MACMILLAN
CANCER SUPPORT

UNDERSTANDING EARLY (LOCALISED) PROSTATE CANCER

> Since my diagnosis I have used my experiences to help others and put their minds at rest as much as I could.

Simon, diagnosed with early (localised) prostate cancer

About this booklet

This booklet is for anyone who has been diagnosed with early (localised) prostate cancer. This is when the cancer cells are only inside the prostate. There is also information for carers, family members and friends.

The booklet explains the different treatments for prostate cancer and their side effects. It has information about making treatment decisions and managing the effects of treatment. It explains the feelings you may experience and possible effects on your relationships.

We hope it helps you deal with some of the questions or feelings you may have.

This booklet does not have information about cancer that has grown through the capsule surrounding the prostate. We have another booklet about this called **Understanding locally advanced prostate cancer** (see page 136).

We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 3 to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

On pages 141 to 150, there are details of other organisations that can help. There is also space to write down questions and notes for your doctor or nurse (see pages 151 to 152).

Quotes

In this booklet, we have included quotes from people who have had early (localised) prostate cancer, which you may find helpful. These are from people who have chosen to share their story with us. This includes Simon, who is on the cover of this booklet. To share your experience, visit **macmillan.org.uk/shareyourstory**

For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm, or visit **macmillan.org.uk**

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

We have some information in different languages and formats, including audio, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call **0808 808 00 00**.

Help us improve our information. Scan the QR code below to tell us what you think.

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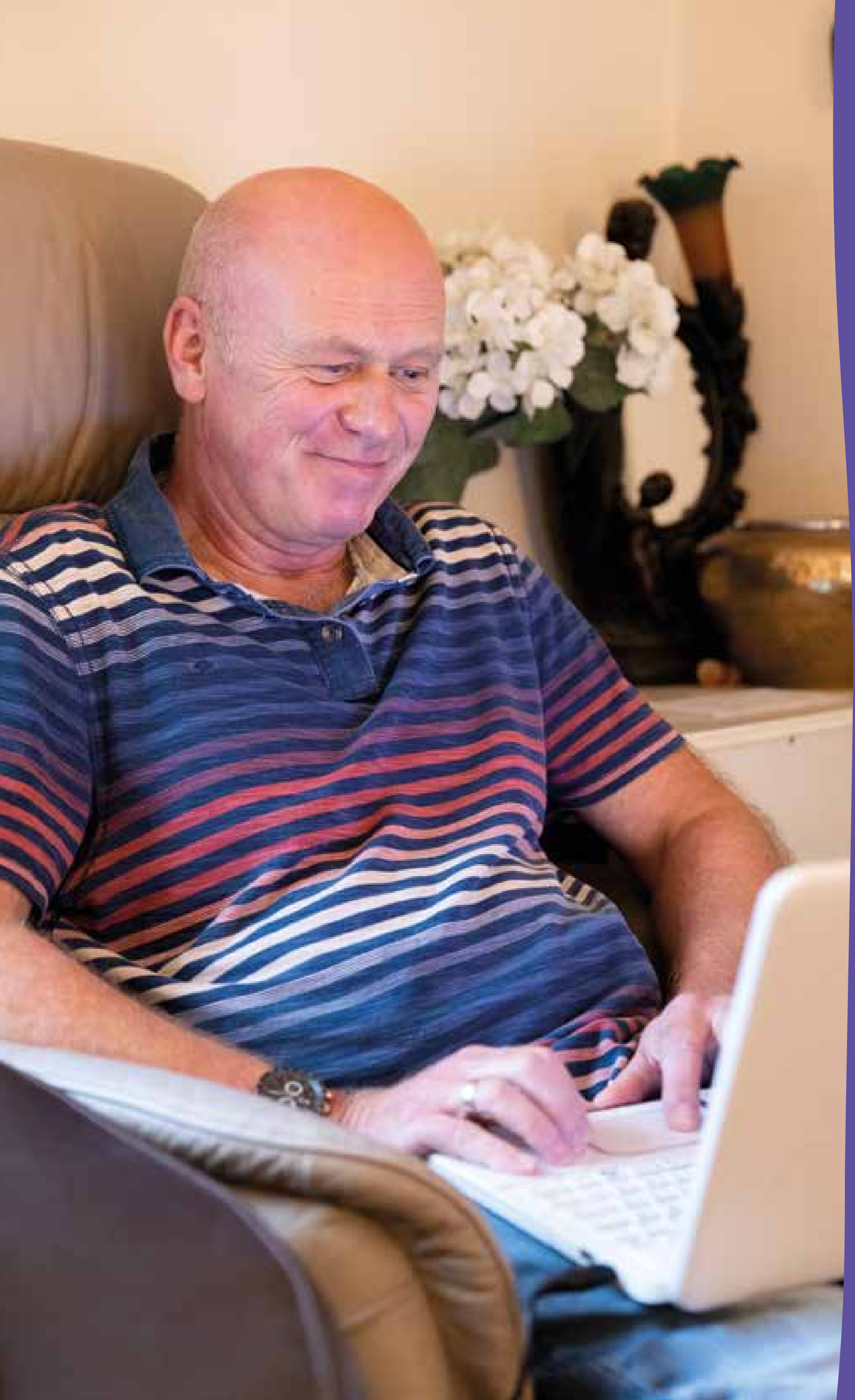


ABOUT PROSTATE CANCER

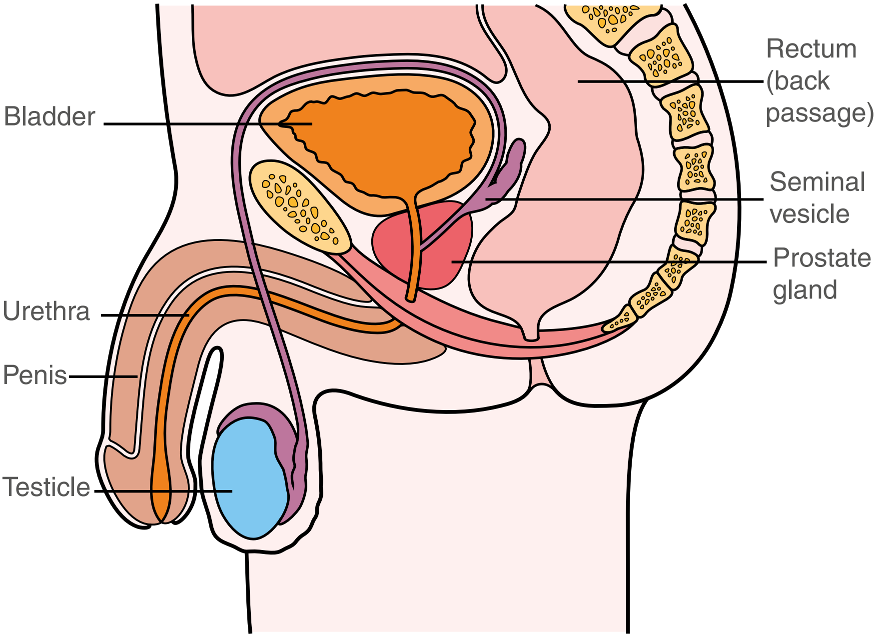
The prostate

The prostate is a small gland about the size of a walnut. It is divided into 2 lobes and surrounded by an outer layer called the capsule. The prostate gets bigger as you get older.

The prostate is below the bladder, surrounding the first part of a tube called the urethra. The urethra carries pee (urine) from the bladder to the penis. The same tube also carries semen, which is the fluid containing sperm. Just behind the prostate is the back passage (rectum). There are also lymph nodes (sometimes called glands) near the prostate – see page 10.

The prostate contains muscle tissue and glandular tissue. Glandular tissue releases (secretes) certain substances.

The prostate



What does the prostate do?

The prostate produces a fluid that mixes with sperm from the testicles to make semen. This fluid is stored in 2 tube-shaped glands called the seminal vesicles. They are found just behind the bladder. During sex, the muscle tissue helps force (ejaculate) prostate fluid and sperm into the urethra.

The sex hormone testosterone is made by the testicles. It controls how the prostate works. Testosterone is responsible for things like your sex drive, getting an erection, and muscle development.

The prostate also produces a protein called prostate-specific antigen (PSA). This helps to make semen more watery. A blood test can measure PSA. This is called a PSA test. Doctors use it to help diagnose different prostate problems, including cancer. We have more information about the PSA test on our website (see page 136).

If you are a transgender woman

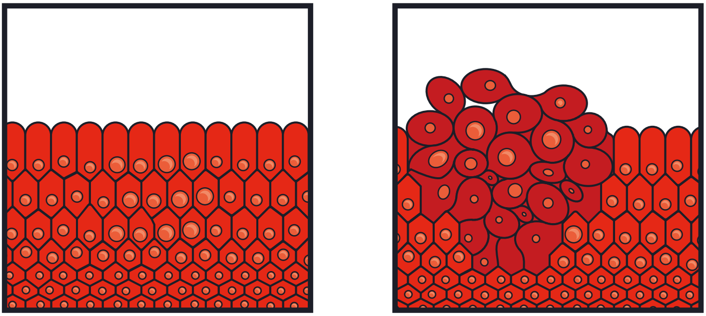
People who have a prostate include men, transgender (trans) women and people assigned male at birth. If you are a trans woman and have had genital gender-affirming surgery as part of your transition, you will still have a prostate. It is important to talk to your GP or nurse if you are worried about prostate cancer or have symptoms.

What is cancer?

Cells are tiny building blocks that make up the body's organs and tissues. Cells receive signals from the body, telling them when to grow and when to divide to make new cells. This is how our bodies grow and heal. These cells can become old, damaged or no longer needed. When this happens, the cell gets a signal from the body to stop working and die.

Sometimes these signals can go wrong, and the cell becomes abnormal. The abnormal cell may keep dividing to make more and more abnormal cells. These can form a lump, called a tumour.

Cells forming a tumour


Normal cells

Cells forming a tumour

Not all tumours are cancer. Doctors can tell if a tumour is cancer by taking a small sample of cells from it. This is called a biopsy. The doctors examine the sample under a microscope to look for cancer cells.

A tumour that is not cancer (a benign tumour) may grow, but it cannot spread to anywhere else in the body. It usually only causes problems if it grows and presses on nearby organs.

A tumour that is cancer (a malignant tumour) can grow into nearby tissue.

Sometimes cancer cells spread from where the cancer started (the primary site) to other parts of the body. They can travel around the body in the blood or through lymph fluid which is part of the lymphatic system (see page 10). When these cancer cells reach another part of the body, they may grow and form another tumour. This is called a secondary cancer or a metastasis.

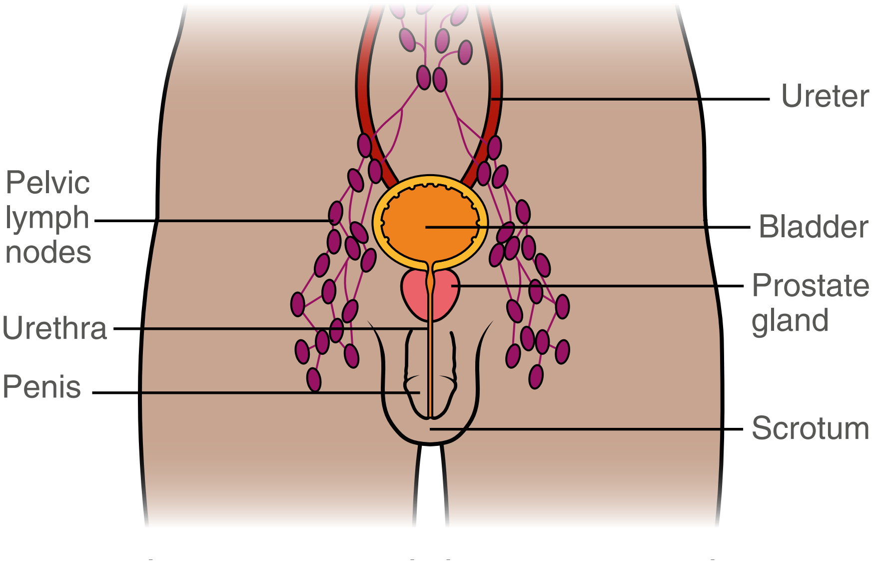
The lymphatic system

The lymphatic system helps protect us from infection and disease. It is made up of fine tubes called lymphatic vessels. These vessels connect to groups of small lymph nodes throughout the body. The lymphatic system drains lymph fluid from the tissues of the body before returning it to the blood.

Lymph nodes are sometimes called lymph glands. They filter bacteria (germs) and disease from the lymph fluid. When you have an infection, some lymph nodes may swell as they fight the infection.

If prostate cancer cells spread to the lymph nodes, they usually go to the nodes close to the prostate. In early prostate cancer, the cells have not spread to the lymph nodes.

Prostate lymph nodes



Early prostate cancer

Prostate cancer is the most common cancer in men in the UK. About 48,600 men are diagnosed with it each year. It is more common over the age of 65. Although it can happen at a younger age, it is uncommon under the age of 50. There is a higher risk of getting prostate cancer at a younger age if you are Black or have a strong family history of prostate cancer (see pages 13 to 15).

Early prostate cancer is when the cancer cells are only inside the prostate. The cancer has not spread through the capsule that surrounds the prostate. It may also be called localised prostate cancer. We call it early prostate cancer in this information.

Sometimes prostate cancer grows very slowly. It may not cause any problems and not all cancers will need to be treated. Other prostate cancers grow faster and need to be treated to stop them spreading.

If you are a trans woman or are non-binary or assigned male at birth, you also need to be aware of prostate cancer. Prostate cancer may affect trans women, but there is not enough evidence to know how common this is.

Prostate cancer UK has detailed information about trans women and prostate cancer (see page 141). The LGBT Foundation can also give you confidential advice and support (see page 149). You can also talk to one of our cancer support specialists (see page 138).

Risk factors and causes

Doctors do not know the exact causes of prostate cancer. But there are risk factors that can increase the chance of getting it. Having one or more risk factors does not mean you will get prostate cancer. There are different risk factors that may affect the risk of getting prostate cancer.

Age

This is the strongest risk factor for prostate cancer and your risk increases from the age of 50. It is uncommon under the age of 50 and more common over the age of 75. Risk factors like ethnicity and family history are linked with getting prostate cancer at a younger age.

Ethnicity

If you are Black, you have a much higher risk of developing prostate cancer. The reason for this is not clear, but it may be because of genetic factors. You are also more likely to develop prostate cancer at a younger age.

If you are Black and aged 45 or over, Prostate Cancer UK has more information about your risk (see page 141). It gives advice on talking to your GP about your risk of getting prostate cancer and helps you to make decisions about having a PSA test.

If you are Asian, your risk of prostate cancer is much lower. We do not know why this is.

Family history

Sometimes there may be a possible family (inherited) link that increases your risk. The risk of prostate cancer is higher if you have:

- either a father or brother who had prostate cancer – the risk is greater if they were diagnosed under the age of 60
- 2 or more close relatives (father, brother, grandfather, half-brother, uncle) on the same side of the family who had prostate cancer
- a mother who had breast cancer
- inherited certain cancer gene changes (mutations).

We get a copy of each of our genes from both parents. Genes are the instructions that tell our cells what to do. Doctors think 5 to 10 out of 100 prostate cancers (5% to 10%) are linked to inherited gene changes.

