A practical guide to tests and treatments

# HAVING TESTS FOR PROSTATE CANCER



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## About this booklet

This booklet is for men who may be having tests for prostate cancer. We hope it answers some of your questions and helps you deal with some of the feelings you may have.

Tests for prostate cancer can be divided into two groups:

- **Diagnostic tests**, which are carried out to find out if you have prostate cancer.
- **Staging tests**, which are done if you've been diagnosed with prostate cancer. The results of staging tests help doctors decide which treatment is most suitable for you.

We have separate booklets for men who have been diagnosed with prostate cancer and already know what stage their cancer is:

- Understanding early (localised) prostate cancer
- Understanding locally advanced prostate cancer
- Understanding advanced (metastatic) prostate cancer.

We can't advise you about the best treatment for you. This information can only come from your GP and specialist doctors, who know your full medical history.

On pages 40–52 are some useful addresses and websites. On page 53 there is space for you to write down questions for your doctor or nurse.

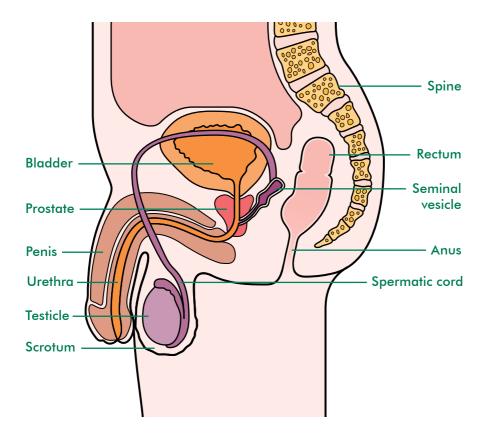
Throughout this booklet, we've included quotes from men who have had tests for prostate cancer. Some are from the website **healthtalk.org** and others are from our online community – visit **macmillan.org.uk/community** Some names have been changed.

If you'd like to discuss this information, call the Macmillan Support Line free on **0808 808 00 00**, Monday–Friday, 9am–8pm. If you're hard of hearing, you can use textphone **0808 808 0121**, or Text Relay. For non-English speakers, interpreters are available. You can also visit **macmillan.org.uk** 

If you find this booklet helpful, you could pass it on to your family and friends, so that they can support you.

## The prostate gland

The prostate is a small gland only found in men. It's about the size of a walnut and gets a little bigger with age. It surrounds the first part of the tube (urethra) that carries urine from the bladder along the penis.



The prostate and surrounding structures

The prostate produces a thick, white fluid that mixes with the sperm produced by the testicles to make semen. It also produces a protein called **prostate-specific antigen (PSA)** that turns the semen into liquid.

The prostate gland contains many small glands which are sometimes called **prostate cells**. These cells are surrounded by muscle and a fibrous capsule.

The growth of prostate cells and the way the prostate gland works depend on the male sex hormone **testosterone**, which is produced in the testicles.

## **Prostate symptoms**

Cancer of the prostate is often slow-growing and symptoms may not occur for many years. Men with early prostate cancer may not have any symptoms, as these only occur when the cancer is large enough to put pressure on the urethra. The prostate can also become enlarged due to a condition called **benign prostatic hyperplasia (BPH)**, which is non-cancerous.

The symptoms of benign (non-cancerous) enlargement of the prostate and prostate cancer are similar. They can include any of the following:

- difficulty passing urine
- passing urine more frequently than usual, especially at night
- the feeling of not completely emptying your bladder
- needing to rush to the toilet to pass urine
- blood in the urine or semen (this is rare)
- pain when passing urine or ejaculating (this is rare).

If you have any of these symptoms, it's important to have them checked by your doctor.

'I had all the symptoms of prostate cancer – difficult to pee, getting up several times during the night, bursting to go and then not being able to go properly. I went to see my GP, who sent me for a blood test to test my PSA level. I didn't know what that was at the time.'

Richard

#### Other symptoms

For a small number of men, the first symptom of prostate cancer may be pain in the back, hips or legs. This is because prostate cancer can sometimes spread to the bones. Although there are many other reasons for this kind of pain, it's a good idea to let your GP know about any pain you haven't experienced before.

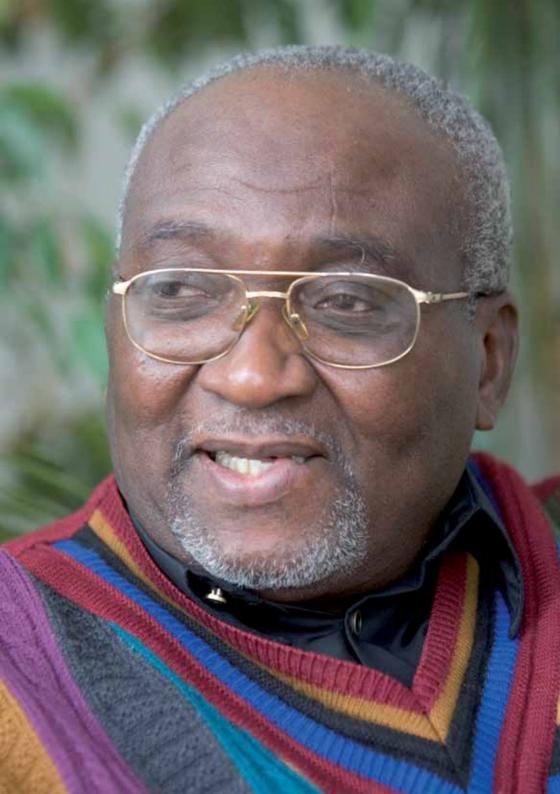
## What is cancer?

Cancer starts in cells in our body. Cells are tiny building blocks that make up the organs and tissues of our bodies. They divide to make new cells in a controlled way. This is how our bodies grow, heal and repair. Cells receive signals from the body telling them when to divide and grow and when to stop growing. When a cell is no longer needed or can't be repaired, it gets a signal to stop working and die.

Cancer develops when the normal workings of a cell go wrong and the cell becomes abnormal. The abnormal cell keeps dividing making more and more abnormal cells. These eventually form a lump (**tumour**). Not all lumps are cancerous. Doctors can tell if a lump is cancerous by removing a small sample of tissue or cells from it. This is called a **biopsy**. The doctors examine the sample under a microscope to look for cancer cells.

A lump that is not cancerous (**benign**) may grow but cannot spread to anywhere else in the body. It usually only causes problems if it puts pressure on nearby organs.

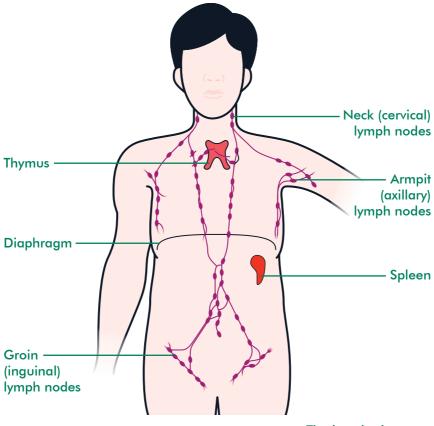
A lump that is cancerous (**malignant**) can grow into nearby tissue. Sometimes, cancer cells spread from where the cancer first started (the primary site) to other parts of the body. They can travel through the blood or lymphatic system (see pages 12–13). When the cells reach another part of the body, they may begin to grow and form another tumour. This is called a **secondary cancer** or a **metastasis**.



## The lymphatic system

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

**Lymph nodes** (sometimes called **lymph glands**) are small and bean-shaped. They filter bacteria (germs) and disease from the lymph fluid. When you have an infection, lymph nodes often swell as they fight the infection. They can be found in many different places in the body, including near the prostate.



The lymphatic system



## **Prostate cancer**

Prostate cancer generally affects men over 50. It's rare in younger men. It's the most common type of cancer in men. Around 41,000 men in the UK are diagnosed with prostate cancer each year.

It differs from most other cancers, in that small areas of cancer within the prostate are very common and may stay dormant (inactive) for many years.

It's thought that about half (50%) of all men over 50 and 8 out of 10 (80%) of men over 80 have some cancer cells in their prostate gland. Most of these cancers grow very slowly and so will never cause any problems, particularly in elderly men.

# How prostate cancer is diagnosed

Men who have symptoms usually start by seeing their GP. Your GP will examine you and ask about your general health.

### **Diagnostic tests**

The first tests used to diagnose prostate cancer are a digital rectal examination and a PSA test.

#### **Digital rectal examination (DRE)**

The rectum (back passage) is close to the prostate gland. Your doctor can feel for any abnormalities in the prostate by gently inserting a gloved finger with lubrication into the rectum. This may be uncomfortable, but shouldn't be painful and doesn't take very long.

If there's cancer in the prostate gland, it may feel hard and knobbly. With benign prostatic hyperplasia (see page 8), the prostate usually feels enlarged, firm and smooth. However, the prostate may feel normal even when cancer cells are present.

'I did have a digital examination which was rather uncomfortable, but thinking of my health and wellbeing it was just a minor inconvenience, so that wasn't a problem at all.'

David

#### PSA (prostate-specific antigen) test

You'll have a sample of blood taken to check for PSA. This is a protein produced by the prostate. There is normally a small amount of PSA in the blood.

Men with prostate cancer tend to have a raised level of PSA. However, this test isn't always reliable and some men who have a raised level of PSA don't have prostate cancer.

The PSA level can also be raised by:

- urine infections or an infection of the prostate (prostatitis)
- recent prostate biopsies (within the last three months)
- having a urinary catheter (a tube to drain urine)
- prostate or bladder surgery (within the last three months)
- recent ejaculation (within the last 48 hours)
- prostate massage.

PSA levels also rise as men get older:

- In men aged 50–59, a PSA level of 3 nanograms per millilitre of blood (ng/ml) or lower is considered normal.
- In men aged 60–69, a PSA level of 4ng/ml or lower is considered normal.
- In men aged 70 and over, a PSA level of 5ng/ml is considered normal.

It's important to let your GP or nurse know about any medicines you are taking before you have your PSA test. This is because some medicines can alter the result of your PSA test.

As a general rule, the higher the level of PSA, the more likely it is to be cancer. Following treatment, the level of PSA will fall. So measuring PSA levels can be a helpful way of assessing the cancer and the effectiveness of treatment.

If your PSA level is raised, or if your GP feels any abnormalities during the digital rectal examination, they will refer you to hospital for a discussion about further tests.

#### Screening for prostate cancer

Screening aims to detect cancer in people who do not have any symptoms. There is currently no screening programme for prostate cancer in the UK. This is because we still don't know how reliable the PSA test is and there are no other tests that have been proven to be accurate enough.

Research suggests that while the lives of some men could be saved by PSA screening, many more men would be unnecessarily treated for cancers that would never have caused serious harm.

If you don't have prostate symptoms but would like to have a PSA test, you should talk to your GP. They can give you information and arrange the test if you'd like to have it.

Our booklet Understanding the PSA test has more information. We also have a video about the PSA test at macmillan.org.uk/PSAtesting

#### PCA3 (prostate cancer antigen 3) test

This test is still being researched. PCA3 is a protein made by normal prostate cells. When prostate cancer is present, more of the protein is made than usual. If a man has high levels of this protein, it can be found in the urine.

The PCA3 test can't diagnose cancer on its own, but it might help doctors decide which men should have a biopsy (see pages 20–21). This would mean that men who are very unlikely to have prostate cancer could avoid the possible risks and side effects of having a prostate biopsy.

The PCA3 test is not available on the NHS at the moment, but it may be available privately. Your doctor or specialist nurse will be able to talk to you about how helpful it might be in your situation.

#### Trans-rectal ultrasound scan (TRUS) biopsy

If the initial tests (digital rectal examination and PSA) show there is a possibility of cancer, you may have a prostate biopsy.

Usually, the first biopsy you have is a TRUS biopsy. A small ultrasound probe is passed gently into the back passage using lubricating gel and an image of the prostate appears on a screen. A needle is then inserted into the prostate in order to take a sample of cells (a biopsy). You will usually have 12 small samples of tissue taken from the prostate. These are examined under the microscope by a pathologist.

Some men find having a TRUS biopsy uncomfortable. You may be given a local anaesthetic to reduce the discomfort. The doctor will also give you antibiotics to reduce the risk of infection.

For 24 hours after this test, it's important to drink plenty of fluids. You may notice blood in your semen for up to a few weeks after the scan. You may also notice a small amount of blood in your urine or when opening your bowels. If these symptoms don't go away, speak to your doctor.

Unfortunately, even if there is cancer in the prostate, it may not be found by a biopsy. This occurs in around 5–10% of men (fewer than 1 in 10). If this happens, you may be offered an MRI scan (see page 27) to decide if another biopsy is needed.

#### **Template biopsy**

You may have your PSA level checked again after a few months. If it has started to rise, you may have another type of biopsy called a template biopsy. This is done under a general anaesthetic. The doctors pass a needle through the skin between the scrotum (the skin that covers the testicles) and the anus. They use a needle which can take many small tissue samples from different areas of the prostate. This test is usually only used if previous biopsies have not shown cancer but your doctor still thinks there may be a high risk you have cancer.

Your doctor can tell you more about biopsies and discuss whether a template biopsy might be helpful in your situation.

## Waiting for test results

It can take a few days to a few weeks for test results to be ready. Many people feel anxious during this time.

You may feel like you have no control over what's going to happen to you. The waiting period might feel very long and the future may feel very uncertain.

There is no right or wrong way to deal with these feelings. Some people find it helps to carry on with normal activities as much as possible. Continuing with everyday activities, such as going to work, can be a welcome distraction from worrying. Other people may feel they cannot concentrate on anything else.

Some men look for information about prostate cancer during this time. Searching for information can help you feel more in control while you wait for your results. However, if you're not sure of the diagnosis, some information can be confusing and upsetting. It may be better to wait until a diagnosis is made before looking for more information. If you do decide to find out more, it's a good idea to make sure the information is from a reliable source. There are some useful websites with reliable, user-friendly information listed on pages 45–52.

### Things that may help

- It might be helpful to divide your day into different activities. For example, you could meet a friend for lunch, or do something you usually enjoy, such as watching sports or going to the cinema. This can provide a distraction from worrying thoughts, make you feel more in control and reduce feelings of uncertainty.
- Try talking to a family member or close friend. Many people find that their fears and worries are reduced simply by telling someone else about them. 'Offloading' in this way can be a relief and you may find that you feel better afterwards. Some people prefer to talk to someone outside their circle of family and friends. You may find it helpful to speak to one of our cancer support specialists on **0808 808 00 00**.
- Try to relax. If you struggle to sleep during this time, simple breathing and relaxation exercises may be useful in reducing anxiety, stress and any muscle tension you have. Many people find this relaxing, and experience a sense of calm when using these simple methods. Almost everyone can learn relaxation techniques. You could do this at home using a CD. You can also download free podcasts from many websites, or you can download relaxation apps to your smartphone.

## Your test results

Once the test results are back, you'll have an appointment with your specialist to discuss them. Some men will be told they don't have cancer, but their specialist might discuss any treatment needed for their symptoms. Others won't need any treatment.

Some men will be told they have cancer. They may need to have further tests, which will help the doctors to plan treatment (see pages 26–29). Other men won't need further tests, and their specialist will discuss what treatment is best for them.

During the appointment, your doctor will outline the different treatment options. They'll explain what each treatment option involves and any potential side effects. It may be helpful to take someone with you to this appointment to help you remember the discussion. You might also like to write down any questions you have. Pages 36–37 give some examples of questions you may want to ask. On page 53 there's space for you to write down your own questions or make notes from the discussion to refer to later.

Sometimes you may be given a choice of treatments, which are thought to be equally effective. There may be no clear benefit of having one treatment over another, but you may have a preference based on what is involved and the possible side effects.

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You may find it helpful to read our booklet Making treatment decisions.



# If you are diagnosed with prostate cancer

If your specialists are certain you have cancer, they may want to carry out further tests to find out more about the **stage** of your cancer. The stage gives information about the extent of the cancer.

The **grade** of your cancer is usually found out when you get your biopsy results. The grade gives information about whether the cancer is a slow- or fast-growing type.

Knowing the stage and grade of the cancer helps you and your doctors decide on the best treatment plan.

There is more information about staging and grading on pages 31–32.

### **Staging tests**

The following tests can be used to help diagnose or stage prostate cancer. You may not need to have all of them. Your doctor should explain the benefits and disadvantages of each test before you agree to have any of them. They will also tell you how and when you will get the results.

The tests may include more blood tests, as well as any of the following.

#### MRI (magnetic resonance imaging) scan

An MRI scan may show whether the cancer has spread into the tissues around the prostate gland or into the lymph nodes near the prostate (see pages 12–13).

This test uses magnetism to build up a detailed picture of areas of your body. The scanner is a powerful magnet so you may be asked to complete and sign a checklist to make sure it's safe for you. The checklist asks about any metal implants you may have, such as a pacemaker, surgical clips or bone pins. You should also tell your doctor if you've ever worked with metal or in the metal industry as very tiny fragments of metal can sometimes lodge in the body. If you do have any metal in your body, it's likely that you won't be able to have an MRI scan. In this situation, another type of scan can be used.

Before the scan, you'll be asked to remove any metal belongings including jewellery. Some people are given an injection of dye into a vein in the arm, which doesn't usually cause discomfort. This is called a contrast medium and can help the images from the scan to show up more clearly. During the test, you'll lie very still on a couch inside a long cylinder (tube) for about 30 minutes. It's painless but can be slightly uncomfortable, and some people feel a bit claustrophobic. It's also noisy, but you'll be given earplugs or headphones. You can hear, and speak to, the person operating the scanner.

MRI scans can also sometimes be used to help you decide whether to have another biopsy, or to help doctors take biopsies more precisely. This usually happens when biopsies have been negative for cancer, but other factors, such as a high PSA level or particular symptoms, suggest that there may still be a risk of prostate cancer.

#### **Bone scan**

The bones are the most common place for prostate cancer to spread to beyond the lymph nodes. A bone scan can reveal any abnormal areas of bone.

A very small amount of a mildly radioactive liquid is injected into a vein, usually in your arm. A scan is then taken of the whole body. Abnormal bone absorbs more of the radioactive substance than the normal bone does, and shows up on the scan as highlighted areas called **hot spots**.

After the injection, you'll have to wait for up to three hours before having the scan, so it's a good idea to take something with you like a book or some music.

The level of radioactivity that is used is very low and doesn't cause any harm. However, you may be asked to avoid long periods of close contact with children or pregnant women for a while after the scan. This is usually for 2–3 days, but the staff at the hospital will give you more information.

This scan can also detect other conditions affecting the bones, such as arthritis. This means that further tests, such as an x-ray of the abnormal area, may be needed to confirm if any hot spots that show up on the scan are cancer.

#### X-rays

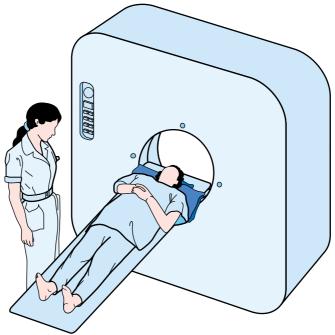
You may have a chest x-ray and x-rays of the bones to check your general health, and to see if the cancer has spread to other parts of the body.

#### CT (computerised tomography) scan

A CT scan takes a series of x-rays, which build up a threedimensional picture of the inside of the body. The scan takes 10–30 minutes and is painless. It uses a small amount of radiation, which is very unlikely to harm you and will not harm anyone you come into contact with. You will be asked not to eat or drink for at least four hours before the scan.

You may be given a drink or injection of a dye, which allows particular areas to be seen more clearly. This may make you feel hot all over for a few minutes. It's important to let your doctor know if you are allergic to iodine or have asthma, because you could have a more serious reaction to the injection.

You'll probably be able to go home as soon as the scan is over.



Someone having a CT scan



# **Staging and grading**

## Staging

The stage of a cancer describes where the cancer is, its size and whether it has spread. There are a few different systems for staging prostate cancer.

A simplified numbered staging system is described below:

- **Stage 1** The cancer is very small and confined within the prostate gland. It can't be felt during a rectal examination.
- **Stage 2** The cancer can be felt as a hard lump during a rectal examination but is still contained within the prostate gland.
- **Stage 3** The cancer has started to break through the outer capsule of the prostate gland and may be in the nearby tubes that produce semen (seminal vesicles).
- **Stage 4** The cancer has spread beyond the prostate gland to nearby structures such as the bladder or back passage (rectum), or to more distant organs such as the bones or liver.

Using the numbered staging system described above, stages 1 and 2 are known as early (localised) prostate cancer. Stage 3 is known as locally advanced prostate cancer. Stage 4 is known as advanced (metastatic) prostate cancer, which means the cancer has spread away from the prostate.

### Grading

The grade of a cancer gives an idea of how quickly it might grow. Prostate cancer is graded according to the appearance of the cancer cells when the biopsy sample is looked at under the microscope.

The **Gleason system** is the most commonly used grading system. It looks at the pattern of cancer cells within the prostate. There are five patterns, which are graded from 1 to 5.

Grade 1 is very similar to normal prostate tissue, whereas grade 5 is very different from normal tissue. Only grades 3 to 5 are cancer.

The biopsy samples are each graded. The most common grade is added to the highest grade of the other samples. This gives a Gleason score of 6–10.

Cancers with a Gleason score of 6 are low-grade. They are usually slow-growing and less likely to spread. High-grade cancers (Gleason score of 8–10) are more likely to grow quickly and to spread.

# Talking to health and social care staff

Most conversations with your healthcare team will probably go well. However, some people occasionally feel as though they're not getting the information they need.

Here are some tips for talking to health and social care staff:

- Ask your doctors and nurses to use simple language and to explain medical terms. If they use words you don't understand, ask them to explain them to you. Sometimes they may forget that you're not as familiar with medical terms as they are.
- Use your own words. Although your doctors or nurses may use medical terms, you don't have to. It's okay to use your own words to describe the problem. Using medical terms that you only partly understand might cause problems, as the healthcare professionals may think you know more than you do.
- If you're embarrassed, say so. We all find certain medical symptoms and problems embarrassing. They're often not the kinds of thing we want to talk about with someone else. Some men find the idea of a digital rectal examination embarrassing. If you can, let your doctor know if you feel uncomfortable about any procedures or examinations so they know how you are feeling.
- Try to think of the questions you definitely want to ask before you meet with your doctor or nurse.

- During appointments, write down the important points on a piece of paper that you can take away with you. Some people are happy for you to record the discussion, so that you can listen to it later. You can also ask your medical team for a copy of any letters summarising the details of your discussion with them.
- Remember, you'll have other chances to ask questions. You may also be given contact details for a specialist nurse you can get in touch with if you've forgotten to ask a question, or if you don't understand something.

Diagnosis and treatment can be a worrying and confusing time. Talking to your health and social care team can help. Many people feel better and more in control when they know what is happening to them and why.

People often feel that hospital staff are too busy to answer their questions. But it's important that you understand what's happening and how the cancer and its treatment is likely to affect you. The staff should be willing to make time for your questions.

'If you don't know or understand something, then ask. The consultants and doctors are there for you, so make use of them'

John



## **Asking questions**

Here are some questions you may want to ask your healthcare team. There's also some note paper on page 53 where you can write down questions and answers.

- 1. What tests do I need?
- 2. When will I get the test results?
- 3. Do I have prostate cancer?
- 4. Do I need more tests?
- 5. Do I need to see any other doctors?
- 6. What are the treatment options?
- 7. What are the risks and benefits of each treatment?
- 8. What does the treatment involve?
- 9. What are the side effects of treatment?
- 10. Can I carry on working?
- 11. How will you know if the treatment has worked?
- 12. What are the chances of the cancer coming back?

- 13. If my cancer does come back, can I have more treatment?
- 14. Will I come back for check-ups and, if so, how often?
- 15. What can I do to help myself?
- 16. Who should I call if I need help between appointments?
- 17. What will happen if I decide not to have treatment?



## If you are a relative or friend

Some families find it difficult to talk or share their feelings. You might think it's best to pretend everything is fine and carry on as normal. You might not want to worry the person who's having tests for cancer, or you might feel you're letting them down if you admit to being afraid. Unfortunately, denying strong emotions like this can make it even harder to talk, and may lead to the person having these tests feeling very isolated.

Partners, relatives and friends can help by listening carefully to what their loved one wants to say. Don't rush into talking about the illness. Often it's enough just to listen and let that person talk when they are ready.



## **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 leaflets or booklets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**. We have booklets on different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer and information for carers, family and friends.

All of our information is also available online at **macmillan**. **org.uk/cancerinformation** There you'll also find videos featuring real-life 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
- large print
- translations.

Find out more at **macmillan.** org.uk/otherformats If you'd 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.

### Help us improve our information

We know that the people who use our information are the real experts. That's why we always involve them in our work. If you've been affected by cancer, you can help us improve our information.

We give you the chance to comment on a variety of information including booklets, leaflets and fact sheets. If you'd like to hear more about becoming a reviewer, email **reviewing@macmillan. org.uk** You can get involved from home whenever you like, and we don't ask for any special skills – just an interest in our cancer information.



### Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we're here to support you. No one should face cancer alone.

#### 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 Monday–Friday, 9am–8pm. Our cancer support specialists can:

- help with any medical questions you have about your cancer or treatment
- help you access benefits and give you financial advice
- 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'd 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's 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.

'Everyone is so supportive on the online community, they know exactly what you're going through. It can be fun too. It's not all just chats about cancer.'

Mal

#### Help with money worries

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

#### **Financial advice**

Our financial guidance team can give you advice 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're 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** 

### Other useful organisations

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

#### Prostate cancer support organisations

#### Bladder and Bowel Foundation

SATRA Innovation Park, Rockingham Road, Kettering NN16 9JH **Tel** 0845 345 0165 **Email** info@bladderandbowel foundation.org **www.bladderandbowel** 

#### foundation.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

St Bartholomew's Hospital, London EC1A 7BE **Tel** 0808 802 0010 (Mon and Wed, 10am–5pm) **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**

4<sup>th</sup> floor, The Counting House 53 Tooley Street, London SE1 2QN **Tel** 0800 074 8383 (Mon–Fri, 9am–6pm, Wed, 10am–8pm) **Email** 

info@prostatecanceruk.org 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**

GF, 6 Hill Street, Edinburgh EH2 3JZ **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 (Prostate Cancer Support Federation)

16 Kirby Street, London EC1N 8TS **Tel** 0845 601 0766 **Email** info@tackleprostate.org **www.tackleprostate.org** An organisation of UK

patient-led prostate cancer support groups.

#### Support with sexual issues

The Sexual **Advice Association** Suite 301, Emblem House, London Bridge Hospital, 27 Tooley Street, London SE1 2PR Tel 020 7486 7262 Email info@sexualadvice association.co.uk www.sda.uk.net 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.

### Cancer information and support

#### **Cancer Black Care**

79 Acton Lane, London NW10 8UT **Tel** 020 8961 4151 **Email** 

info@cancerblackcare.org.uk www.cancerblackcare.org.uk

Offers information and support to people with cancer from ethnic communities and their friends, carers and families.

#### Cancer Focus Northern Ireland

40–44 Eglantine Avenue, Belfast BT9 6DX **Tel** 0800 783 3339 (Mon–Fri, 9am–1pm) **Email** hello@cancerfocusni.org **www.cancerfocusni.org** Offers a variety of services to people affected by cancer, including a free helpline, counselling and links to local support groups.

#### Cancer Research UK www.cancerhelp.org.uk

Has patient information on all types of cancer and has a clinical trials database.

#### **Cancer Support Scotland**

Calman Cancer Support Centre, 75 Shelley Road, Glasgow G12 0ZE **Tel** 0800 652 4531 **Email** info@ cancersupportscotland.org **www.cancersupport scotland.org** 

Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

#### **Maggie's Centres**

1<sup>st</sup> Floor, One Waterloo Street, Glasgow G2 6AY **Tel** 0300 123 1801 **Email** enquiries@ maggiescentres.org **www.maggiescentres.org** The centres provide information about cancer, benefits advice, and emotional or psychological support.

#### **Penny Brohn Cancer Care**

Chapel Pill Lane, Pill, Bristol BS20 0HH **Tel** 0845 123 2310 (Mon–Fri, 9.30am–5pm) **Email** helpline@pennybrohn.org **www.pennybrohn** 

#### cancercare.org

Offers a combination of physical, emotional and spiritual support, using complementary therapies and self-help techniques.

#### Riprap www.riprap.org.uk

Developed especially for teenagers who have a parent with cancer.

#### Tenovus

Head Office, Gleider House, Ty Glas Road, Cardiff CF14 5BD Tel 0808 808 1010 (Mon-Sun, 8am-8pm) www.tenovus.org.uk Aims to help everyone get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, an 'