called the urethra.

It is normal for the prostate to swell as a man gets older, but if the swelling gets too big, it can block the urethra, making it difficult to pass urine. This swelling is called benign prostate enlargement or BPE.

BPE is not cancer. In most cases, BPE is not a serious health concern and is a treatable condition.

What does the prostate do?
The prostate makes a thick white fluid that mixes with sperm from your testicles to make semen. It also produces a protein called prostate-specific antigen or PSA. PSA helps reduce the thickness of semen, so it is thinner and more fluid.

Do men have hormones?
Hormones are chemicals that carry messages around the body. In men, a hormone called testosterone is made by the testicles and controls how the prostate works. Testosterone is responsible for a man’s sex drive and getting an erection. For this reason, you may hear testosterone called a “sex hormone”.

Do trans women have a prostate?
Yes. If you are a trans woman or a non-binary individual assigned male at birth, you have a prostate.

Some trans women may have had genital reconstructive, or gender reassignment, surgery. Although converting a man’s anatomy to a woman’s anatomy involves removing the penis and the testicles, this surgery does not remove the prostate.

If you are taking hormones or testosterone blockers, these may reduce the risk of prostate cancer by lowering your testosterone levels. It is still very important to have a prostate check if you have any known symptoms or are at increased risk of prostate cancer.

Urine
Urine, or pee, is often called a waste product. This is because it is produced by the kidneys, which are responsible for filtering toxins from the blood.

Protein
Proteins are found in every cell in the body.

Antigen
Typically, an antigen is a substance that causes your immune system to produce antibodies. Although PSA is called an antigen, biochemically, it is an enzyme which means it causes a chemical reaction. In the prostate, this chemical reaction is the reduction in the thickness of the semen.
We know it can be a difficult conversation to have, but we encourage you to speak to your doctor.

**About prostate cancer**

**What is prostate cancer?**
Our bodies are made up of trillions of tiny cells, which are the basic building blocks of all living things. Cells continuously divide to make new cells. It is how we grow and how the body heals itself.

Sometimes a cell becomes abnormal. It is not fully understood why this happens, but when abnormal cells keep dividing and make more and more abnormal cells, eventually a lump of tissue forms, called a tumour.

Not all tumours are cancerous. Benign means the tumour is not cancer, but it might still grow in size. Malignant means the tumour is cancer. Some malignant tumours grow very fast, while others grow much more slowly. If a malignant tumour is left untreated, it may spread to other parts of the body. This spreading of cancer cells is called metastasis.

For detailed cancer information, take a look at our About Cancer page.

Prostate cancer means there are cancer cells inside the prostate that have formed a malignant tumour. If you have recently been diagnosed with prostate cancer, you are not alone. Prostate cancer is the most common cancer among men in Europe, but there are treatment options.

**What causes prostate cancer?**
The exact cause of prostate cancer is unknown. But certain things increase a man’s chance of developing it. These are called risk factors. Having a risk factor for cancer does not mean a man will get prostate cancer; it just means he has an increased risk.

**What are the stages of cancer?**

**What does localised, locally-advanced, and metastatic mean?**
If you have been diagnosed with prostate cancer, you may have heard the terms localised, locally-advanced, or metastatic. All of the different terms can feel overwhelming.
Cancer is often described in stages. These are used to explain the size of the tumour and how far the cancer has spread. Although there are different ways of describing the stage of cancer, one of the simplest ways to understand it is using numbers from 1 to 4.

We have described the stages in their simplest form below.

**Understanding stages and cancer terms**

<table>
<thead>
<tr>
<th>Stages 1 and 2</th>
<th>“Early” or “localised.”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stages 3 and 4</td>
<td>“locally-advanced.”</td>
</tr>
</tbody>
</table>

**Stage 1**
The tumour is contained or “localised” in the prostate. The cancer is in the very early stages, and the tumour is too small to be felt during a *prostate check*.

**Stage 2**
The tumour is within the prostate. It is still small, but it may be felt during a *prostate check* and may be visible on a *scan*. The cancer cells are dividing, and there is an increased risk of the tumour growing and the cancer cells spreading.

**Stage 3**
The tumour has started to break through the wall of the prostate, and the cancer cells may be in the nearby tubes that produce semen. This is called “locally-advanced cancer” because the tumour has grown immediately outside the prostate but has not spread to other or “distant” parts of the body.

**Stage 4**
The tumour has grown outside the prostate. The cancer cells may be in or around the bladder (such as the bladder neck or urinary sphincter), the back passage (rectum), or in the pelvic floor muscle, which lies underneath the prostate at the base of the pelvis.

**Metastatic disease and metastasis**
Prostate cancer can spread to the local lymph nodes or bones and even organs such as the liver, lungs, and brain. This spread of cancer cells throughout the body is called “metastasis”, or you may hear it called “metastatic prostate cancer.” When cancer spreads or metastasises to other organs, it is referred to as metastatic disease.
Sometimes, cancer cells are found in the pelvic lymph nodes but have not spread elsewhere in the body. This is called node-positive disease, rather than a metastatic disease, as the cancer cells have not spread to other lymph nodes or organs around the body.

Node-positive disease can be treated. You may be offered surgery to remove the diseased lymph nodes, radiotherapy of diseased lymph nodes and/or hormone therapy.

What do grades of cancer mean?
Stages and grades are different. Stages inform your doctor of the size of the tumour and how far the cancer cells have spread. Grades give your doctor an idea of how fast the tumour might grow, and cancer might spread. In general, a lower grade indicates slower-growing cancer, and a higher grade indicates a faster-growing one.

If you have been diagnosed with prostate cancer, your doctor may refer to your “Gleason score” which is a common way of grading prostate cancer. Your Gleason score will help your doctor plan and discuss your treatment options with you.

Your doctor may also refer to an “ISUP grade”. This is another tool used for grading cancer.

Risk of prostate cancer

What increases the risk of getting prostate cancer?
Four main risk factors increase a man’s chance of developing prostate cancer. If you feel you have any risk factors for developing prostate cancer, you should speak to your doctor.

Age
Age is the biggest risk factor for prostate cancer. In Europe, prostate cancer is commonly diagnosed in men over 65, but it can happen in younger men.

Ethnicity
Black men have twice the risk of developing prostate cancer than white men. Asian men, on the other hand, have a lower risk. It is unknown why a man’s ethnicity or race increases or lowers his prostate cancer risk.

Gleason score
The Gleason score is used after a biopsy has been taken and a pathologist has looked at the cells. The score helps your doctor predict how the cancer might behave and the treatment you need.

ISUP grade
The International Society of Urological Pathology (ISUP) grade categorises prostate cancer into 5 groups from 1 to 5. The lower the ISP grade, the better your prognosis is.
Family history
We all inherit our genes from our parents. Some prostate cancers may be linked to genes passed from generation to generation by either parent. Although a man’s risk of developing prostate cancer increases if he has a family history, most men who get prostate cancer do not have a family history.

If you have close family members diagnosed with prostate cancer under the age of 60 and are concerned about your risk, speak to your doctor.

Diet
It is well-known that eating a balanced diet and doing regular physical exercises keeps you healthy. A balanced diet includes eating plenty of vegetables, fruit, and fibre, and limited red meat, processed foods, high-fat foods, sugar, and alcohol. Men who are very overweight or obese may increase their risk of developing prostate cancer.

Symptoms
What are the symptoms of prostate cancer?
Prostate cancer may cause no signs or symptoms in its early stages. More advanced prostate cancer may cause signs and symptoms, such as:

- difficulty passing urine
- a less powerful stream of urine
- blood in the urine
- blood in the semen
- bone pain (commonly in the back)
- losing weight without trying
- problems controlling bowel movements
- erection problems called erectile dysfunction

Difficulty passing urine and a less powerful stream of urine are commonly caused by an enlarged prostate, called benign prostate enlargement, or BPE (previously called benign prostatic hyperplasia or BPH). BPE is not cancer and is a treatable condition.

If you or a family member are experiencing any of the above symptoms, it is important to get a prostate check. It can feel frightening when you experience symptoms that may be cancer, but it is always best to get checked.

How should I approach my doctor?
If you feel frightened, anxious, or embarrassed about prostate problems, it is always best to speak to your doctor.

If you have previously visited the doctor but not managed to talk about your symptoms, now is the time to speak up.

It is important to find the words that are right for you. We have listed some potential “icebreakers” for you below. Why not say them aloud and see which one feels the most natural to you. You may even find rehearsing what you want to say boosts your confidence and comfort level.

Genes
Genes are made of DNA. They contain “information” that determines our traits. For example, having red hair is a genetic trait passed from generation to generation.

Processed foods
Processed foods include ready meals, takeaways, savoury snacks, cakes, and biscuits.

Obese
Obese means you are very overweight, with a lot of body fat, which puts you at risk of serious health problems.
I want to ask you about a men's health issue
I'm having some problems that I want to talk to you about
I think I might have a prostate problem
I'm having some problems peeing/weeing
I'm having some problems getting/keeping an erection
My friend/brother/father/uncle has been diagnosed with prostate cancer
I'm worried about prostate cancer
I’ve had blood in my pee/wee/semen

Just remember, your doctor is a healthcare professional. He/she will listen to you and discuss the best way forward.

**Tests**

**What checks and tests are available for prostate cancer?**
While you may have heard about “screening” for cancer, for example, mammograms to check for breast cancer, not all countries have a prostate cancer screening programme. For this reason, it is very important to get a prostate check if you have any of the known symptoms or family history of prostate cancer.

**Digital rectal examination (prostate check)**
A prostate check, or digital rectal examination, is a quick and simple test to see if you might have a prostate problem. It involves your doctor inserting a gloved and lubricated finger into your back passage (rectum) to feel your prostate.

Digital rectal examination

We realise this might seem embarrassing, but the examination is over very quickly. You may be aware of some pressing and get a brief urge to pass urine, but the examination itself is not usually painful.

**Prostate-specific antigen (PSA) test**
Prostate-specific antigen or PSA is a protein produced only by the prostate. A PSA test is a simple blood test that measures the amount of PSA protein in your blood. It can help to diagnose or rule out prostate cancer as a cause of your symptoms.

If PSA levels in the body are high, it could be a sign that something abnormal is happening in the prostate. High PSA levels do not mean you have prostate cancer, but high PSA levels should be investigated to rule out prostate cancer. Download our **PSA testing leaflet** for more information.

**What happens if you are ‘at risk’ of prostate cancer?**
There is no single test for prostate cancer. Your doctor will discuss the available tests with you and use the results to see if you are “at-risk” of having prostate cancer.

Your risk is based on several factors, including your **PSA level** and the results of your prostate examination, as well
as your age, family history, and ethnic group. If you are “at risk,” you should be referred to a hospital to discuss further tests. Such tests might include an ultrasound, CT scan, MRI scan, or bone scan.

**MRI**
Magnetic resonance imaging, or MRI scan, creates pictures of the inside of your body using magnets and radio waves. An MRI scan provides a detailed look inside your prostate. The results will help your doctor decide if you need to have a biopsy. It may also help your doctor find out if any cancer cells have spread to other parts of your body.

During the MRI scan, you will be asked to lie on the scanner bed. The scan itself can take some time (30 to 40 minutes) to complete. The bed will move into the scanner, which is like a narrow tunnel. There is a 2-way intercom inside the scanner, so you will be able to communicate with the **radiographer** the whole time. You will also be given a device to hold in your hand with a panic button. If you feel anxious during the scan, just let the radiographer know by pressing the button.

The scan itself is painless, but it can feel uncomfortable as you have to lie very still. It is also very noisy inside the scanner, and you will be given ear defenders to wear. Some people find it claustrophobic inside the scanner and have said wearing a sleep mask helped ease their fear.

*Having an MRI scan*
You may need to have an injection of dye, called a contrast. The dye helps tissue inside your body show up more clearly on the scan. This is usually given via a **cannula** in your arm. You may feel the dye passing through your veins as either a warm or cold sensation. Some men have said it feels as though you will lose bladder control. So although this won’t happen, it can feel uncomfortable, but it is not painful.

**CT scan**
Computed tomography, or CT scan as it is commonly known, uses x-rays taken at different angles. These x-rays are sent to a computer which creates a 3-dimensional (3D) image of the inside of your body. A CT scan does not take very long to complete. The results may help your doctor find out if any cancer cells have spread to other parts of your body.

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**Radiographer**
A radiographer is a healthcare professional who is a specialist at diagnosing illness and injuries using x-ray images.

**Cannula**
A cannula is a thin tube inserted into a vein.
During the CT scan, you will be asked to lie on the scanner bed. The bed moves forwards and backwards through the hole of the scanner. You will be able to communicate with the radiographer the whole time.

**Having a CT scan**

You may need to have an injection of dye, called a contrast. The dye helps tissue inside your body show up more clearly on the scan. This is usually given via a cannula in your arm. You may feel the dye passing through your veins as either a warm or cold sensation. Some men have said it feels as though you will lose bladder control. So although this won’t happen, it can feel uncomfortable, but it is not painful.

**Bone scan**

Your doctor might recommend that you have a bone scan to determine if cancer cells have spread to your bones.

Before the bone scan, you will need to have radioactive dye injected into a vein in your arm or hand. Only a small amount of radioactive dye is used, and it is safe. You will need to wait for 2 to 3 hours for the dye to travel through your veins and into your entire body before the scan itself takes place.

During the bone scan, you will be asked to lie on the scanner bed. The scanner will move very slowly down your body and take pictures. The scanner will pick up any abnormal areas of bone, called “hot spots.” Not all bone abnormalities are cancer, and the scanner may pick up other conditions, such as arthritis.

**Having a bone scan**

This can be an extremely stressful time for you, especially waiting for the results. If you are struggling to cope, try not to hide your emotions. Talk to your family and friends. If you have not done so already, speak to your doctor about professional support, such as counselling services or local support groups.

**PSMA PET-CT Scan**

PET-CT scans use a mildly radioactive drug to show up areas of your body where cancer cells are more active than normal cells. Prostate-specific membrane antigen, or PSMA, is a protein found on the surface of prostate cancer cells. PSMA PET-CT scans look for areas of the body where the PSMA protein is found, showing the presence of prostate cancer cells.

Although PSMA PET-CT scans are not commonly used, there is evidence to suggest that this type of scan is more accurate than others at detecting if your cancer has spread to other parts of the body. In time, PSMA PET-CT scans will likely become the standard scans used to detect the extent of prostate cancer spread throughout the body.

**Radiographer**

A radiographer is a healthcare professional who is a specialist at diagnosing illness and injuries using x-ray images.

**Cannula**

A cannula is a thin tube inserted into a vein.
Ultrasound
An ultrasound uses sound waves to send images to a computer. This allows your doctor to see inside your body. An ultrasound of your prostate involves your doctor or a sonographer inserting a lubricated wand-like device, called a probe, into your back passage (rectum).

The examination does not take long. It might feel uncomfortable, but it is not usually painful.

Biopsy
A biopsy of the prostate is the most accurate way of seeing if you have prostate cancer. However, a biopsy involves your doctor using a thin needle to take small tissue samples from your prostate. Because of this, a biopsy is only done when other tests strongly suggest you have prostate cancer.

Biopsy samples are sent to a laboratory where a pathologist looks at them under a microscope to check for cancer cells. The results will help your doctor plan and discuss your treatment options with you.

There are 2 main types of prostate biopsy:
1. a trans-rectal ultrasound biopsy, or TRUS
2. a trans-perineal biopsy

It is important to discuss the risks and benefits of each procedure with your doctor to make sure it is the right one for you.

Trans-rectal ultrasound biopsy (TRUS)
During a TRUS biopsy, your doctor will insert a lubricated ultrasound probe into your back passage (rectum). The ultrasound probe scans the prostate, and an image appears on a screen. The doctor uses this image to guide where to take the biopsy from. You will be given a local anaesthetic to numb the area and minimise any discomfort from the procedure.

Patients who have a TRUS biopsy are at risk of developing a severe infection, known as sepsis. You will be provided with detailed information about the known risks before you consent to have the procedure done.

Trans-perineal biopsy
Your doctor will insert a lubricated ultrasound probe into your back passage (rectum) to see the prostate during a trans-perineal biopsy. The biopsy needle will then be passed through the skin between the testicles and the back passage. A trans-perineal biopsy is commonly done under local anaesthetic, so the area will be numbed to minimise any discomfort from the procedure. It is becoming more popular because it is thought to have a lower risk of serious infection.

Sonographer
A sonographer is a healthcare professional who is a specialist at performing ultrasounds.

Pathologist
Pathologists are doctors who diagnose diseases by examining cells and tissue samples.

Probe
A wand shaped device that produces sound waves which send images to a computer. This allows a doctor to see inside the body.

Local anaesthetic
A local anaesthetic temporarily numbs an area of the body. It is usually given as an injection.
Common treatments

What treatments are available for prostate cancer?
There are different treatments for prostate cancer. The treatment you are offered will vary depending on your age, overall health, and your tumour’s stage and grade. Your doctor will discuss the results from your diagnostic tests and your treatment options with you.

The main treatments include monitoring the cancer, surgery to remove the prostate, radiotherapy, and hormonal therapy.

What are the most common side effects of prostate cancer treatments?
The prostate is close to the bladder and rectum. It is surrounded by a delicate network of nerves and blood vessels that enable you to get an erection. Treatments for prostate cancer can affect your urinary, bowel, and sexual functioning.

It is important to communicate with your doctor about any side effects you are experiencing as you undergo treatment. Ongoing communication will enable your doctor to manage your side effects as early as possible.

Leaking urine
It is normal to experience some loss of bladder control (called urinary incontinence) and leak urine after surgical or radiation treatment, but for most men, this will improve over time. For more information, see our section on what it is like living with prostate cancer.

Bowel problems
Damage to the rectum caused by surgery or radiation therapy can lead to bowel problems, including bleeding from the rectum, diarrhoea, or an urgency to go to the toilet. But this is very rare. Some men find they have softer stools during radiotherapy, but this resolves in time after the treatment has stopped.

Erectile dysfunction
Some treatment can damage the nerves and blood supply to the penis, making it difficult to get or keep an erection, called erectile dysfunction. Unfortunately, erectile dysfunction is the most common side effect of prostate cancer treatment. However, there are options for managing this during treatment. Most men (with intact nerves) see an improvement over time once treatment has stopped.

For more information, see our section on what it is like living with prostate cancer.

Monitoring cancer
Monitoring means your doctor will keep a close eye on you rather than recommending treatment straight away. You may feel fearful or angry about monitoring your cancer rather than receiving treatment. But all treatments have side effects, and your doctor will not recommend treatment if he or she believes the risks outweigh any benefit you might get.

There are two types of monitoring. Check with your doctor which type you are being offered.

Diagnostic tests
Diagnostic tests are used to confirm or rule out conditions and diseases. They can include blood tests, scans, and biopsies.

With intact nerves
If you are undergoing surgery, depending on the stage and grade of your cancer, you may be offered nerve-sparing surgery. Nerve-sparing surgery aims to reduce the risk of erectile dysfunction and leaking urine.

Unfortunately, some cancers cannot be removed without cutting or damaging the nerves, meaning you might always need treatments to help get an erection.
**Active surveillance**
The aim of active surveillance is to avoid unnecessary treatments. If your doctor has recommended active surveillance, you have low-risk prostate cancer, which has been found at an early stage. Your doctor does not anticipate that the cancer will cause you any immediate symptoms or problems.

Active surveillance may continue for many years if your prostate risk does not increase, but it requires you to follow a scheduled regime which includes PSA tests, prostate checks, as well as an MRI and/or repeated prostate biopsies. Up to half of men on active surveillance never need treatment. If the tests show that your tumour is growing or changing at any stage, you will be offered treatment. Your treatment options, such as surgery, will aim to cure the cancer.

**Watchful waiting**
The aim of watchful waiting is to delay or to avoid the side effects of treatment. If your doctor has recommended watchful waiting, you may not be well enough to have surgery or radiotherapy. It could also be because your doctor does not anticipate that the cancer will cause any problem in your lifetime. Your doctor will prepare a follow-up plan with you, including what checks and tests you will have and how often.

Some men on watchful waiting may still need treatment. If the tests show that your tumour is growing at any stage, or the cancer cells have started to spread to other organs, you will be offered treatment. The treatment offered will aim to control the spread of the cancer and manage any symptoms you have.

**Surgery**

*Radical prostatectomy*
You may be offered an operation to remove your prostate, called a radical prostatectomy. There are 3 different ways of removing the prostate: **laparoscopic** or “keyhole” surgery, **robot-assisted keyhole surgery**, or **open surgery**. Your doctor will discuss the surgery method, which is most appropriate for you.

A radical prostatectomy is a major operation, and each method has its risks. The aim of the surgery is to cure the cancer.

**Radiotherapy**
Radiotherapy uses high energy x-ray beams (radiation) to destroy cancer cells. There are two different types of radiotherapy:
1. external beam radiotherapy
2. brachytherapy

Radiotherapy treatment is painless, but there are side effects caused by both types of treatment that may cause you problems. Your doctor will discuss your options and the potential side effects with you.

**External beam radiotherapy**
External beam radiotherapy uses a machine, called a linear accelerator, or LINAC, to give the radiation treatment from the outside of the body. Using the machine, the **radiographer** can direct the treatment to an exact point on your body. The aim is to destroy the cancer cells inside your prostate.

*Laparoscopic*
During laparoscopic, or keyhole, surgery, a surgeon will remove the prostate using several small cuts in your tummy. The surgeon will also use a small camera, called a laparoscope, to help them see the prostate clearly during the procedure.

**Robot-assisted keyhole surgery**
Robot-assisted keyhole surgery is done by trained surgeons, so it is only available in certain hospitals. It is sometimes called RARP or RALP. During the procedure, the surgical equipment is attached to robotic arms, which are controlled by the surgeon.

**Open surgery**
Open surgery involves one large cut into your tummy or the area between your scrotum and back passage.

**Radiographer**
External beam therapy is given by a trained therapeutic radiographer. Therapeutic radiographers specialise in treating cancer using radiotherapy techniques.
body without damaging healthy tissue or organs. External beam therapy is often given in addition to other prostate cancer treatments, particularly hormone treatments (also called Androgen Deprivation Therapy or ADT).

**Having external beam radiotherapy treatment**

Before you have external beam radiotherapy, you will need a **CT scan**. The results will help the radiographer work out the exact point and dose of radiotherapy. A permanent mark will be made on your skin to ensure the radiation beam is directed to the same position at every treatment session.

**Brachytherapy**

Brachytherapy is a radiation treatment given from the inside of the body. Small, radioactive metal pieces, commonly referred to as “seeds,” are inserted directly into the prostate under a **general anaesthetic**. Radiation is slowly released from the seeds over a few months. The radiation destroys the cancer cells inside the prostate, but it limits radiation that reaches the nearby tissues and organs. Your doctor will discuss any concerns you might have about radiation and advise on modern techniques to reduce this risk.

**Having brachytherapy**

During the procedure, an ultrasound probe will be passed into your back passage (rectum). This helps the doctor work out how many seeds to inject into the prostate and exactly where they should be placed. The stage of your cancer will determine the dose of radiation your doctor advises.

**Hormone therapy**

**Testosterone** causes prostate cancer to grow, so the most common way of controlling how much testosterone there is in your body is to have hormone therapy. This is also known as androgen deprivation therapy or ADT. Your doctor may recommend hormone therapy to reduce the amount of testosterone in your body. It is usually available as injections, implants, tablets, or a nasal spray.

**CT scan**

A CT scan uses x-rays taken at different angles to a 3D image of the inside of your body.

**General anaesthetic**

A general anaesthetic is a controlled way of forcing you to fall asleep, so you are unaware of the procedure being done.

**Testosterone**

A hormone, or chemical, made by the testicles which controls how the prostate works.
Some men may have hormone therapy before, during, or after radiotherapy or chemotherapy. Other men may only have hormone therapy. Hormone therapy is used for all prostate cancer stages, but it is the main treatment for men with advanced prostate cancer.

Your doctor will discuss your treatment options with you.

**LHRH agonists**

LHRH agonists are usually given as injections or implants. They work by blocking messages from the brain that tell your testicles to make testosterone. Treatment with these drugs is sometimes called “chemical” or “medical castration.” This is because the effect on the body is the same as having your testicles removed.

Common LHRH agonists are shown below. All drugs have a generic name and a name given by the pharmaceutical company that produces them. This is called a trade name.

<table>
<thead>
<tr>
<th>Generic name</th>
<th>Trade name(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Buserelin</td>
<td>Suprefact®</td>
</tr>
<tr>
<td>Goserelin</td>
<td>Zoladex®, Reseligo®</td>
</tr>
<tr>
<td>Leuprorelin or Leuprolide</td>
<td>Eligard®, Staladex®, Enanton®, Prostap®, Lucrin®, Lutrate®</td>
</tr>
<tr>
<td>Triptorelin</td>
<td>Decapeptyl SR®, Salvacyl®, Diphereline®, Gonapeptyl®</td>
</tr>
</tbody>
</table>

Your doctor will discuss which LHRH agonists treatment is recommended for you.

It is common for the body to produce a testosterone surge when you first start LHRH agonist treatment. This is called a “flare”. Flares can make your symptoms worse to begin with, and they may cause the tumour to grow quickly for a short time. Because of this, you will also be given tablets to take, known as anti-androgen. These tablets stop testosterone from reaching the cancer cells, so they cannot grow.

**LHRH antagonists**

LHRH antagonists work in a slightly different way to LHRH agonists. They prevent the testicles from making testosterone but do not cause flares as LHRH agonists do, so you will not need to take anti-androgen tablets.

Degarelix (Firmagon®) is the LHRH antagonist treatment available in Europe. It is given as a monthly injection under the skin.

**Orchidectomy**

Some men may be offered an operation to remove their testicles. This is called an orchidectomy, or surgical castration. An orchidectomy is a straightforward operation. It is usually done using a local anaesthetic, but it can be done under a ‘general’ anaesthetic. With both types of anaesthesia, you will not feel anything during the surgery. If you have a ‘local’ you will be awake the whole time and if you have a ‘general’ you will be asleep during the procedure. Once done, an orchidectomy cannot be reversed, so you need to be sure this is the right treatment option for you.

Advanced prostate cancer
Cancer that has spread from the prostate to other parts of the body through the bloodstream.

LHRH
Luteinising hormone-releasing hormone (LHRH).
**Anti-androgens**

Anti-androgens are a group of drugs that stop testosterone from entering the cancer cells, preventing the cells from growing. They are usually given alongside other hormone treatments or radiotherapy. But you may be offered anti-androgen treatment on its own to see if it will shrink your tumour.

If you are prescribed anti-androgen tablets, you will also need to have regular blood tests. This is to check your levels of blood cells and how well your liver and kidneys are working.

Your doctor will discuss which anti-androgen drug best manages your stage of prostate cancer. You may want to know the names of the different anti-androgen drugs that may be available to you. Please be aware that some of the drugs listed may not be available across the whole of Europe.

<table>
<thead>
<tr>
<th>Generic name</th>
<th>Trade name(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bicalutamide</td>
<td>Casodex®, Bicalutamid®</td>
</tr>
<tr>
<td>Flutamide</td>
<td>Flutasin®, Flutamid®</td>
</tr>
<tr>
<td>Nilutamide</td>
<td>Anandron®</td>
</tr>
<tr>
<td>Cyproterone</td>
<td>Cyprostat®</td>
</tr>
<tr>
<td>Apalutamide</td>
<td>Erleada®, Erlyand®</td>
</tr>
<tr>
<td>Darolutamide</td>
<td>Nubeqa®</td>
</tr>
<tr>
<td>Enzalutamide</td>
<td>Xtandi®</td>
</tr>
</tbody>
</table>

**Abiraterone**

Abiraterone (Zytiga®, Yonsa®) is a different type of hormone therapy. It is usually offered to men with **advanced prostate cancer** whose cancer does not respond to other treatments. It is taken as tablets rather than injections.

Like other hormone treatments, it works by stopping the body from producing testosterone, but differently from other treatments. Abiraterone treatment is not a cure, but it can help keep the cancer under control and help with some of your symptoms.

If you choose to take abiraterone, you will also have to take steroid tablets. Taking steroids in combination with abiraterone will lower your chances of having side effects of the treatment.

**Chemotherapy**

Chemotherapy is usually offered to men who have been diagnosed with **advanced prostate cancer** and are fit enough to tolerate the treatment. Chemotherapy is not a cure, but it can help keep the cancer under control.

Common chemotherapy drugs include:
1. Docetaxel
2. Cabazitaxel

Chemotherapy is a powerful medication that destroys cancer cells in the body. It is given directly into your bloodstream through a vein. The drug travels around your whole body, killing any cancer cells it finds. Sometimes healthy cells can also get damaged during treatment.

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**Advanced prostate cancer**

Cancer that has spread from the prostate to other parts of the body through the bloodstream.
Chemotherapy can cause various unpleasant side effects. Each man reacts differently to the treatment but choosing to have chemotherapy is not an easy decision. Take your time discussing the potential side effects and benefits with your doctor, as well as your family.

**Other treatments**

**High intensity focused ultrasound (HIFU)**
High intensity focused ultrasound, or HIFU, uses ultrasound beams to generate heat, destroying areas of the prostate containing cancer cells. It is usually only given to men with *early-stage* prostate cancer.

The treatment can be given to the whole prostate if you have several tumours or given to a small area of the prostate. Both methods are done under a **general anaesthetic** or a **spinal anaesthetic**.

During the procedure, an ultrasound probe is gently passed into the back passage (rectum). The probe is surrounded by a cooling balloon to protect your back passage from the heat. As well as generating heat, the probe also produces ultrasound images of the prostate. This helps your doctor see the tumour(s) more clearly.

**Having HIFU treatment**
HIFU is a specialised technique and is not available in all hospitals. In some countries, HIFU may be available as part of a clinical trial.

**Cryotherapy**
Cryotherapy involves having thin needles inserted into the prostate through the skin between the testicles and the back passage (rectum). Once in place, gas is passed through the needles and freezes the tumour(s), destroying the cancer cells inside. It is usually only given to men with *early-stage* prostate cancer.

The treatment can be given to the whole prostate if you have several tumours or given to a small area of the prostate. Both methods are done under a **general anaesthetic** or a **spinal anaesthetic**.

**Early-stage**
Early stage cancer means your cancer is Stage 1 or Stage 2. This means the tumour is contained, or “localised” in your prostate.

**General anaesthetic**
A general anaesthetic is a controlled way of forcing you to fall asleep, so you are unaware of the procedure being done.

**Spinal anaesthetic**
A spinal anaesthetic numbs the lower half of your body, so you will not be able to feel anything during the procedure.
**Having cryotherapy treatment**
During the procedure, an ultrasound probe is gently passed into the back passage. The probe produces ultrasound images of the prostate to help your doctor see the tumour(s) more clearly and make sure the needles are inserted correctly.

Cryotherapy is a specialised technique and is not available in all hospitals. In some countries, cryotherapy may be available as part of a clinical trial.

**Living with cancer**

**What is it like living with prostate cancer?**
Living with prostate cancer can affect your everyday life, work, and relationships. You may experience side effects from treatment, even when the treatment has finished, which can affect your physical health. You may also be worried about your cancer coming back, which can greatly impact your mental health.

It is important to know that you are not alone. Talk to your doctor about local support groups or counselling services that may be helpful to you and your loved ones.

**Physical and emotional effects**

**Extreme tiredness**
Extreme tiredness, or fatigue, is very common in men with prostate cancer and can affect everyday tasks, social activities, sleep, and overall concentration. If you are feeling fatigued, you should not drive.

Some men cope better with fatigue than others. If you are usually active, you may feel frustrated by an extreme lack of energy. These feelings are normal. Sometimes small changes to help improve your fatigue can help you feel in control of your cancer.

**Leaking urine**
If you have had surgery to treat your prostate cancer, then you may find you leak urine. This is entirely normal. Some men find they only leak a little, and some men find they leak a lot. For most men, the leaking lessens over time. Leaking urine can feel embarrassing, but there are products you may find helpful. Incontinence pads line your underwear and absorb any leaking urine. They are discrete, so no one will know it is there.

Talk to your doctor about other treatments and products that may be helpful to you.

**Difficulty passing urine**
If you are having difficulty passing urine, it may be because your tumour is causing your prostate to press against the **urethra**. Your doctor may recommend medication or an operation to remove part of your prostate, called a trans-urethral resection of the prostate, or TURP. This operation will not cure your cancer but will help you pass urine much more easily.

**Sex and relationships**
Being diagnosed with prostate cancer can affect your desire for sex. You might feel down, angry, or stressed, and these emotions can change your feelings about sex.

_Urethra_
The urethra is the tube that empties urine from the bladder.
Some treatment can damage the nerves and blood supply to the penis, making it difficult to get or keep an erection, called erectile dysfunction. If you have had hormone therapy, this can also affect your desire for sex.

If you have a partner, talking about sex and how you are dealing with your cancer can help. It can be difficult talking about sex, but your doctor can help you get treatment and support.

**Emotions**
Being told you have cancer can be a big shock, even if you had prepared yourself for the possibility of your tests being positive. Advances in science, medicine, and technology mean that many people are cured of cancer or live with it for many years. Despite this, a cancer diagnosis can cause different fears and emotions for you and your loved ones.

Living with prostate cancer can affect your everyday life, work, and relationships. If you are struggling to cope, try not to hide your emotions. Talk to your family and friends.

If you think speaking to a professional might help, ask your doctor for the details of local counselling services to get you the help you need.

**Hormone changes**
Testosterone is mainly made by the testicles and controls how the prostate works. Hormone therapy lowers the amount of testosterone in your body, which can affect your overall mood, including your desire for sex. You may feel tearful or angry, or just not your usual self. These feelings are normal and can be caused by hormone therapy.

**Practical issues**

*Will I be able to work?*
For some men, returning to work helps them get back to everyday life. But not everyone can continue working. You may decide to work part-time or take early retirement. There is no right or wrong answer.

You may need to take time off work, depending on the treatment options offered to you. You may also need to take extra breaks at work, particularly if you are feeling exhausted.

You might find it helpful to look at your company policies and employee handbook or speak to the Human Resources department at your workplace for more advice.

*Will I be able to travel?*
If you drive, you need to be very careful about how your treatment is affecting you. Do not drive if you are tired or do not feel well. If you plan to travel abroad, having cancer can affect where you go and how long you go away. Having cancer should not stop you from travelling. Still, it may affect travel insurance, car hire insurance, what you need to take with you, and the activities you do while you are away.

**Palliative care**
If you have advanced prostate cancer, you may hear the term supportive, or palliative, care. The focus of palliative care is to manage any pain you have and help find ways of coping with distressing symptoms. It also provides support for your family and for people looking after you.

Palliative care is not just for men in the final stages of their life, but it does include support to help you prepare for this. Various professionals will be on hand to help manage
your symptoms and offer you and your family the emotional and practical support you need. The type of professionals and services available to you will depend on your needs and your local area.

## Recurrence

### What happens if the cancer comes back?

It can be extremely difficult to find out that your cancer has come back. All of the thoughts and feelings you had when you were first diagnosed can come back too. These feelings and fears may even be stronger than before. Some men find that using the same coping mechanisms they did during their first cancer diagnosis helps them deal with another cancer diagnosis.

For many men, even when the cancer comes back after treatment, it may still be slow-growing, and they continue to live long and active lives. Your doctor will discuss your treatment options with you.

If your cancer has come back, you may hear it called “recurrence,” as well as other terms like local, locally-advanced, regional, distant, or metastasis. These terms can feel very overwhelming.

### Local recurrence

The new tumour is in the prostate again. The cancer has not spread to other parts of the body. If you have local recurrence, you might be offered further treatment to get rid of the cancer again.

### Regional or locally-advanced recurrence

The cancer has spread to the area just outside the prostate, but it has not spread to other parts of the body. You might be offered further treatment to get rid of the cancer again.

### Distant or metastatic recurrence

The cancer has spread, or “metastasised,” to other parts of your body. There may also be cancer cells in your blood or bones. Treatment can no longer cure the cancer.

Hearing that your cancer cannot be cured is distressing and can be a shock. There still may be treatments to help control the spread of the cancer cells, such as hormone therapy or chemotherapy.

Your doctor may start talking to you about supportive or palliative care. The focus of palliative care is to manage any pain you have and help find ways of coping with distressing symptoms. Palliative care is not just for men in the final stages of their life. Men with metastatic recurrence may receive palliative care for many months or years.
My notes and questions
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