Rarely, prostate cancer may be linked to changes in certain genes. They are called BRCA1 and BRCA2. These altered genes increase the risk of breast and ovarian cancer in women. If you have inherited the BRCA2 gene change, your risk of prostate cancer is 5 times higher. The BRCA1 gene may also increase your risk, but this is not as clear.

Prostate cancer risk is also higher if you have Lynch syndrome. Lynch syndrome is also called hereditary non-polyposis colorectal cancer (HNPCC). Lynch syndrome is rare but can increase the risk of a number of cancers.

Talk to your GP if you have a family history of cancer and are worried about your risk of prostate cancer.

We have more information about family history and cancer in our booklet **Cancer genetics – how cancer sometimes runs in families** (see page 136).

Body weight and diet

Being very overweight (obese) may increase the risk of having a more advanced prostate cancer. It may also increase the risk of having a faster-growing type of prostate cancer.

Eating a balanced diet and doing regular physical activity will keep you to a healthy weight. We have more information in our booklets **Healthy eating and cancer** and **Physical activity and cancer** (see page 136).

STAGE, GRADE AND RISK GROUPS

Staging

The stage of a cancer describes its size and how far it has spread. The results of your tests help your doctors decide on the stage. We have more information about these tests in our booklet **Having tests for prostate cancer** (see page 136).

Doctors often use the TNM staging system or a number staging system for prostate cancer.

TNM staging system

This gives information about:

- the tumour (T)
- whether the cancer has spread to any lymph nodes (N) – early prostate cancer is always N0 as it has not spread to the lymph nodes
- whether the cancer has spread to another part of the body, called metastasis (M) – early prostate cancer is always M0 because it has not spread to another part of the body.

Tumour

Doctors put a number next to the T to describe the size and spread of the cancer.

T1 – the tumour is contained in the prostate. It is too small to be felt on rectal examination or seen on a scan. It may have been diagnosed by a biopsy for a raised PSA level. Or, it may have been diagnosed by chance after surgery to remove part of the prostate to make peeing (passing urine) easier.

T2 – the tumour is still contained in the prostate. But it can be felt when the doctor does a rectal examination or is seen on a scan. T2 tumours are divided into:

- T2a – the tumour is only in half of 1 of the 2 lobes of the prostate
- T2b – it is in more than half of 1 lobe
- T2c – it is in both lobes.

T1 and T2 tumours are not likely to affect the lymph nodes or to spread. Doctors call this early or localised prostate cancer.

T3 and T4 tumours have started to spread outside the prostate and may be growing into tissues or organs close by. If the cancer has not spread to another part of the body, such as the bones, it is called locally advanced prostate cancer.

When it has spread to another area, it is called advanced or metastatic prostate cancer.

Number staging system

Number staging brings together different parts of the TNM staging system and gives it a number stage. Early (localised) prostate cancer is contained in the prostate and has not spread outside it. It is:

- stage 1 when the cancer is very small
- stage 2 when the cancer is a bit bigger.

Gleason score and Grade Group

A doctor decides the grade of the cancer by how the cancer cells look under the microscope. This information comes from your biopsy results.

The grade gives an idea of how quickly the cancer might grow or spread. Doctors use a combination of 2 systems to grade the cancer. These are called:

- Gleason score
- Grade Group.

Gleason score

This examines the pattern of cancer cells in the prostate tissue, and how they look and act, compared with normal cells.

There are 5 different patterns, graded from 1 to 5. Grade 1 and 2 look like normal prostate tissue. But grade 5 is very different to normal tissue.

There may be more than 1 grade. The doctor examines all the biopsy samples taken and decides on:

- the most common grade
- the highest grade.

They add these together to give your Gleason score. A Gleason score of 7 could be:

- 3 + 4 – the most common grade is 3 and the highest grade is 4

or

- 4 + 3 – the most common and highest grade are both 4, but there is also some grade 3 present.

What your Gleason score means

If your Gleason score is between 6 and 10, the cancer is:

- Gleason score 6 – slow growing
- Gleason score 7 – intermediate grade (between slow and fast-growing)
- Gleason score 8 to 10 – high grade (more likely to grow quickly).

Grade Group

This grades the cancer between 1 and 5 based on your Gleason score. The lower the Grade Group, the less likely the cancer is to grow and spread.

There are 5 Grade Groups:

- Group 1 – Gleason score 6
- Group 2 – Gleason score 7 (3+4)
- Group 3 – Gleason score 7 (4+3)
- Group 4 – Gleason score 8
- Group 5 – Gleason score 9 to 10.

If you are in Group 3, where the highest grade is most common, you may need more treatment than Group 2.

Risk groups for early prostate cancer

Early prostate cancer is divided into risk groups. Before planning your treatment, your cancer doctor will look closely at your risk group. This helps you and your doctors to decide on the best treatment for you. The treatment options for each risk group can be different.

To work out your risk group, your doctors look at:

- your PSA level
- your Gleason score – the pattern of the prostate cells and how they compare with normal prostate cells (see pages 20 to 21)
- the stage of the cancer – the size of the tumour and how far it has spread.

Low-risk prostate cancers

Low-risk prostate cancer has all of the following:

- a PSA level of under 10
- a Gleason score of 6 or under
- a stage number of T1 to T2a.

These low-risk cancers are unlikely to grow or spread for many years.

Intermediate-risk prostate cancers

Intermediate-risk prostate cancer has any of the following:

- a PSA level 10 to 20
- a Gleason score of 7 or under
- a stage number of T2b.

These cancers are unlikely to grow for a few years.

High-risk prostate cancers

High-risk prostate cancer has any of the following:

- a PSA level that is higher than 20
- a Gleason score of 8 to 10
- a stage number of T2c or more.

High-risk cancers are more likely than the other risk groups to grow or spread in a few years. They are more likely to be locally advanced prostate cancer. Your doctor and specialist nurse can give you more information about your risk group.

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you, your cancer diagnosis and your treatment is collected in a cancer registry. This is used to plan and improve health and care services. Your hospital will usually give this information to the registry automatically. There are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research.

Talk to your doctor or nurse if you have any questions. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out.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TREATING EARLY PROSTATE CANCER

Treatment overview

There are different treatments that can cure early prostate cancer. Your doctor and nurse will help you understand what they involve and how they may affect your life. Making treatment decisions can be difficult, but there is support to help you. We have more information in our booklet **Making treatment decisions** (see page 136).

Your treatment will depend on:

- your general health
- your age
- the risk group of the cancer (see pages 22 to 23)
- your preferences.

Your doctor will talk to you about the different things to think about when making treatment decisions. They will explain the different benefits and disadvantages of each treatment. You and your doctor can then decide on the best treatment for you. How you feel about treatments and your preferences are a personal choice. What is important to one person might not be to someone else. You can also use the NHS online decision aid called Predict. Visit **prostate.predict.nhs.uk**

Treatments

The main treatments for early prostate cancer include the following:

- Active surveillance to monitor the cancer, which can help to avoid unnecessary treatment (see pages 41 to 43).
- Surgery to remove the prostate (prostatectomy). This is usually done with keyhole surgery (laparoscopic) or robotic surgery, which means you usually recover quickly – see pages 45 to 56.
- External radiotherapy, which you usually have over a few weeks as an outpatient. Depending on the risk group of the cancer, you may have hormonal therapy as well (see pages 57 to 69).
- Internal radiotherapy called brachytherapy. You may have this on its own or with external radiotherapy. Brachytherapy gives high doses of radiation directly to the prostate (see pages 70 to 78).
- High-intensity focused ultrasound (HIFU) or cryotherapy, which are much less commonly used – see pages 86 to 91.

Sometimes a type of monitoring called watchful waiting, which does not involve scans or biopsies, may be suitable (see page 44). You might decide to have this if you are older and have other health conditions that make it difficult to have surgery or radiotherapy. If there are signs the cancer is growing or causing you symptoms, you can start hormonal therapy (see pages 80 to 85).

Risk groups

In early prostate cancer, doctors usually offer treatments based on the risk group of the cancer.

Low-risk prostate cancer

This type of prostate cancer is very slow growing. It is not likely to cause problems for a long time. Sometimes it never causes problems. Different treatments can be used to cure it. Surgery or radiotherapy are the main treatments, and these are widely available on the NHS.

To begin with, you and your doctor may talk about whether you need treatment. This usually depends on:

- the risk of the cancer progressing
- your feelings about the advantages and disadvantages of treatment.

Your doctor assesses the risk of the cancer progressing using your biopsy, PSA test and scan results (see pages 22 to 23). You can also use the online decision aid called Predict. Visit **prostate.predict.nhs.uk**

There may be benefits in avoiding treatment and its side effects. But not having treatment may also involve a certain amount of risk. Even without treatment, there is usually very little or no chance of dying from low-risk prostate cancer in the next 10 years after your diagnosis. But there is a small risk of the cancer spreading compared with having treatment straight away. To manage this risk, your doctor may advise monitoring the cancer. This means having regular tests to make sure the cancer stays under control. This is called active surveillance (AS) – see pages 41 to 43.

If you are older, a decision to avoid treatment may be easier to make. You may feel that low-risk prostate cancer is unlikely to cause you a problem within your lifetime and you could safely avoid treatment.

If you are younger and preserving your erectile function is a priority, avoiding treatment may be important for your quality of life. But you might also worry about the small risk of the cancer progressing in future years.

Some people may also find monitoring stressful. You need a PSA test every few months, and you would have an MRI scan every 1 or 2 years. Depending on your PSA results or changes on the MRI scan, you may also need another biopsy.

Whether to have active surveillance or immediate treatment is a personal choice that only you can make. It is important to remember that if you do choose active monitoring, you can decide to have treatment any time if you change your mind.

Intermediate-risk prostate cancer

You usually have treatment with either external radiotherapy (see pages 57 to 69) or surgery (see pages 45 to 56) straight away. If you have radiotherapy, you may also have brachytherapy (see pages 70 to 78). This is sometimes called a boost. You will also usually have hormone therapy before, during and for a few months after radiotherapy. It makes the cancer easier to treat with radiotherapy and reduces the risk of prostate cancer coming back.

You may decide to have active surveillance if you do not want treatment straight away. If you do not want surgery or radiotherapy, you may choose watchful waiting (see page 44).

High-risk prostate cancer

You usually need more treatment to cure the cancer as there is a higher risk of it spreading. You can have treatment with either a prostatectomy or radiotherapy.

If you have radiotherapy, you will also have brachytherapy as a boost. You will also have hormonal therapy, which may continue for 3 years after radiotherapy.

If your doctor thinks the cancer may not have been completely removed after a prostatectomy, they may advise having radiotherapy afterwards. It destroys any remaining cancer cells left behind.

How your treatment is planned

After your test results, you and your doctor start to talk about your treatment. Your doctor usually meets with other specialists to get their opinions too.

> After the diagnosis I was so confused. When you are told, you only hear one thing – cancer. But my Macmillan nurse phoned me that evening and told me all the things I'd forgotten or missed during diagnosis. Macmillan nurses are angels.

Dougie

Multidisciplinary team (MDT) meeting

A team of specialists meet to talk about the best treatment for you. They are called a multidisciplinary team (MDT).

The MDT look at national treatment guidelines or the latest evidence for the type of cancer you have. If you have any treatment preferences, your doctor will tell them about this.

The MDT will usually include the following professionals:

- Urologist – a doctor who treats problems with the prostate, kidneys, bladder and male reproductive system.
- Surgeon (urologist) – a doctor who specialises in operating on the prostate.
- Oncologist – a doctor who treats people who have cancer.
- Clinical nurse specialist (CNS) – a nurse who gives information about cancer, and support during treatment.
- Radiologist – a doctor who looks at scans and x-rays to diagnose problems.
- Pathologist – a doctor who looks at cells or body tissue under a microscope to diagnose cancer.

The MDT may also include:

- a physiotherapist
- a dietitian
- a counsellor or psychologist.

Talking about your treatment plan

After the MDT meeting, you will usually see your specialist doctor and nurse. They will talk to you about your treatment plan. It can help to write down your questions before you see them. You may want to ask a family member or friend to come with you. They can help remember what is said and talk with you about it afterwards. You need to know as much as possible before you can make any treatment decisions.

Your specialist doctor should explain:

- the aim of the treatment – whether it is to cure the cancer or control it
- the benefits of the treatment
- the disadvantages of the treatment – for example, the risks and side effects
- any other treatments that may be available
- what may happen if you do not have the treatment.

Cancer treatments can be complex. It can also be hard to concentrate on what you are being told if you are feeling anxious. If the doctor says something you do not understand, ask them to explain it again.

Most people worry about the side effects of treatment. Your doctor or nurse will explain how side effects can be controlled and what you can do to manage them. They can also tell you if your treatment is likely to cause any late effects and how these can be managed.

You may need more than one meeting with your doctor or nurse to talk about your treatment plan.

> ‘I had several treatment options but opted for radiotherapy as I thought it would be less invasive. My consultant was fantastic but I found it very difficult to get information on treatment success rates and possible side effects. I wish that I could have sat down with other guys who had been through it.’
>
> **Rob**

Making treatment decisions

You and your doctor decide on the right treatment plan for you. Your doctor is an expert in the best treatments. But you know your preferences and what is important to you. You can decide how involved you want to be in your treatment plan.

When you make treatment decisions, there are different things you may want to think about:

- How you feel about different treatments. You may want surgery, or you may feel it is not the best treatment option for you.
- How you would cope with treatments if you have other health conditions. You may prefer not to have surgery if, for example, you have heart problems. Or if you have a bowel condition, you may want to avoid radiotherapy.
- How much side effects such as erection difficulties are likely to bother you. If active surveillance is suitable, you can avoid erectile dysfunction (ED). After surgery you are more likely to get ED straight away, while with radiotherapy it may be less likely or take longer to develop.
- Whether the cancer is very unlikely to cause you problems over your lifetime. If not, monitoring the cancer with active surveillance or watchful waiting may be more suitable for you.
- How you are likely to cope without having treatment. If this would be difficult for you, then active surveillance may not be best option.
- What your treatment options would be if the cancer came back. You may be able to have radiotherapy after surgery. But it may not be possible to have surgery if you have already had radiotherapy.

Treatment effects on your sex life

The effects of treatment on your sex life and relationships may be a big concern for you (see pages 104 to 115). Your doctor and nurse will explain the likely effects of treatments on your sex life.

Talking about your sex life with your healthcare team can be uncomfortable. But your doctor and nurse are used to talking about these issues, and it is important to ask questions. There are different treatments and support available to improve sexual difficulties. Your doctor or nurse can explain these. Try to let them know how you identify your gender or sexual orientation if there are issues you want to talk about. If you have a partner, it may help to bring them with you for support.

Prostate Cancer UK provides specific information and support for gay and bisexual men about the side effects of treatment and living with prostate cancer (see page 141).

Fertility

Prostate cancer treatments can affect your fertility. If this is a concern for you, talk to your doctor or nurse. You may be able to store sperm before treatment starts. We have more information in our booklet **Cancer and fertility – information for men** (see page 136).

Giving your permission (consent)

Doctors need your permission (consent) before you have any treatment. They will give you all the information you need to make your decision. We explain this in our section on talking about your treatment plan.

You can give consent in writing when you sign a form that your doctor gives you, agreeing to a treatment. Or it can be a spoken (verbal) agreement with your doctor. Your doctor records your consent in your patient notes.

You may decide not to have treatment even when your doctor advises you to have it. If you refuse treatment, your decision must be respected. But your doctor needs to make sure you have all the information you need to make your decision. You need to understand all your treatment options and what will happen if you do not have the treatment. Always talk to your doctor about any concerns you have, so they can give you the best advice.

Second opinion

A second opinion is an opinion from a different doctor about your treatment. If you think you want a second opinion, talk to your specialist doctor or GP first. Tell them your concerns or ask them to explain anything you do not understand. This might help reassure you.

If you still want a second opinion, you can ask your specialist doctor or GP to arrange it. They are usually happy to do this. You may have to travel to another hospital to get a second opinion. Getting a second opinion could delay your treatment. Check with your doctor if this delay could be harmful to you.

If the doctor you see for the second opinion gives you the same advice, this can reassure you. Sometimes they give you other treatment options to think about.

We have more information about getting a second opinion on our website (see page 136).

Active surveillance

If you have early prostate cancer that is low risk or sometimes intermediate risk (see pages 22 to 23), your doctor may talk to you about active surveillance. Instead of having treatment to cure the cancer straight away, they monitor the cancer (surveillance) with tests to see if it is growing. In low-risk cancers there is a lot of evidence that it is safe to do this.

Some prostate cancers may grow so slowly that you never need treatment. Or it may be a long time before you do.

Active surveillance means you avoid or delay side effects that can happen with surgery or pelvic radiotherapy.

If tests show the cancer is growing more quickly or you get symptoms, you have treatment to cure the cancer straight away. The risk of the cancer growing without being found with tests is very low.

You will need to talk to your doctor about whether active surveillance is right for you. They will explain the benefits and disadvantages.

You can think about how certain side effects may affect your life, as well as how you feel about how the cancer is managed. You can then decide what is the best option for you. You can also use the NHS online decision aid called Predict. Visit **prostate.predict.nhs.uk**

If at any time you do not feel comfortable with having active surveillance, talk to your doctor. They can arrange for you to start treatment to cure the cancer.

What does active surveillance involve?

Your doctor will arrange for you to have regular tests, for example:

- a multi-parametric MRI scan when you start active surveillance (if you have not already had an MRI scan)
- another MRI scan 12 to 18 months later
- a PSA blood test every 3 to 4 months
- a rectal examination after 12 months.

You may have an MRI scan if the cancer changes. You usually only need a prostate biopsy if there are any signs the cancer may be growing.

After the first year of active surveillance you may have tests less often, for example:

- a PSA blood test every 6 months.
- a rectal examination every 12 months.

If the cancer is not getting any bigger or growing more quickly, it is safe to continue with active surveillance.

Benefits of active surveillance

- You avoid or delay having a prostatectomy or radiotherapy.
- You can avoid or delay the side effects of treatment.
- Your chance of living for another 10 years with active surveillance is the same as with prostatectomy or radiotherapy.

Disadvantages of active surveillance

- You may feel very anxious about not having a treatment that could cure the cancer.
- You may find it too worrying to wait for test results or look out for symptoms.
- There is a small risk the cancer may grow outside the prostate or spread to other parts of the body during active surveillance.

Watchful waiting

If you are not well enough to have a prostatectomy (see pages 45 to 56) or radiotherapy (see pages 57 to 78), your doctor may talk to you about watchful waiting (watch and wait). Or you may choose this approach if you decide you do not want radiotherapy or surgery.

The aim of watchful waiting is to control the symptoms of prostate cancer rather than cure it. You can have treatment if there are signs the cancer is growing, or if it is starting to cause symptoms.

Watchful waiting means you will not have as many tests as with active surveillance.

Instead of having treatment you see your doctor regularly, usually your GP. They will ask if you have any new symptoms, such as difficulty passing urine (peeing) or bone pain. If you do have symptoms, you may have regular blood tests to check your PSA levels.

If you have any symptoms, or your PSA level rises, your GP will refer you back to the specialist at the hospital. They will usually recommend hormonal therapy. This will not cure the cancer, but it can often help control it for many years.

Surgery

Surgery to remove the prostate to treat prostate cancer is called a radical prostatectomy. There are different types of radical prostatectomy

The aim of a radical prostatectomy is to remove all of the cancer cells. It is usually only done when the cancer is contained in the prostate and has not spread to the surrounding area.

A prostatectomy is a big operation and may not be suitable for everyone. It depends on your general health, or any other health condition that could increase the risks of surgery. Your doctor will tell you about other treatments that may also be effective. For example, these may include:

- active surveillance (see pages 41 to 43)
- radiotherapy (see pages 57 to 78)
- brachytherapy (see pages 70 to 78).

Before the operation, the surgeon (a urologist) will explain what will happen and tell you about the possible side effects and risks (see pages 52 to 56).

Types of operation

There are different ways of doing a prostatectomy. Your surgeon will explain the type of operation you will have. It is often done using laparoscopic (keyhole) surgery, with or without a robotic assisted technique. But it is also sometimes done using open surgery.

During the operation, the surgeon usually removes the seminal vesicle which helps make semen. They may also remove the lymph nodes close to the prostate and check them for cancer cells. This depends on your risk of having cancer in the lymph nodes.

Laparoscopic (keyhole) prostatectomy

In this operation, your surgeon does not need to make a large cut. Instead, they remove the prostate using 4 or 5 small cuts (each about 1cm long) in the tummy (abdomen).

The surgeon puts a small tube with a light and camera on the end (laparoscope) through one of the cuts. This shows an image of the prostate on a video screen. They use smaller, specially designed equipment to cut away the prostate from surrounding tissues. They remove the prostate through one of the small cuts.

Robotic-assisted laparoscopic prostatectomy

This is when a laparoscopic prostatectomy is assisted by a machine. It is now a very common way of doing a laparoscopic prostatectomy. Instead of the surgeon holding the tube with the camera (laparoscope) and the surgical equipment, they are attached to robotic arms. The surgeon controls the robotic arms, which they move very precisely. This means the nerves that control erections and passing urine are less likely to be damaged. Your stay in hospital is also likely to be shorter if the robot is used.

Surgeons need special training to do this type of surgery. This means it is not available in all hospitals in the UK. Your surgeon will tell you if it is suitable for you and where you may be able to have it done.

Open prostatectomy

The surgeon makes a cut in your lower tummy (abdomen), so they can remove the whole prostate. Or, sometimes they remove the prostate through a cut they make in the area between the scrotum and the back passage. This area is called the perineum.

Before surgery

Before the operation, your surgeon or specialist nurse will explain the possible risks and side effects (see pages 52 to 56).

You usually have an appointment at a pre-assessment clinic to have tests to check your general health. The nurses may also advise you on what you can do to be fitter for surgery, such as giving up smoking or reducing your weight.

You will be encouraged to start pelvic floor exercises to strengthen the pelvic floor muscles. You can do these at home. This can help reduce urinary leakage (incontinence) after the surgery.

If you think you might need help at home after surgery, tell your nurse when you go into hospital. They can talk to you about the support that is available.

After your prostatectomy

You will be encouraged to start moving around as soon as you can after your operation. This can help reduce the risk of complications such as blood clots. You may also need to have injections when you go home to prevent blood clots. The nurses can tell you more about this.

After a prostatectomy, you will usually have a drip (intravenous infusion) into a vein in your arm. This will stay in for a few hours after your operation, until you are eating and drinking again.

Wound

If you have had an open prostatectomy, you will have a wound on your tummy or a wound between your scrotum and back passage. After a robotic or laparoscopic prostatectomy, you will have a few small wounds in the tummy area.

You may also have a small tube going into the wound. This is called a drain. It helps to remove any fluid that is collecting there. It is usually removed after a few days.

Before you go home the nurses will advise you on how to take care of your wound. They will advise you what to look out for and who to contact if you have any concerns.

Pain

You may have some pain or discomfort after surgery. Painkillers will help with this. In hospital, you may have pain medicines through a drip in your vein, or by injection. This will then be replaced with painkiller tablets. Tell the staff on the ward if you are still in pain. You will be given a supply of tablets to take home with you.

You might have some discomfort for a couple of weeks, particularly when you walk. Taking painkillers regularly should help this. Talk to your doctor or nurse if you are still getting pain.

Catheter

You will have a tube (catheter) to drain urine from the bladder into a bag. Your catheter will usually stay in for a short time after you go home. The catheter lets urine drain while any swelling settles down and the urethra heals. The nurses will explain what to expect. Try to drink plenty of fluids to help keep the catheter draining well.

The nurses will show you how to look after your catheter before you go home. They will give you some spare bags. A district nurse can visit you at home if needed. If you have any problems with your catheter, contact your doctor, nurse, or the ward as soon as possible. The catheter is often removed at the clinic 1 to 2 weeks after the operation.

It is normal to leak urine for a period of time after the catheter has been removed. Your doctor and nurse will talk to you about this.

Going home

If you had laparoscopic or robotic surgery, you can usually go home after 1 to 2 days. After open surgery, it is usually between 3 and 7 days.

You can usually get back to normal activities 4 to 12 weeks after surgery, depending on the operation you had. If you had robotic-assisted surgery, you usually recover faster.

It is important to remember that even if you have small wounds, you have still had major surgery. You will feel tired so try to get plenty of rest and eat well. Do some light exercise, such as walking, to build up your energy. You can slowly increase the amount you do.

Your doctor or nurse can give you advice on when you can start doing things such as driving or returning to work. They can also give you advice on when you can have sex again. We have more information on sex and prostate cancer (see pages 104 to 115).

Follow-up after surgery

After your prostate has been removed, your PSA level should drop so low that it is not possible to detect it in the blood. Your PSA level will be checked about 6 to 8 weeks after surgery. This can help your doctors to know whether they have removed all of the cancer.

You will have a clinic appointment to see the surgeon. They will check that your wound is healing properly and tell you about:

- the tissue removed during surgery (pathology)
- the stage of the cancer
- any further cancer treatment you need
- your recovery after surgery.

Side effects of a radical prostatectomy

Erection problems

Surgery to the prostate can cause problems getting or keeping an erection. This is called erectile dysfunction (ED). This is caused by damage to the nerves and blood vessels close to the prostate that help you get an erection. Surgeons can operate in a way that tries to protect these nerves or blood vessels. This is called a nerve-sparing technique. It is only possible if the cancer has not spread to the edges of the prostate. During surgery, if the surgeon thinks there is cancer in the nerves or surrounding area, they remove some or all the nerves.

Whether you will have problems getting an erection after a nerve-sparing operation depends on different factors. For example, it may depend on your age and if:

- you had erection problems before treatment
- you have any other medical conditions, such as diabetes
- you are taking medicines for high blood pressure
- you have had surgery called a transurethral resection of the prostate (TURP)
- the surgeon was able to spare some or all of the nerves.

You can ask your surgeon about your risk of ED. Your ability to have an erection may slowly return after surgery. But this may take 1 or 2 years. It is less likely to return if you have further treatment after surgery, such as hormonal therapy (see pages 80 to 85) or radiotherapy (see pages 57 to 78).

A prostatectomy can quickly cause erectile dysfunction (ED) problems. You may be offered penile rehabilitation using different ED treatments soon after treatment. This is called an ED recovery package. We have more information about treatments to help ED (see pages 110 to 114).

Ejaculation

If you have your prostate removed, you can still have an orgasm even without an erection, but there will be no ejaculation. This is called a dry ejaculation or dry orgasm. It may cause some discomfort at first, but this usually improves with time. You may pass a small amount of urine when you orgasm. Talk to your doctor or nurse if you are having this problem. They may be able to give you some advice.

Infertility

Having your prostate removed will affect your ability to make someone pregnant. The prostate and seminal vesicle produce semen, which is normally mixed with sperm from the testicles. Removing the prostate means you will not be able to ejaculate any more.

It is important to talk to your cancer doctor or specialist nurse about fertility before treatment. It may be possible to store sperm before your surgery. We have more information in our booklet **Cancer and fertility – information for men** (see page 136).

Bladder problems

Urine leaking from the bladder (urinary incontinence) is a less common side effect of a prostatectomy. It is usual to have some incontinence when the catheter is first removed. This usually improves within a few weeks or months after surgery. You will be encouraged to do pelvic floor exercises to strengthen the pelvic floor muscles. You can wear a pad to manage the incontinence.

Sometimes, you may have some incontinence when you cough, sneeze, or exercise. This is called stress incontinence. It is rare to be completely incontinent. If you are having problems, talk to your doctor or nurse. They can refer you to a continence team, who can give you advice about treatments. If these are not successful, you may be able to have an operation.

Another less common side effect of surgery is scarring to the entrance of the bladder (the bladder neck) or the urethra. Scar tissue can narrow the bladder neck or the urethra and make passing urine difficult. This causes urine to build up in the bladder and overflow, causing you to leak urine. This can usually be treated with a small operation that opens up the bladder neck or the urethra. If you are having problems passing urine after your operation, talk to your cancer doctor or specialist nurse.

> **‘I had prostate surgery and for about the first 3 months after my catheter was removed, I had urinary incontinence. I was getting through a lot of pads. However, I kept doing my pelvic floor exercises and I have found that things have generally got better.’**
>
> **David**

Macmillan toilet card

If you need to use a toilet urgently, you can show this card in places such as shops, offices, cafés, and pubs. You can use it during or after treatment. We hope it allows you to get access to a toilet without any awkward questions. But we cannot guarantee that it will work everywhere. We have more information about how to order a Macmillan toilet card on our website (see page 136).

Benefits of a prostatectomy

- If the cancer has not spread outside the prostate, removing it may cure the cancer and you will not need any more treatment.
- If the cancer comes back, you will still be able to have further treatment.
- If you had urinary symptoms before surgery, these may improve after surgery.

Disadvantages of a prostatectomy

- There may be a small risk of problems after the surgery, such as bleeding or infection.
- Surgery may cause long-term problems with erectile dysfunction and incontinence.
- Removing your prostate means you will no longer be able to make someone pregnant.

Radiotherapy

Radiotherapy uses high-energy rays to treat cancer. It destroys cancer cells in the area where the radiotherapy is given. The aim of radiotherapy for early prostate cancer is to try to cure the cancer. Doctors call this radical radiotherapy. At the same time, they try to make sure radiotherapy causes as little harm as possible to healthy tissue and organs close by. These include the bladder, back passage (rectum) and bowel.

Radiotherapy for prostate cancer can be given in different ways:

- external beam radiotherapy – radiotherapy is given from outside the body (externally) from a radiotherapy machine
- brachytherapy – radiotherapy is given from inside the body (internally).

External beam radiotherapy is the most common way of giving radiotherapy for early prostate cancer. If you have brachytherapy, it may be given on its own or with external radiotherapy.

You might have radiotherapy with hormonal therapy. Your cancer doctor may advise you to have hormonal therapy for 3 to 6 months before radiotherapy. Hormonal therapy can shrink the cancer, which helps make radiotherapy more effective.

You may be given hormonal therapy (see pages 80 to 85) before and after radiotherapy. The length of time you take it for after depends on the risk group you are in.

Smoking

If you smoke, it is important to try to stop. Stopping smoking can make radiotherapy work better. It also reduces the side effects of treatment.

It can be difficult to stop smoking, but you can get support. Your doctor or nurse can give you advice. There are also NHS services to help people stop smoking.

We have more information to help you give up smoking on our website (see page 136).

What is external beam radiotherapy?

You have external beam radiotherapy as an outpatient in the radiotherapy department. Radiotherapy is given using a machine that is like a big x-ray machine. This is called a linear accelerator (often called a LINAC).

You usually have it as a series of short, daily treatments. The treatments are given from Monday to Friday, with a rest at the weekend. Radiotherapy is not painful, but you will need to lie still while you have it.

You usually have radiotherapy over 4 weeks. But in some hospitals, you may have it over 7 weeks. The total overall dose of radiation is higher when you have it over 7 weeks. When you have it over 4 weeks, the dose you get for each treatment session is higher. Both ways are effective, and the side effects are the same (see pages 63 to 68).

Sometimes a type of radiotherapy called stereotactic ablative radiotherapy (or SABR) is given – see page 60. You have this over a much shorter time because it involves much higher doses of radiation.

Your doctor or nurse will explain more about this.
The radiotherapy does not make you radioactive. It is safe for you to be with other people during external radiotherapy, including children.

Types of external beam radiotherapy

There are different, complex techniques that are used to treat prostate cancer more effectively. They can treat the cancer very exactly while protecting healthy tissue and reducing side effects.

Intensity modulated radiotherapy (IMRT)

This is usually the type of radiotherapy you have. It uses advanced computers to calculate and deliver radiation directly to the cancer from different angles. IMRT shapes the radiation beams to the size of the tumour. The strength (intensity) of the dose can be changed depending on the tissue. Doctors can deliver an even higher radiation dose to the cancer while giving lower doses to healthy tissue.

Volumetric modulated arc therapy (VMAT)

This is a newer technique that works in a similar way to IMRT. The radiation dose can be changed even more accurately during treatment. The machine rotates around you and quickly delivers radiotherapy beams in continuous arcs (curves) precisely to the cancer. VMAT can be given in shorter treatment sessions. It is currently only available in some hospitals. Doctors still need to find out if it is as effective as IMRT.

Stereotactic ablative radiotherapy (SABR)

SABR allows large doses of radiotherapy to be given very precisely to small areas. SABR uses many smaller, thin beams of radiation. The beams are directed from different angles that meet at the tumour. It can deliver large doses of radiation to the prostate. This means you have all your treatment over a few days, instead of weeks.

SABR is not a standard treatment for prostate cancer, but it is currently being used in several hospitals. It does not seem to cause an increase in side effects.

We have more information on our website about SABR (see page 136).

Planning external beam radiotherapy

Your cancer doctor plans your radiotherapy carefully to make sure it is as effective as possible.

During the planning visit, you will have a CT scan. The scan will help your doctor work out the exact dose and area of your treatment.

Before your scan, you may need to have a special diet or take medicine to empty your bowel. You may also need to drink water to fill your bladder. This is to get very clear CT pictures to help plan your treatment.

You may have a small amount of liquid passed into your rectum to empty your bowel. This is called an enema. The hospital will send you information if you need to prepare for your scan.

During the scan, you need to lie still in the same position you will be in for your radiotherapy.

The person who gives you your treatment (radiographer) will make some permanent marks (tattoos) the size of a pinpoint on your skin. These are used to make sure you are in the correct position for every treatment session. The marks also show where the beams will be directed. This is only done with your permission. It may be a little uncomfortable. If you are worried about this, talk to the radiographer.

Sometimes you may have tiny gold grains passed into your prostate using an ultrasound probe. These are called fiducial markers. They show the position of the prostate to help the radiographer see the position of the prostate before each session. This may help reduce side effects and any possible damage to organs close to the prostate. They are often used with SABR.

> **‘One of the most surprising things about radiotherapy was the tattoos. The radiotherapy has to be absolutely accurate on the prostate. And to do that they have to have reference points that the laser can line up with.’**
>
> **Paul**

Image-guided radiotherapy (IGRT)

To make sure the treatment is delivered very precisely, the radiographers take images before or during each session of radiotherapy. These show the size and shape of the cancer, and make sure the cancer is in the same position as in your planning scan.

Rectal spacers

A small amount of liquid gel, or an inflatable biodegradable balloon, is put into the space between the prostate and rectum before treatment. It moves the rectum away from the prostate and reduces the amount of radiation reaching the rectum. This reduces radiotherapy side effects of the rectum.

You need a general anaesthetic to have a rectal spacer put in. The doctor injects the spacer as a liquid through a small needle between the rectum and the prostate. It stays in place during radiotherapy and is gradually absorbed by the body. You may be a bit sore at the injection site for a short time. There is a risk of infection and you may need to take antibiotics to reduce this. There is a very small risk of complications if the spacer is not injected correctly, which may delay your treatment. Your doctor will explain what is involved and the possible risks and benefits.

Although the use of rectal spacers is approved by the National Institute for Health and Care Excellence (NICE) they are not available in all hospitals. You can talk to your doctor about this. They may be available through private healthcare.

Treatment sessions

The radiographer will explain what will happen. At the start of each treatment session (called a fraction), they make sure you are in the correct position on the couch and that you are comfortable.

When everything is ready, they leave the room so you can have the radiotherapy. The treatment only takes a few minutes. You can talk to the radiographers through an intercom or signal to them during the treatment. They can see and hear you from the next room.

During treatment, the radiotherapy machine may automatically stop and move into a new position. This is so the radiotherapy can be given from different directions.

Side effects of external beam radiotherapy

Side effects usually build up slowly after you start treatment. They may continue to get worse for a couple of weeks after treatment. But after this, most side effects improve gradually over the next few weeks.

Your doctor, nurse, or radiographer will talk to you about this. They will explain what to expect and give you advice on what you can do to manage side effects.

Always tell them about your side effects. There are usually things they can do to help. We list the common side effects here, but you may not get all of these. We have more detailed information in our booklet **Understanding pelvic radiotherapy** (see page 136).

Late effects

Side effects that do not improve or happen months to years after radiotherapy are called long-term or late effects. Improved ways of giving radiotherapy such as IMRT are reducing the risk of late effects, particularly on the bowel. Your doctor or nurse will explain these to you.

Bowel side effects during treatment

Radiotherapy to the prostate can irritate the back passage (rectum) and bowel. You may get diarrhoea, wind and cramping pains in your tummy (abdomen). Your doctor can prescribe medicines to help control these side effects. Some men get pain in the back passage and may have some bleeding.

If you have diarrhoea, drink at least 2 to 3 litres (3½ to 5½ pints) of fluids a day. Avoid caffeine and alcohol. During treatment, your nurse or radiographer may advise you to make some changes to your diet such as eating less fibre. These side effects usually improve by 6 weeks after finishing treatment.

Late bowel effects

With modern radiotherapy techniques, late effects to the bowel are now less common. Late effects may be similar to the immediate side effects. You may feel you need to rush urgently to go to the toilet, or, rarely, you might have some leakage or soiling (bowel incontinence). Sometimes blood vessels in the bowel lining become more fragile and bleed. If you notice any bleeding from the back passage, always tell your doctor so they can check it.

Symptoms can often be managed with medication and changes to your diet. If problems do not improve, ask to be referred to a bowel specialist (a gastroenterologist or bowel surgeon). We have more information about bowel problems after pelvic radiotherapy in **Managing the bowel late effects of pelvic radiotherapy** (see page 136).

Bladder side effects during treatment

Radiotherapy can also cause inflammation of the bladder (cystitis). You may:

- feel you want to pass urine (pee) more often (frequency)
- have a burning feeling
- being unable to wait to empty your bladder (urgency).

Your doctor can prescribe medicines to help. Drinking 2 to 3 litres (3½ to 5½ pints) of fluids a day can help. Avoid drinks containing caffeine and alcohol. These side effects usually disappear slowly a few weeks after treatment has finished.

Sometimes you may have difficulty passing urine and need to have a tube put into the bladder to drain urine (urinary catheter).

If you had urinary problems when you were diagnosed, you may find these improve after radiotherapy finishes.

Late bladder effects

The symptoms of bladder irritation you get with treatment (frequency and urgency) may not completely go away, or they may develop later.

The bladder lining may bleed easily, causing blood in your urine. You may get leakage of small amounts of urine (urinary incontinence). But this is rare. We have more information in our booklet **Managing the bladder late effects of pelvic radiotherapy** (see page 136).

Tiredness

Radiotherapy causes tiredness, especially towards the end of treatment. It may last for a couple of months or longer after treatment has finished. Make sure you get plenty of rest. But try to balance this with regular physical activity, such as short walks. This will help give you more energy.

We have more information about this in our booklets **Coping with fatigue (tiredness)** and **Physical activity and cancer** (see page 136).

Effects on the skin

The skin in the treated area may become red (if you have light skin) or darker (if you have dark skin). It may also become dry, flaky, and itchy. Sometimes the skin around the back passage (rectum) and scrotum becomes moist and sore. The radiographer or your specialist nurse will give you advice. They can prescribe a cream or dressings and painkillers if you need them.

Your pubic hair may fall out. It usually starts to grow back a few weeks after you have finished treatment. It may be thinner than before.

> After radiotherapy, urinary incontinence never really happened. I was a bit sore for a few weeks after, and chronic fatigue for several months.

Simon, diagnosed with early localised prostate cancer

Erection problems

Radiotherapy for prostate cancer can cause problems getting or keeping an erection. This is called erectile dysfunction (ED). ED may not happen straightaway after radiotherapy, but can develop slowly over 2 to 5 years. About 30 to 45 out of 100 men who do not have any problems before radiotherapy develop ED after treatment (30 to 45%).

You may have a higher risk of ED if:

- you are older – older men are more likely to get ED than younger men
- you already had ED before treatment
- you have other medical problems that also affect ED, such as diabetes or heart disease
- you are taking hormonal therapy drugs (see pages 80 to 85), which also affect ED and your desire to have sex.

Ask your cancer doctor about your risk of ED. If you develop ED, there are different treatments that can help. After radiotherapy and brachytherapy, some men ejaculate little or no semen.

Infertility

Radiotherapy to the prostate may cause permanent infertility. If you find this difficult to cope with or are worried, talk to your cancer doctor. You may be able to store sperm before treatment starts. We have more information in our booklet **Cancer and fertility – information for men** (see page 136).

PSA levels after external radiotherapy

After radiotherapy, it can take time for your PSA level to drop. It usually goes down gradually. It may not get to its lowest level until about 18 months or longer after treatment. Your doctor and specialist nurse can give you more information about this. We have more information about PSA after treatment on our website (see page 136).

Benefits and disadvantages of external beam radiotherapy

Radiotherapy and a radical prostatectomy are both treatments that may cure early prostate cancer. They are equally effective in treating the cancer.

To choose the treatment that is best for you, it can help to look at the benefits and disadvantages of each one. You can then make your decision with your doctor.

Benefits of external beam radiotherapy

- You do not need surgery or a general anaesthetic, which may have risks if you have other health conditions.
- You can keep doing most of the daily things you usually do.
- Urinary problems may happen less often than after a prostatectomy.

Disadvantages of external beam radiotherapy

- You have to go to hospital as an outpatient for 4 to 7 weeks, Monday to Friday.
- Bowel side effects may be worse in the short term than with a prostatectomy.
- It may be some time before you and your doctors know if treatment has been successful.
- If the cancer comes back after radiotherapy, it is more difficult to have surgery to remove the prostate.

Brachytherapy

Brachytherapy (internal radiotherapy) gives high doses of radiation directly to the prostate. Areas close by, such as the rectum and the bladder, get a much lower dose.

Brachytherapy can be given:

- on its own to treat low-risk prostate cancer, or with hormonal therapy
- before or after external beam radiotherapy for intermediate-risk and high-risk early prostate cancer – this is sometimes called a boost.

There are 2 ways of giving it:

- Radioactive seed implants or low-dose rate (LDR) brachytherapy – small, radioactive metal 'seeds' are placed in the prostate and stay there permanently. They slowly release radiation until it has been used up. After a year, about 95% of the radiation will have gone.
- High-dose rate (HDR) brachytherapy – thin tubes are placed in the prostate. They are attached to a machine that sends a radioactive source into the tubes for a set time. The source and tubes are then removed.

There may be some differences in how each hospital gives brachytherapy. Your doctor or nurse will explain what will happen.

You usually have antibiotics before brachytherapy and for a few days after to help prevent infection. You may also be given tablets to help you pass urine (pee) more easily after treatment.

Brachytherapy may not be suitable for you if you have a lot of urinary symptoms.

Radioactive seed brachytherapy

This is the most common type of brachytherapy for early prostate cancer. You have this treatment done in a day.

You will have a general or a spinal anaesthetic (injection of painkillers into the spine). If you have a spinal anaesthetic, you will be awake but will not feel any pain.

Planning

Your doctor passes an ultrasound probe into the back passage (rectum) to take pictures of the prostate. This helps them plan how many radioactive seeds are needed and where they should be placed.

Before the scan, you may need to have a special diet for 24 hours. You may also have a small amount of liquid passed into your rectum (enema). This makes sure your bowel is empty, so the ultrasound picture is clear.

Implanting the seeds

The doctor passes an ultrasound probe into the rectum to show your prostate and help guide them. They pass a special needle through the skin between the scrotum and back passage (perineum) to insert the seeds into the correct position in the prostate.

Sometimes they put a tube (catheter) into your bladder to drain urine during the procedure. They insert water into the catheter to help show up the area around the bladder. You will have it removed before you go home.

After treatment

You can usually go home on the same day, but someone will need to take you. You will not be able to drive, because of the anaesthetic. Your doctor or nurse will explain what to expect after treatment. Before you go home, they will give you antibiotics and tablets to help you to pass urine more easily. Take them exactly as explained.

They also give you a card to carry with you at all times. It explains the treatment you have had and gives your hospital contact details.

Precautions

The radioactivity from the seeds is absorbed from inside the prostate, so it is safe for you to be around other people. As a precaution, you should avoid periods of close contact with children and anyone pregnant for the first few months. It is safe for them to be in the same room as you. But you will be asked to keep a certain distance from them. Avoid holding or hugging anyone who is pregnant or children for more than a few minutes each day.

Your doctor or nurse will give you specific advice about the safety precautions you need to follow.

Sex

Your doctor will advise you to use a condom during sex for the first 2 months after the seeds have been put in. There is a slight risk of passing a seed in your semen when you ejaculate. Place used condoms in a plastic bag and dispose of them in a bin bag.

If you receive anal sex, doctors usually advise avoiding this for several months. This is to protect your partner until most of the radiation has worn off. If you are worried, talk to your doctor or nurse.

Your semen may be coloured black or brown for a short time. This is caused by some bleeding during the procedure. It is harmless. You will still need to use contraception to avoid a pregnancy.

Physical activity

After brachytherapy, you need to avoid heavy lifting or energetic physical activity for 2 to 3 days. The area between your legs can feel bruised and inflamed for a few days. Your doctor can prescribe painkillers to take.

HDR brachytherapy

You will have a general or a spinal anaesthetic (injection of painkillers into your spine) to have HDR brachytherapy. If you have a spinal anaesthetic, you will be awake but will not feel any pain. You may need to stay in hospital overnight.

If you are having HDR brachytherapy on its own, you will usually have 2 treatments. If you are having HDR as a boost after external radiotherapy, you only need 1 treatment.

Having the tubes put in

Your doctor passes an ultrasound probe into the back passage (rectum) to take pictures of the prostate. This helps them to plan the number of tubes needed and where they should be placed. They sometimes also use a CT scan to help position the tubes.

Your doctor passes the tubes that deliver the brachytherapy into your prostate through the skin between the scrotum and back passage. They may also put a tube into the bladder to drain urine (catheter). This prevents any swelling of the prostate stopping you passing urine. They remove the catheter before you go home.

When the tubes are in, you have a CT or MRI scan. This helps your doctor plan exactly how much radiation to give the prostate.

Having HDR brachytherapy

The nurses take you to a treatment room that has the HDR machine. They attach the tubes to the machine. The machine sends the radioactive source into the tubes going into the prostate. A computer monitors how long the radioactive source stays in place. The treatment takes about an hour.

The tubes can be uncomfortable, and you must stay lying down while they are in place. After HDR brachytherapy is finished, the radioactive material is returned to the machine and the tubes are removed.

After treatment

After treatment you have no radioactive material inside you, so there is no risk in being around other people.

Your doctor or nurse will explain what to expect after treatment. Before you go home, they will give you antibiotics and tablets to help you to pass urine more easily. Take them exactly as they explained.

You need to avoid doing heavy lifting or energetic physical activity for 2 to 3 days. The area between your legs can feel bruised and inflamed for a few days. Your doctor can prescribe painkillers to take.

Side effects of brachytherapy

Brachytherapy causes similar side effects to external beam radiotherapy (see pages 63 to 68). If you have brachytherapy on its own, some side effects may be less severe. If you have it with external beam radiotherapy, they may be more severe.

Erection problems

Brachytherapy for prostate cancer can cause problems getting and keeping an erection. This is called erectile dysfunction (ED) (see page 105).

You may have ED immediately after treatment due to swelling and bleeding. But this can improve as these problems settle down. Sometime ED develops gradually over months or years.

The risk of permanent ED after brachytherapy can depend on different things. If you had ED before brachytherapy, it is more likely you will have it afterwards. Having external radiotherapy and hormone therapy will also increase the risk of ED.

Ask your cancer doctor about your risk of ED. If you develop ED, there are different treatments that can help.

After brachytherapy, some men ejaculate little or no semen.

Infertility

Having brachytherapy on its own can still cause infertility, but the risk may be lower than with external beam radiotherapy. If you find this difficult to cope with or are worried about your fertility, talk to your cancer doctor. You may be able to store sperm before treatment starts.

Bowel problems

Brachytherapy may cause some bowel problems for a few weeks after treatment. These are similar to the side effects caused by external radiotherapy (see pages 63 to 68). Sometimes they last for months.

Brachytherapy on its own is less likely than external beam radiotherapy to affect the bowel and cause late bowel effects. If bowel problems do not improve or develop later on (late effects), contact your doctor straight away. Always tell them if you pass blood from the back passage.

Effects on the bladder

These can be more of a problem after brachytherapy. If you already have difficulties passing urine, you will not usually have brachytherapy, as it may make bladder problems worse.

You may see some blood in your urine and semen for a few weeks after treatment. If bleeding gets worse or you have large clots, tell your doctor straight away. Drinking plenty of water helps flush your bladder and prevent blood clots.

You may also:

- have discomfort or pain passing urine
- need to pass urine urgently and more often.

Drinking plenty of water and avoiding caffeine and alcohol will help improve your symptoms. With HDR brachytherapy, these symptoms should improve after a few weeks. If you had radioactive seed brachytherapy, it may take longer. Your symptoms will improve over the following months as the seeds lose their radioactivity.

Not being able to pass urine

Brachytherapy may cause swelling of the prostate. This may make it difficult to pass urine. If this happens, you may need to have a catheter put in your bladder until the swelling goes down. This usually takes 2 to 4 weeks. Sometimes a catheter needs to be in for a longer time until you can have surgery to remove part of the prostate (TURP).

Sometimes radiotherapy can narrow the urethra. This is called a stricture. This causes difficulties with passing urine. This may happen weeks, months or even years after treatment finishes. A stricture can be treated by passing a thin, plastic tube through the urethra to widen (dilate) it.

Benefits and disadvantages of brachytherapy

If you have a low-risk cancer, you may be asked to decide between external beam radiotherapy and brachytherapy. This is because your doctor thinks they are both effective treatments for you. It is important to talk about the possible advantages and disadvantages of each treatment with your doctor or nurse. You can then decide with them which treatment is right for you.

Benefits of brachytherapy

- You usually only need 1 or 2 visits to hospital, rather than weeks of external beam radiotherapy treatment.
- There may be a lower risk of some side effects because there is less damage to the surrounding healthy tissue.
- You can usually get back to your day-to-day activities within a few days.

Disadvantages of brachytherapy

- You need a general or a spinal anaesthetic.
- With radioactive seeds (not with HDR brachytherapy) you need to avoid close contact with children or anyone who is pregnant for a few months after treatment.
- Short-term urinary side effects may be more severe than with external beam radiotherapy.

Hormonal therapy

Prostate cancer needs the hormone testosterone to grow. Testosterone is mainly made by the testicles. Hormonal therapies reduce the amount of testosterone in the body, or stop it reaching the prostate cancer cells.

Testosterone is important for:

- sex drive (libido)
- getting an erection
- facial and body hair
- muscle development and bone strength.

Doctors often advise having hormonal therapy with radiotherapy (including brachytherapy), to make your treatment more effective – see pages 57 to 78. This is usually if you have intermediate-risk or high-risk early prostate cancer (see pages 22 to 23).

You may have hormonal therapy before, during and after radiotherapy. It can be given:

- a few months before radiotherapy, to shrink the cancer (neo-adjuvant treatment)
- after radiotherapy, to reduce the chance of the cancer coming back (adjuvant treatment).

Your doctor will talk to you about how long you should have hormonal therapy for. They will also explain the possible side effects.

If you have intermediate-risk prostate cancer, you may have hormonal therapy for a few months after radiotherapy. With high-risk prostate cancer, you may be advised to have it for 2 to 3 years.

Hormonal therapy on its own

Doctors do not usually advise having hormonal therapy instead of surgery (see pages 45 to 56) or radiotherapy (see pages 57 to 78). Hormonal therapy alone cannot cure the cancer. But depending on your general health and preferences, you may decide to have hormonal therapy on its own. For example, you may decide this if you:

- are not well enough to have surgery or radiotherapy
- do not want to have surgery or radiotherapy
- are having watchful waiting and the cancer starts to grow.

Hormonal therapy can slow down or stop the cancer cells growing for many years. It also causes some side effects. It is important to talk to your doctor or nurse before you decide.

Types of hormonal therapy

There are different types of hormonal therapy. Your doctor or nurse will explain the treatment that is most suitable for you.

LHRH agonists

The pituitary gland in the brain makes make a hormone called luteinising hormone (LH). This hormone tells the testicles to make testosterone.

LHRH agonists interfere with this action and stop the testicles making testosterone. You have them as an implant injection or an injection under the skin.

The commonly used LHRH agonists are:

- goserelin (Zoladex®, Zoladex LA®)
- leuprorelin
- triptorelin (Decapeptyl®, Gonapeptyl®).

A nurse or doctor at your GP practice or hospital can give you these drugs.

You have goserelin as an injection of a small pellet (implant) under the skin of your tummy (abdomen). The drug is released slowly as the pellet dissolves. You have it every 4 weeks, or as a longer-acting injection every 12 weeks.

Leuprorelin and triptorelin are given as an injection under the skin or into a muscle. You have these monthly, or every 3 or 6 months.

The first time you have one of these drugs, it can cause a temporary increase in testosterone. This can make any symptoms worse for a short time. This is sometimes called tumour flare. To prevent this, your doctor usually asks you to take an anti-androgen drug, such as bicalutamide (Casodex®). You take it for a short time before and after starting the LHRH agonist.

Anti-androgen drugs

These drugs stop testosterone from reaching the cancer cells. You take them as tablets. You may have anti-androgen drugs with radiotherapy, instead of having an LHRH agonist with radiotherapy. Or you may have an anti-androgen before and after the first injection of a LHRH agonist. This is to prevent any symptoms getting temporarily worse (tumour flare).

Anti-androgen drugs include:

- bicalutamide (Casodex®)
- flutamide – but this is less commonly used.

Side effects of hormonal therapy

Reducing the level of testosterone can cause different side effects. There are different ways hormonal side effects can be managed or treated. Your doctor or nurse will explain this to you. Some side effects are only likely to affect you when you have hormonal therapy for over 6 months.

Different hormonal therapies have different side effects. It is important to discuss these with your doctor or nurse before treatment, so you know what to expect.

Common side effects

Erection difficulties and reduced sex drive

Erection difficulties are called erectile dysfunction (ED) – see page 105. This usually improves after you stop treatment, depending on how long you take it for. But it may take a few months.

If you have ED, there are drugs and treatments that may help. Even with a low sex drive, some ED treatments may work for you.

Hot flushes and sweats

These may reduce as your body adjusts to hormonal treatment. They usually gradually improve after treatment finishes. Talk to your doctor if you are having problems. They can give you advice and may be able to prescribe medicines to help.

Tiredness and difficulty sleeping

Feeling tired is a very common side effect of hormonal therapy. Regular physical activity can help reduce tiredness. Hot flushes may make sleeping difficult, so managing these may help you to sleep better. We have more information in our booklet **Coping with fatigue (tiredness)** – see page 136.

Mood changes

Talking to a family member, close friend or counsellor about how you feel may help with changes in your mood.

Memory and concentration problems

These changes may be caused by the hormone therapy, or because of tiredness or feeling anxious.

Other side effects

If you have hormonal therapy for 6 months or more, you may have other side effects. The benefits of hormonal therapy generally outweigh the possible risks. Your doctor or nurse will talk to you about this.

Other possible side effects include the following.

Weight gain and loss of muscle strength

You may have gain weight (especially around the middle) and lose muscle strength. Regular physical activity and a healthy, balanced diet can help manage this. You can find more information in our booklets **Physical activity and cancer** and **Healthy eating and cancer** (see page 136).

Breast swelling or tenderness

This is more common if you have flutamide or and bicalutamide over a longer period. Some men have low-dose radiotherapy to their chest before treatment to prevent breast swelling. If you are taking bicalutamide, another option is to take a hormonal drug called tamoxifen to reduce breast swelling.

Bone thinning (osteoporosis)

The risk of this is increased with long-term hormonal treatment. You may have a scan to check your bones before you start treatment. Regular weight-bearing exercises such as walking, dancing, hiking, or gentle weight-lifting can help keep your bones healthy. Your doctor may give you advice on diet and exercise. They may advise you to take calcium and vitamin D tablets. Depending on your bone health, they may talk to you about taking bone-strengthening drugs called bisphosphonates, or a drug called denosumab (Prolia®). We have more information about this in our booklet **Bone health** (see page 136).

Increased risk of heart disease and diabetes

Not smoking, being physically active, eating healthily and keeping to a healthy weight can help reduce these risks. Our booklets **Physical activity and cancer** and **Healthy eating and cancer** have more information you may find helpful (page 136).

Other treatments

Treatments called cryotherapy and high-intensity focused ultrasound (HIFU) treatment are sometimes used to treat:

- early prostate cancer (usually low-risk)
- prostate cancer that has come back after radiotherapy or brachytherapy (see pages 57 to 69).

Unfortunately, these treatments are not routinely available in all NHS hospitals. It is important to talk to your specialist doctor and nurse first to find out if a treatment is available in your area. Usually you can only have cryotherapy or HIFU on the NHS as part of a clinical trial (see pages 93 to 95). Doctors still do not know enough about how effective they are compared to existing treatments for early prostate cancer.

Some private clinics also offer these treatments. These treatments are not suitable for everyone. It depends on where the cancer is in the prostate, and the risk group of the cancer. Your doctor can explain more about this.

Cryotherapy and HIFU can be used to treat the whole prostate when the cancer is in more than one area. They are also used when there is only one small area of cancer in the prostate (focal therapy).

If there are areas of cancer that are growing quickly (high-grade) you can have focal treatment to these. Very slow-growing areas of cancer may not be treated. You may have fewer side effects, because less healthy tissue is damaged.

Possible benefits and disadvantages of cryotherapy and HIFU

If you are thinking about having cryotherapy or HIFU, your doctor can explain the benefits and disadvantages.

They will also tell you about the other treatment options available to you. Doctors do not know how effective HIFU or cryotherapy are compared to existing treatments for early prostate cancer. Active surveillance, which involves monitoring the cancer, may be an option (see pages 41 to 43).

Side effects, such as erection difficulties and urinary problems may be less of a problem with these treatments. But they may still affect you. If you have already had treatment for prostate cancer, the side effects may be worse.

Some people may prefer to have HIFU or cryotherapy even although there is not enough evidence about them yet. They may feel there is less risk of certain side effects and want to avoid surgery or radiotherapy. Or, it may be because these treatments can be given in a short hospital stay and recovery is usually quick.

If the cancer comes back after either cryotherapy or HIFU you may still be able to have treatment with surgery or radiotherapy. You will have your PSA level checked regularly after treatment.

Cryotherapy

You usually have cryotherapy under a general anaesthetic or a spinal anaesthetic. You can usually go home when you have recovered from the anaesthetic.

Cryotherapy destroys cancer cells by freezing them with a special gas. The doctor passes thin needles through the skin behind the scrotum (perineum). They pass an ultrasound probe into the back passage (rectum), to give a picture of the prostate on a screen. This is so the doctor can guide the needles into the right place. They pass the gas, which freezes the cancer cell, through the needles into the area of the prostate where the cancer is.

Side effects of cryotherapy

Urinary problems

After cryotherapy, you may have problems passing urine (peeing). To prevent this, you have a tube (catheter) put into your bladder to drain urine into a bag. It is left in for 2 weeks. You may have some urine leaking from the bladder (incontinence) when it is removed, but this usually improves within a few months. Doing regular exercises to strengthen your pelvic floor muscles can help improve your bladder control.

Long-term urinary problems

Sometimes urinary problems take longer to improve or do not completely go away. If you are having problems with incontinence, talk to your doctor or nurse.

Pain and swelling

After the treatment, you may have some pain in your lower tummy or back passage (rectum). You will be given painkillers for this. You may have some bleeding from the back passage, but this is not common.

You may have some swelling, numbness, or tingling around the penis and scrotum. This happens 1 to 2 weeks after cryotherapy. It will slowly improve over a few months.

Erection problems

Cryotherapy can cause problems getting an erection. This is called erectile dysfunction (ED) – see page 105. ED may not happen straight after treatment. It may develop slowly after treatment, over 2 to 5 years. Different treatments can help if you have ED (see pages 110 to 114).

Rectal fistula

Rarely, cryotherapy can damage the tissues surrounding the prostate and cause a small hole between the rectum (back passage) and the urethra. This is called a rectal fistula. If you have a rectal fistula, you will need an operation to repair it.

High-intensity focused ultrasound (HIFU)

You have HIFU under a general anaesthetic or a spinal anaesthetic. You can usually go home when you have recovered from the anaesthetic.

The surgeon passes a probe into the back passage (rectum). It produces beams of high-energy ultrasound that heats and destroys the area of prostate cancer cells. The probe is surrounded by a cooling balloon so the high-energy beams are only given to the areas with cancer. This means the normal prostate tissue is protected.

Side effects of HIFU

Urinary problems

After HIFU, you may have problems passing urine (peeing). To prevent this, the surgeon puts a tube (catheter) into your bladder to drain urine into a bag. It is left in for 1 to 2 weeks. You are likely to have some urine leaking from the bladder (incontinence) when the catheter is first removed, but this usually improves within a few months. You may also have problems needing to pass urine straight away (urgency). Doing regular exercises to strengthen your pelvic floor muscles can help to improve your bladder control.

Sometimes a TURP operation is done before HIFU to reduce bladder problems afterwards. We have more information about this on our website (see page 136).

Urinary retention

This happens when you cannot empty your bladder properly after the catheter is removed. HIFU can cause the prostate to swell. This may block the tube from the bladder that urine passes through (urethra). If your urine flow is weak or very slow, tell your doctor or nurse. If you cannot pass urine at all, contact your doctor or nurse straight away or go to your nearest emergency department (A&E).

Long-term urinary problems

Some people may have long-term urinary problems such as leakage (incontinence) after HIFU. This is more likely if you have already had external beam radiotherapy. Another late effect of HIFU can be a narrowing in the urethra (urethral stricture). If you are having problems passing urine, talk to your doctor or nurse.

Pain and bleeding

After treatment, you may have some pain in your lower tummy or back passage (rectum). You will be given painkillers for this. You may have some bleeding from the back passage.

Erection problems

HIFU can cause problems getting an erection. This is called erectile dysfunction (ED) – see page 105. ED may not happen straight after treatment. It can develop slowly, over 2 to 5 years. Different treatments can help if you have ED (see pages 110 to 114).

Rectal fistula

Rarely, HIFU can damage tissues surrounding the prostate and cause a hole between the rectum (back passage) and the urethra. This is called a rectal fistula. If you have a rectal fistula, you will need an operation to repair it.

> ‘I was accepted onto a clinical trial which involved taking 2 drugs. My doctors wanted me to have chemotherapy, but it was refused because although the tumour was quite large, it was still within the prostate and hadn't broken out. Instead, I was put forward for the clinical trial and luckily was selected.’

Tim

Clinical trials

Clinical trials are medical research studies involving people. Doctors may use cancer clinical trials to:

- test new treatments to see if they work better than current treatments
- find which treatments have fewer side effects
- find new ways to combine treatments to see if they work better
- test new cancer drugs to find out more about them and their side effects
- improve the way treatments are given to try to reduce side effects.

Results from clinical trials can improve cancer treatments and help people live longer. Trials can also look at improving things like diagnosis and symptom management.

Taking part in a trial

Your cancer doctor or specialist nurse may talk to you about taking part in a clinical trial. Or you could ask them if there are any trials suitable for you.

Usually, cancer clinical trials happen in several hospitals around the country. You may have to travel to take part in a trial.

A research nurse or doctor will give you information about the trial. It is important to understand what is involved before you agree (consent) to take part. You can ask the research nurse or doctor any questions you have.

They will also explain the possible benefits and any possible risks of the trial. Clinical trials are designed to be as safe as possible. The researchers will monitor you closely during and after the trial.

If you decide not to take part in a trial, your cancer doctor and specialist nurse will respect your decision. You do not have to give a reason for not taking part. Your decision will not change your care. Your cancer doctor will give you the standard treatment for the type and stage of cancer you have.

We have more information about cancer clinical trials.
Visit **macmillan.org.uk/clinicaltrials**

Giving blood and tissue samples

During your diagnosis and treatment doctors often take blood samples. They may also take a small piece of tissue or a sample of cells. These tissue samples are called biopsies. The samples can be looked at under a microscope. Your cancer doctor may ask your permission to store and use these blood or tissue samples for cancer research. This will only happen after they have done all the tests you need.

Your samples can only be stored for research if you give your consent. Your cancer doctor can answer any questions you have.

Your name is removed from the samples before they are stored. This means you cannot be identified.

Vascular photodynamic therapy (VDT)

Researchers are always looking for new ways to treat early prostate cancer. One treatment that is currently being researched is a type of photodynamic therapy (PDT) called vascular photodynamic therapy (VDT).

PDT uses a light source (laser) and a light-sensitive drug to destroy cancer cells. The drug is called padeliporfin (TOOKAD®). Vascular means blood vessels. VDT may be used if the cancer is in one side of the prostate.

It is only available in hospital as part of a clinical trial.

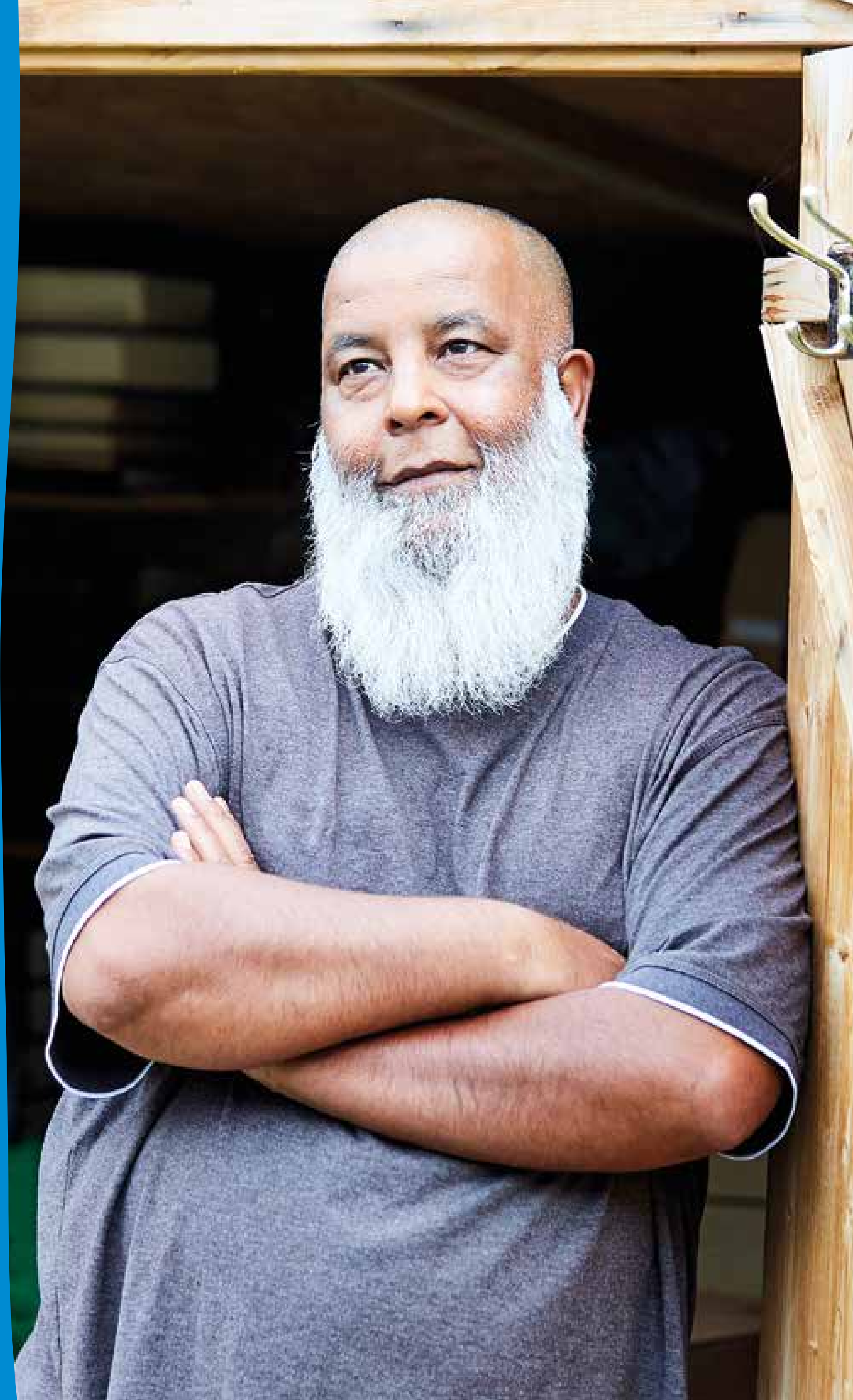
During VDT, the doctor passes hollow needles into the prostate through the area between your scrotum and the back passage (perineum). They use an ultrasound scan to look at the prostate and make sure the needles are in the right position.

The doctor then passes optical fibres through the needles and give you the light-sensitive drug as an injection into your vein. The drug is taken up (absorbed) by the blood vessels in the prostate. The doctor uses a laser to shine a light along the fibres. The light activates the drug to destroy the blood vessels to the cancer. This makes the prostate cancer cells die.

The drug makes you very sensitive to light for up to 48 hours after treatment. Your doctor or nurse will explain the precautions you need to take to protect your eyes and skin. They will talk to you about the other side effects before you go home.

VDT may also cause urinary problems and problems getting an erection (called erectile dysfunction or ED). Your doctor can tell you more about the risk of these side effects.

AFTER TREATMENT



Follow-up after treatment

After treatment has finished, you will have follow-up appointments. Your doctor or nurse will talk to you about the type of follow-up you will have.

After treatment to cure prostate cancer you have regular check-ups every few months for the first year. These continue for several years depending on your situation, but with longer gaps between appointments. During a follow-up visit, your doctor will usually ask questions about the side effects of treatment and if you have any bowel, bladder or sexual problems.

Monitoring your PSA level

You will not have your PSA level checked until 6 weeks after you finish treatment. After this, you may have it tested:

- at least every 6 months for the first 2 years
- at least once a year after the first 2 years.

You will usually have a PSA test 1 to 2 weeks before your follow-up appointment, so your doctor can see the results. You do not usually need a rectal examination unless your PSA level changes.

Your PSA level tells doctors how well treatments are working. Or, if you are having active surveillance it tells your doctor if you need to start treatment (see pages 41 to 43).

If prostate cancer comes back, the first sign is usually a rise in the PSA level. You usually need more than one rise in the PSA level to find if prostate cancer has come back. Doctors also look at how quickly it rises.

If the cancer comes back, it is more likely to do this in the first few years after treatment. When prostate cancer comes back in the area of the prostate, it may still be cured. It is important to have careful follow-up during this time.

After a prostatectomy the PSA level usually drops to a very low or undetectable level within 2 months. If you have radiotherapy, your PSA level drops more slowly, and may take 6 months to a few years to reach its lowest level. Sometimes there is a temporary rise in the first couple of years after radiotherapy. This is called a PSA bounce. Usually your PSA level will fall the next time it is checked.

If you have hormone treatment and radiotherapy, the PSA level will often be lower. It usually remains low for months or longer after the injections have stopped. The level usually rises after this and stabilises at a slightly higher level.

Symptoms

It can also be helpful to be aware of symptoms to look out for. Symptoms may be linked to long-term or late side effects of treatment. Do not wait until your appointment to report any new symptoms or symptoms that do not go away. Tell your team about them immediately. For example, these symptoms may include:

- urinary or bowel symptoms (including bleeding from the bladder or back passage)
- pain in any area of the bones
- any changes in feeling or strength in your legs.

You may find you feel anxious before your clinic appointments. This is natural. It may help to get support from family, friends or a support organisation. You can also call the Macmillan Support Line on **0808 808 00 00**.

If early prostate cancer comes back in the same area

Treatment for early prostate cancer usually cures it. Hormone therapy (see pages 80 to 85) in addition to radiotherapy (see pages 57 to 78) helps to reduce the risk of the cancer coming back. But if prostate cancer comes back in the prostate or area around it, you can usually have further treatment which may cure it. This treatment is sometimes called salvage treatment. You can often continue to live a long and active life. Prostate cancer that comes back in the prostate area is called recurrent prostate cancer.

If your PSA level rises quickly or over time, your doctor usually does tests to check for cancer. Before you have further treatment, they need to check the cancer has not spread to other parts of the body.

You may have a CT scan, PET scan or an MRI scan. A newer scan called a PSMA PET scan may be able to detect very small amounts of prostate cancer, but it is not widely available.

If tests show the cancer has come back, treatment will depend on:

- your general health
- results of your scans
- whether you have any symptoms
- the treatment you have already had.

If you have had a prostatectomy as your first treatment, you can usually have external pelvic radiotherapy (see pages 57 to 69). You may also be given hormonal therapy (see pages 80 to 85).

If you had radiotherapy as your first treatment, it may be possible to have brachytherapy to treat a recurrence (see pages 70 to 78). Occasionally, surgery with a prostatectomy may be possible. But this is often not an option because of the risk of serious side effects. HIFU or cryotherapy may also be used (see pages 86 to 91).

If the cancer is slow growing, your doctor may suggest monitoring it for a time instead of treating it straight away. If you have hormonal therapy alone, you usually have intermittent treatment.

Well-being and recovery

Even if you already have a healthy lifestyle, you may choose to make some positive lifestyle changes after treatment. Making small changes can improve your health and well-being. It can help your body recover and to manage some side effects. It may also help reduce the risk of other illnesses, such as heart disease and strokes.

Eat well and keep to a healthy weight

Your GP can advise you and give you information about your ideal weight. Eating a healthy diet and keeping to a healthy weight reduces the risk of heart problems, diabetes and developing some other cancers. Try to:

- only eat as much food as you need
- eat a balanced diet with lots of fruit and vegetables
- eat less saturated fat and less sugar
- become more physically active.

We have more information in our booklets **Physical activity and cancer** and **Healthy eating and cancer** (see page 136).

Keep active

Being physically active will help you keep to a healthy weight and can reduce stress and tiredness. It also helps keep your bones strong and your heart healthy.

Stop smoking

If you smoke, giving up is one of the healthiest decisions you can make. Smoking increases your risk of bone thinning (osteoporosis) and is a major risk factor for smoking-related cancers and heart disease.

The NHS has a lot of information and support to help you give up smoking. Look on the NHS website for the country where you live.

Look after your bones

Hormonal treatments for prostate cancer can increase the risk of bone thinning (osteoporosis). Keeping physically active and eating a healthy diet with enough calcium and vitamin D helps keep your bones healthy. If you smoke, you should stop as this can also increase your risk of bone thinning.

Limit alcohol

NHS guidelines suggest that you should:

- not regularly drink more than 14 units of alcohol in a week
- spread the alcohol units you drink in a week over 3 or more days
- try to have several alcohol-free days every week.

A unit of alcohol is half a pint of ordinary-strength beer, lager or cider, one small glass (125ml) of wine, or a single measure (25ml) of spirits.

There is more information about alcohol and drinking guidelines at **drinkaware.co.uk**

Sex

Treatments for prostate cancer can cause sexual difficulties. Or you may have side effects that make you feel less interested in having sex. These can include:

- tiredness
- changes to your bladder or bowel
- hormonal effects, such as weight gain or breast swelling.

We have included information about managing the side effects of treatment throughout this booklet. As your side effects improve, you may feel more interested in having sex.

If cancer and its treatments affect your sex life, it can feel very difficult to cope with. You do not need to be in a relationship to feel this. But there are different ways to manage sexual difficulties.

Cancer and its treatments can also affect how you feel and think about your body (body image). You may feel less sexually attractive. If you are having issues with your body image, ask your doctor or nurse for advice. You may also find our booklet **Body image and cancer** useful (see page 136).

Certain lifestyle changes may help improve body image concerns, such as being more physically active, eating healthily and managing your weight. Ask your doctor or nurse for advice. We also have more information about this in our booklets **Physical activity and cancer**, **Healthy eating and cancer** and **Managing weight gain after cancer treatment** (see page 136).

Sexual difficulties

Prostate cancer treatments can have a direct effect on your sex life. For example, they can cause difficulties getting or keeping an erection. This is called erectile dysfunction (ED).

You may already have had sexual difficulties before your diagnosis. These are more common as you get older and are linked with conditions such as high blood pressure and raised cholesterol.

Cancer treatments may cause difficulties getting or keeping an erection. After a prostatectomy this may happen soon after treatment. With radiotherapy, you may not have ED problems immediately after treatment, but it may develop over years.

Treatment can also affect your ability to have an orgasm or to ejaculate. After prostatectomy you will not ejaculate but can still have an orgasm. After external radiotherapy or brachytherapy (see pages 57 to 78), you do not usually produce much semen but can still orgasm.

Some treatments can reduce your sex drive (libido). Hormonal therapy (see pages 80 to 85), which you may have with radiotherapy, lowers your desire to have sex (libido). It may also lower your ability to get and maintain an erection.

If you are having sexual difficulties, there are different ED treatments to help you (see pages 110 to 114).

> My partner came with me to appointments, so there were no assumptions about my sexuality. This took a great deal of pressure off me.

Simon, diagnosed with early localised prostate cancer

Talking about sex

You may find it difficult to talk about sex with your doctor or nurse. But it is important to have your questions answered and to get the help you need. Your doctor, specialist nurse or GP should make you feel comfortable during conversations about sex.

You may want to think about whether there is someone in your healthcare team you feel more comfortable talking to. To help you feel prepared, plan what you want to say in advance and write down your questions. If you have a partner, you may want them with you at these discussions. Or you may prefer to talk confidentially with your doctor or nurse. If you need more specialist advice your doctor or nurse can refer you to an ED clinic or a sex therapist.

If you find it difficult talking to your doctor or nurse or getting information, there is other support available. You can talk to in confidence to a cancer information nurse specialist on our Macmillan Support Line or through email (see page 138). Prostate Cancer UK also has a helpline where you can talk or chat online to a specialist prostate nurse (see page 141).

Sex and treatment

If you have questions about sex during or after treatment, ask your doctor or nurse. Having sex will not affect how well your treatment works. In some situations, they may advise you to be cautious about sex during treatment or immediately after it finishes.

For example, after surgery you may be advised to wait until your wound has healed.

Side effects of pelvic radiotherapy, such as skin changes or tiredness, may make having sex difficult or you may not feel up to it. You may decide to wait until your side effects improve.

We have more information in our **Understanding pelvic radiotherapy side effects** booklet (see page 136).

If you identify as LGBT+

There may be times when it helps your healthcare team to know how you identify your gender or sexual orientation. It may help you feel better supported. They can give the right information and support to you, and your partner if you have one.

The impact of cancer and cancer treatment are often the same whatever your sexual orientation or gender. But you may have some specific questions about how these will affect your sexual well-being.

> **‘Being gay, I didn’t have the guts to talk to my doctor. I felt there was no one like me to talk to. But I’ve since had the opportunity to help others with my experiences.’**

Simon, diagnosed with early localised prostate cancer

Prostate treatment and anal sex

Pelvic radiotherapy can affect the back passage (rectum) and cause side effects. If you receive anal sex, your healthcare team may advise you to wait until 8 weeks after treatment. This avoids making side effects worse or causing longer-term problems. Your doctor or nurse can explain when it should be safe to receive anal sex. You can talk to them about long-term changes to the rectum that may make receiving anal sex difficult.

After a prostatectomy, you are usually advised to wait for 6 weeks before you receive anal sex.

Prostate Cancer UK has more information for gay and bisexual men and trans (transgender) women – see page 141.

If your healthcare team cannot help, they can refer you to a sex therapist or another specialist who can. If you want to talk things through, call the LGBT Foundation for confidential advice and support (see page 149).

Managing sexual difficulties

There are practical ways to help manage sexual difficulties. Your doctor or nurse will give you information about these.

If you are taking hormonal therapy, it is likely to lower your sex drive. Treatments for ED do not increase sex drive, but you may still want to try them.

Most treatments aim to increase the blood supply to the penis. You may need to try a treatment a few times to start with. Some men may use more than one method.

Because a prostatectomy can cause ED problems quickly, you may be offered penile rehabilitation soon after treatment. This is called an ED recovery package. You regularly use one or more treatments, such as tablets or a pump, to encourage blood flow to the penis. This is to help the penis recover – it is not just for sex. When you are ready to start having sex, you should have a better chance of getting an erection. Your doctor or nurse can tell you more about this.

> **‘My sexual function hasn’t returned to a great level, but has been manageable with medication. The limited sensation this gave me actually improved my self-confidence and mental state more than it did my sex life.’**
>
> **Simon, diagnosed with early localised prostate cancer**

Tablets

This is the most common treatment for ED. These tablets work by improving the blood supply to the penis. You take them before you have sex. There are different ones you can try. Some may work better for you than others. You need to have sexual stimulation to get an erection. If you have heart problems, these may not be recommended for you. They should not be taken with certain drugs. Your doctor or nurse can explain more about this and their possible side effects.

Tablets to treat ED include the following:

- Sildenafil (Viagra®) – you take it about 60 minutes before sex and it should be prescribed by your GP.
- Vardenafil (Levitra®) – this is like sildenafil and you take it 25 to 60 minutes before sex
- Avanafil (Spedra®) – you take it 15 to 30 minutes before sex
- Tadalafil (Cialis®) – you take it at least 30 minutes before sex.

Other treatments for ED

If drug treatment does not work for you or is not suitable, talk to your doctor about other possible options.

Injections

These may work better than tablets if you have ED that is caused by nerve damage. You inject a drug called alprostadil directly into the penis, using a small needle. The drug improves blood flow in the penis. This causes an erection in 5 to 20 minutes. A healthcare professional will give you the first dose and show you how to do the injection yourself. You start with a low dose of the injection, which you can increase to find the right dose for you.

Pellets or creams

You can get alprostadil as pellets (MUSE®) or as cream (Vitaros®). You put it in the opening of the penis to cause an erection. The drug may cause a burning feeling in the urethra or pain in the penis as it starts working. A healthcare professional will explain more about it and its side effects. They will show you how to do it and give you the first dose.

Pumps

Vacuum pumps can be used to produce an erection. They are also called vacuum erection devices (VEDs). The pump is a hollow tube that you put your penis into. It makes the penis fill with blood by creating a vacuum. You put a stretchy ring around the base of the penis to hold the erection. You should not wear it for more than 30 minutes.

Penile implants

These are sometimes used after other methods have been tried. You need a small operation to insert the implant into your penis. One type uses semi-rigid rods that keep the penis fairly stiff all the time. They allow the penis to be bent down when an erection is not needed. The other type uses inflatable rods that can be turned on when needed to produce an erection.

Infertility

Most treatments for prostate cancer are likely to cause infertility. This means you will no longer be able to get someone pregnant. If you want to have children, this can be very upsetting.

If your fertility is a concern for you, talk to your specialist before treatment. It is usually possible to store sperm before your treatment starts. The sperm may then be used later as part of fertility treatment.

We have more information in our booklet **Cancer and fertility – information for men** (see page 136).

Relationships

If you have a partner

If you have a partner, talking openly with them can help you feel closer. It can also help you make changes to your sex life together. Talking about things can help you avoid misunderstandings and find ways to cope with problems.

There are different ways you can show your partner you care about them. This can include spending time together and showing affection through touching, holding hands or putting an arm around them. You may also find new ways to share sexual pleasure.

Talking to a counsellor or sex therapist may help you and your partner adapt to changes in your sex life. You can ask your partner to come to appointments with you. This will help them understand the issues you are dealing with.

If you are single

If you are not in a relationship, it is natural to worry about meeting a new partner or about your sex life. You may need some time to come to terms with what has happened. It may help to talk to a counsellor or sex therapist. The College of Sexual and Relationship Therapists (COSRT) has a list of nationwide counsellors and therapists who can offer advice and support (see page 142).

YOUR FEELINGS AND RELATIONSHIPS

Your feelings

It is common to have many different emotions when you are told you have cancer. These can be difficult to cope with. We talk about some common feelings here. Partners, family and friends may also have some of the same feelings.

There are lots of different reactions to cancer. You might not have any of the emotions we talk about here. There is no right or wrong way to feel. You will cope with things in your own way.

Talking to family, friends or other people affected by cancer, may help. Or you may get support from your healthcare team.

Shock and denial

You may find it hard to believe that you have cancer when you are first diagnosed. It is common to feel shocked and numb. You may not be able to understand all the information you are given. You may find that you keep asking the same questions. At first, it can be hard to talk about the cancer. Or you might find it hard to think or talk about anything else. Both reactions are normal. Your mind is trying to process what is happening. These feelings usually get easier over time.

Fear and anxiety

You may be anxious or frightened about whether treatments will work and what will happen in the future. This can be one of the hardest things to cope with. It can help to try to focus on things you can control. You may want to find out more about the cancer, your treatment options, and how to manage any side effects. It can also help to talk about your feelings. Try to keep doing the things that are important to you and that you enjoy.

Sadness and depression

You may feel sad if you have to change your plans because of the cancer, or if your future feels uncertain. Feeling sad is a natural reaction to changes or loss. This feeling may come and go during and after your treatment. For most people, these periods of sadness get better. But for some people, the sadness may continue or get worse. If you think the sadness may be turning into depression, there are things you can do to help.

Avoidance

You may cope by trying not to find out much about the cancer. Or by not talking about it. If you feel like this, tell people that you do not want to talk about it right now. You can also tell your cancer doctor if there are things you do not want to know or talk about yet.

Sometimes, it may be hard to accept that you have cancer. This can stop you making decisions about treatment. If this happens, it is very important to get help from your healthcare team.

You may feel that your family or friends are avoiding you or avoiding talking about the cancer. This is usually because they are also finding it difficult to cope. They may need support too. Try to tell them how this makes you feel. It may help you, and your family and friends, to talk openly about how you are feeling.

Anger

You may feel angry about your diagnosis. You may also resent other people for being well. These are normal reactions. They are more likely when you feel frightened, stressed or unwell. You may get angry with your family, friends or partner. Tell them you are angry at your illness and not at them. Finding ways to relax can help with anger. This can include talking about or writing down how you feel, doing gentle exercise, having relaxation therapy or meditating.

Guilt and blame

You may feel guilty or blame yourself for the cancer. You may want to find reasons for why it has happened to you. Most of the time, it is impossible to know exactly what causes a cancer. Over time, a combination of different risk factors may cause a cancer. Doctors do not fully understand all these factors yet. Try to focus on looking after yourself and getting the help and support you need.

Feeling alone

You may feel alone or isolated. This could be because you do not think you have support. Family and friends may live far away, be busy, or feel uncomfortable talking about the cancer. Try to tell your family and friends how you feel. This can help them find ways to support you.

You may have times when you want to be alone for a while. But if you find you are avoiding people a lot of the time, try to talk to your doctor or nurse.

If you need more support, you can call the Macmillan Support Line on **0808 808 00 00** and talk to one of our cancer support specialists. Our website can help you find local support groups. Visit **macmillan.org.uk/supportgroups** You can also talk to other people affected by cancer on our Online Community. Visit **macmillan.org.uk/community**

If you need more help

You may find it very difficult to cope with your emotions and may need more help. This does not mean you are failing in any way.

Talk to your doctor or nurse if:

- you feel anxious or worried a lot of the time
- you think you may be depressed.

They can refer you to a specialist doctor, psychologist or counsellor who can help. They may also prescribe medicines to help.

We have more information in our booklet **How are you feeling? The emotional effects of cancer** (see page 136).

Coping with your emotions

You may feel that the cancer has taken over your life. This is a common reaction. It can be very hard to cope with. But there are lots of things you can do to help you feel differently:

- You may find it helps to try to keep doing your usual activities.
- You may want to think about what is important to you. This could mean spending time with family, planning a holiday or starting a new hobby.
- You might decide to change your lifestyle. This could be eating healthily, being physically active or trying complementary therapies.
- Making plans can help you feel more in control.
- You might find knowing more about the cancer and your treatment options also helps you cope. It means you can make a plan with your healthcare team.
- Making choices and being active in your own care can help you feel more in control.

If you feel you are not coping well, or need more support, talk to your doctor or nurse.

If you are a family member or friend

If you know someone with cancer, you might find it hard to talk about the cancer or your feelings. You might think it is best to pretend everything is fine. You might not want to worry them. Or you might feel you are letting them down if you admit you are worried or scared.

But not talking to the person with cancer about how you feel may make them feel alone.

You can support the person with cancer by listening and talking with them. Do not feel you have to talk about the cancer. Often it is enough just to listen and let the person with cancer talk when they are ready.

You may find some of the courses on our Learn Zone website helpful. There are courses to help with listening and talking. Visit **macmillan.org.uk/learnzone** to find out more.

We have more information in our booklet **Talking with someone who has cancer** which you may find helpful (see page 136).

If you are looking after a family member or friend with cancer, you may be a carer. We have more information and practical tips for carers in our booklet **Looking after someone with cancer** (see page 136).

Talking to children about cancer

Deciding what to tell children about cancer is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them. Children do not always show their feelings, but their behaviour may change at home or at school.

Talking to children about the cancer can:

- help them understand what is going on
- help them feel supported
- prepare them for any changes.

It may also help with some of your own anxiety too.
For example, not telling them about hospital appointments may cause extra stress.

How much you tell children will depend on their age and how mature they are. It may be best to start by giving them small amounts of information, and then tell them more when they are ready. Teenagers usually understand what cancer is. Some will want to know more.

Whether they are teenagers or young children, talking about the cancer helps them cope.

Teenagers

It can help to encourage teenagers to ask questions, ask them their opinion and try to give them time to think about what is happening. They may have to, or want to, take on more responsibilities to help – perhaps cooking meals or looking after younger children. This can be hard at a time when they may want more freedom and independence.

Sometimes teenagers may find it hard to talk about a cancer diagnosis. You can encourage them to talk to someone they trust, who can support and listen to them. This might be a grandparent, family friend, teacher or counsellor. They may also find support online. The website **riprap.org.uk** offers information and support for teenagers who have a parent with cancer.

We have more information in our booklet **Talking to children and teenagers when an adult has cancer** (see page 136).

FINANCIAL SUPPORT AND WORK

Financial help and benefits

When you are affected by cancer, you might need help with extra costs. Or you might need financial support if you have to stop working.

Statutory Sick Pay

If you work for an employer and take time off sick, you may be able to get Statutory Sick Pay. Your employer will pay this for up to 28 weeks.

Benefits

Benefits are payments from the government to people who need financial help. You can find out more about benefits and apply for them online. Go to **gov.uk** if you live in England, Wales or Scotland, or **nidirect.gov.uk** if you live in Northern Ireland.

Here are some benefits that you might be able to get if you are affected by cancer.

Employment and Support Allowance (ESA)

This benefit is for people under State Pension age who have an illness or disability that affects how much they can work. There are different types of ESA, so it is a good idea to speak to a welfare rights adviser to see if you can make a claim.

Universal Credit

Universal Credit (UC) is a benefit for people under State Pension age who are either:

- out of work – for example, because of an illness or because they are caring for someone
- on a low income.

UC can include money for basic living costs, looking after children and housing.

Personal Independence Payment

This benefit is for people aged 16 to State Pension age who have problems moving around or looking after themselves. You must have had these problems for 3 months and expect them to last for at least 9 months, unless you are terminally ill.

Attendance Allowance

This benefit is for people at or over State Pension age who have problems looking after themselves because of an illness or disability. This could mean problems getting out of bed, having a bath or getting dressed. You must have had these problems for at least 6 months, unless you are terminally ill.

Special rules

If you are terminally ill, you can apply for some benefits using a fast-track process called special rules. You can apply if your doctor thinks you may be reasonably expected to live for less than 6 months. Your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate. It does not matter if you live longer than 6 months. Your doctor or specialist nurse will need to fill out a form for you.

Help for carers

Carer’s Allowance is a weekly benefit to help people who look after someone with a lot of care needs. If you do not qualify for it, you may still be able to apply for Carer’s Credit.

Carer’s Credit helps prevent gaps in your National Insurance record if you have to stop working while you are caring for someone else. You do not get money, but it protects your right to a State Pension later in life.

Macmillan Grants

Macmillan Grants are small, mostly one-off payments to help people with the extra costs cancer can cause. They are for people who have a low level of income and savings.

If you need things like extra clothing, help paying heating bills or even a relaxing holiday, you may be able to get a Macmillan Grant.

How much you get will depend on your situation and needs. A grant from Macmillan does not normally affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. This includes life and travel insurance. A cancer diagnosis might also mean that you can get a payout from an insurance scheme that you already have.

If you are thinking about buying insurance or making a claim, one of our financial guides can help. You can call them on **0808 808 00 00**.

We have more information in our booklet **Travel and cancer**. Our Online Community forum on **Travel insurance** may also be helpful (see page 136).

More information

The benefits system and other types of financial support can be hard to understand. Macmillan has experienced welfare rights advisers and financial guides. You can speak to one by calling the Macmillan Support Line on **0808 808 00 00**.

You can also get information about benefits and other types of financial help from Citizens Advice (see page 148) or Advice NI (see page 147) if you are in Northern Ireland.

Our booklet **Help with the cost of cancer** has lots more information (see page 136).

Work

You may not know how cancer will affect your work, now or in the future.

It is a good idea to talk to your manager soon after you are diagnosed. If your workplace has a human resources (HR) or personnel department, contact them as soon as you can. If they know how the cancer or treatment may affect your ability to work, they can support you better.

Some people stop working during cancer treatment and for a while after, until they feel ready to go back. Others keep working, perhaps with reduced hours or other changes to their job.

Some people may decide not to go back to work. Or they may choose to do something different. Others may not be able to go back to work because of the effects of cancer on their health. Going back to work may depend on the type of work you do or how much your income is affected.

It is important not to do too much, too soon. Your cancer doctor, GP or specialist nurse can help you decide when and if you should go back to work.

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful (see page 136). There is also lots more information at **macmillan.org.uk/work**

Employment rights

If you have, or have ever had, cancer, the law considers this as a disability. This means you cannot be treated less favourably than people who do not have cancer because you have cancer, or for reasons connected to the cancer. That would be discrimination.

The law also says your employer must make reasonable adjustments (changes) to your workplace and their work practices to help you stay at work or return to work.

If you live in England, Scotland or Wales, you are protected by the Equality Act 2010. If you live in Northern Ireland, you are protected by the Disability Discrimination Act 1995.

Our booklet **Your rights at work when you are affected by cancer** has more information (see page 136).

FURTHER INFORMATION

About our information

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

Order what you need

You may want to order more booklets or leaflets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

We have booklets about different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer treatment and information for carers, family and friends.

Online information

All our information is also available online at **macmillan.org.uk/information-and-support** You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- eBooks
- large print
- translations.

Find out more at **macmillan.org.uk/otherformats**

If you would like us to produce information in a different format for you, email us at **cancerinformationteam@macmillan.org.uk** or call us on **0808 808 00 00**.

The language we use

We want everyone affected by cancer to feel our information is written for them.

We try to make sure our information is as clear as possible. We use plain English, avoid jargon, explain any medical words, use illustrations to explain text, and make sure important points are highlighted clearly.

We use gender-inclusive language and talk to our readers as ‘you’ so that everyone feels included. Where clinically necessary we use the terms ‘men’ and ‘women’ or ‘male’ and ‘female’. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected. Our aims are for our information to be as clear and relevant as possible for everyone.

You can read more about how we produce our information at **macmillan.org.uk/ourinfo**

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we are here to support you.

Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

Macmillan Support Line

Our free, confidential phone line is open 7 days a week, 8am to 8pm. Our cancer support specialists can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Call us on **0808 808 00 00** or email us via our website, **macmillan.org.uk/talktous**

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face. Visit one to get the information you need, or if you would like a private chat, most centres have a room where you can speak with someone alone and in confidence.

Find your nearest centre at **macmillan.org.uk/informationcentres** or call us on **0808 808 00 00**.

Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That is why we help to bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting **macmillan.org.uk/selfhelpandsupport**

Online Community

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at **macmillan.org.uk/community**

The Macmillan healthcare team

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have been affected in this way, we can help.

Financial guidance

Our financial team can give you guidance on mortgages, pensions, insurance, borrowing and savings.

Help accessing benefits

Our benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break. Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants.

We can also tell you about benefits advisers in your area. Visit **macmillan.org.uk/financialsupport** to find out more about how we can help you with your finances.

Help with work and cancer

Whether you are an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit **macmillan.org.uk/work**

Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on **0808 808 00 00** to speak to a work support adviser (Monday to Friday, 8am to 6pm).

Other useful organisations

There are lots of other organisations that can give you information or support.

Details correct at time of printing.

Prostate cancer support organisations

Bladder and Bowel Community

Home Delivery Service **0800 031 5406**
Email **help@bladderandbowel.org**
www.bladderandbowel.org
Provides information and advice on a range of symptoms and conditions related to the bladder and bowel, including incontinence, constipation and diverticular disease.

Orchid

Helpline **0808 802 0010**
Email **helpline@orchid-cancer.org.uk**
www.orchid-cancer.org.uk
Funds research into men’s cancers and their diagnosis, prevention and treatment. Offers free information leaflets and fact sheets, and runs an enquiry service supported by Orchid Male Cancer Information Nurses.

Prostate Cancer UK

Helpline **0800 074 8383**
www.prostatecanceruk.org
Provides information and support to men with prostate cancer and their families. Has offices in London, the Midlands, Scotland, Wales and Northern Ireland.

Prostate Scotland

Tel **0131 603 8660**
Email **info@prostatescotland.org.uk**
www.prostatescotland.org.uk
A Scottish charity set up to provide information, advice and support on prostate health and diseases of the prostate. You can watch videos online and download free leaflets and booklets.

Tackle Prostate Cancer

Tel **0800 035 5302**
Email **helpline@tackleprostate.org**
www.tackleprostate.org
An organisation of UK patient-led prostate cancer support groups.

Support with sexual issues

College of Sexual and Relationship Therapists (COSRT)

Tel **020 8106 9635**
www.cosrt.org.uk
The UK's leading membership organisation for therapists specialising in sexual and relationship issues.

Prostate Cancer UK sexual support service

Specialist nurses **0800 074 8383**
www.prostatecanceruk.org/get-support/sexual-support
A service for you or your partner to talk to a specialist nurse with an interest in helping with sexual problems after treatment for prostate cancer.

Sexual Advice Association

www.sexualadviceassociation.co.uk
Aims to improve the sexual health and well-being of men and women, and to raise awareness of how sexual conditions affect the general population.

General cancer support organisations

Cancer Black Care

Tel **020 8961 4151**
www.cancerblackcare.org.uk
Offers UK-wide information and support for people from Black and ethnic minority communities who have cancer. Also supports their friends, carers and families.

Cancer Focus Northern Ireland

Helpline **0800 783 3339** (Mon to Fri, 9am to 1pm)
Email **nurseline@cancerfocusni.org**
www.cancerfocusni.org
Offers a variety of services to people affected by cancer in Northern Ireland.

Cancer Research UK

Helpline **0808 800 4040** (Mon to Fri, 9am to 5pm)
www.cancerresearchuk.org
A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

Cancer Support Scotland

Tel **0800 652 4531** (Mon to Fri, 9am to 5pm)
Email **info@cancersupportscotland.org**
www.cancersupportscotland.org
Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

Macmillan Cancer Voices

www.macmillan.org.uk/cancervoices

A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.

Maggie's

Tel **0300 123 1801**
Email **enquiries@maggies.org**
www.maggies.org

Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Penny Brohn UK

Helpline **0303 3000 118** (Mon to Fri, 10am to 2pm)
Email **helpline@pennybrohn.org.uk**
www.pennybrohn.org.uk

Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Riprap

www.riprap.org.uk

Developed especially for teenagers in the UK who have a parent with cancer. Has an online forum where teenagers going through similar experiences can talk to each other for support.

Tenovus

Helpline **0808 808 1010** (Mon to Fri, 9am to 5pm, and Sat to Sun, 10am to 1pm)

www.tenovuscancercare.org.uk

Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online ‘Ask the nurse’ service.

General health information

Health and Social Care in Northern Ireland

online.hscni.net

Provides information about health and social care services in Northern Ireland.

NHS.UK

www.nhs.uk

The UK’s biggest health information website. Has service information for England.

NHS Direct Wales

www.nhsdirect.wales.nhs.uk

NHS health information site for Wales.

NHS Inform

Helpline **0800 22 44 88** (7 days a week 8am to 8pm)

www.nhsinform.scot

NHS health information site for Scotland.

Patient UK

www.patient.info
Provides people in the UK with information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics. Also reviews and links to many health- and illness-related websites.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel **0145 588 3300** (Mon to Fri, 10am to 4pm)
Email **bacp@bacp.co.uk**
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on their ‘How to find a therapist’ page.

UK Council for Psychotherapy (UKCP)

Tel **020 7014 9955**
Email **info@ukcp.org.uk**
www.psychotherapy.org.uk
Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

Emotional and mental health support

Mind

Helpline **0300 123 3393** (Mon to Fri, 9am to 6pm)
Email **info@mind.org.uk**
www.mind.org.uk
Provides information, advice and support to anyone with a mental health problem through its helpline and website.

Samaritans

Helpline 116 123
Email **jo@samaritans.org**
www.samaritans.org
Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

Financial support or legal advice and information

Advice NI

Helpline **0800 915 4604**
Email **advice@advice.net**
Provides advice on a variety of issues including financial, legal, housing and employment issues.

Benefit Enquiry Line Northern Ireland

Helpline **0800 232 1271**
(Mon, Tue, Wed and Fri, 9am to 5pm, and Thu, 10am to 5pm)
Textphone **028 9031 1092**
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland. You can also call the Make the Call helpline on **0800 232 1271** to check you are getting all the benefits you are eligible for.

Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use their online webchat or find details for your local office by contacting:

England

Helpline **0800 144 8848**
www.citizensadvice.org.uk

Scotland

Helpline **0800 028 1456**
www.cas.org.uk

Wales

Helpline **0800 702 2020**
www.citizensadvice.org.uk/wales

Support for older people

Age UK

Helpline **0800 678 1602** (Daily, 8am to 7pm)
www.ageuk.org.uk
Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

LGBT-specific support

LGBT Foundation

Tel **0345 330 3030** (Mon to Fri, 9am to 9pm)
Email **helpline@lgbt.foundation**
www.lgbt.foundation
Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

Live Through This

www.livethroughthis.co.uk
A safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage. Also produces resources about LGBT cancer experiences. LTT runs a peer support group with Maggie's Barts.

Cancer registries

The cancer registry

A national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services. There is one in each country in the UK:

National Cancer Registration and Analysis Service

Tel **0207 654 8000**
Email **enquiries@phe.gov.uk**
www.ndrs.nhs.uk
Tel (Ireland) **0214 318 014**
www.ncri.ie (Ireland)

Scottish Cancer Registry

www.ndrs.nhs.uk/cancer-registration-your-rights-and-privacy

Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel **0292 010 4278**
phw.nhs.wales/services-and-teams/welsh-cancer-intelligence-and-surveillance-unit-wcisu

Northern Ireland Cancer Registry

Tel **0289 097 6028**
Email **nicr@qub.ac.uk**
www.qub.ac.uk/nicr

Your notes and questions

Your notes and questions

Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by Dr Jim Barber, Consultant Clinical Oncologist, and Dr Ursula McGovern, Consultant Medical Oncologist.

With thanks to: Jane Booker, Macmillan Urology Clinical Nurse Specialist; Mr Christian Brown, Consultant Urological Surgeon; Sharon Clovis, Prostate Clinical Nurse Specialist; Mr Daniel Good, Consultant Urological Surgeon; Dr Mohammed Kagzi, Consultant Clinical Oncologist; Dr Duncan McLaren, Consultant Clinical Oncologist; David Stafford, Macmillan Lead Nurse in Urology Cancer Services; and Professor Jonathan Waxman, Professor of Oncology.

Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.

We welcome feedback on our information. If you have any, please contact **cancerinformationteam@macmillan.org.uk**

Sources

Below is a sample of the sources used in our early (localised) prostate cancer information. If you would like more information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

C. Parker, E. Castro, K. Fizazi, et al. Prostate cancer: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up. Annals of Oncology, 2020, Volume 31, Issue 9, p1119-1134. Available from https://www.esmo.org/guidelines/genitourinary-cancers/prostate-cancer
National Institute for Health and Care Excellence (2019) Prostate cancer: diagnosis and management (NICE guideline NG131) Available at https://www.nice.org.uk/guidance/ng131

Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer. They are produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we are here to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.

5 ways you can help someone with cancer

Share your cancer experience
Support people living with cancer by telling your story, online, in the media or face to face.

Campaign for change
We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

Help someone in your community
A lift to an appointment. Help with the shopping.
Or just a cup of tea and a chat. Could you lend a hand?

Raise money
Whatever you like doing you can raise money to help.
Take part in one of our events or create your own.

Give money
Big or small, every penny helps.
To make a one-off donation see over.

Call us to find out more 0300 1000 200
macmillan.org.uk/getinvolved

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Mr/Mrs/Miss/Other

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Surname

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Postcode

Phone

Email

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OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

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Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box. ☐

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.

If you would rather donate online go to **macmillan.org.uk/donate**

Registered with FUNDRAISING REGULATOR

Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851, 89 Albert Embankment, London SE1 7UQ

This booklet is about early prostate cancer. It is for anyone who has been diagnosed with early prostate cancer. There is also information for carers, family members and friends.

The booklet explains the signs and symptoms of early prostate cancer. It explains how it is diagnosed and how it can be treated. It also has information about emotional, practical and financial issues.

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. For information, support or just someone to talk to, call **0808 808 00 00** (7 days a week, 8am to 8pm) or visit **macmillan.org.uk**

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

Need information in different languages or formats? We produce information in audio, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call our support line.

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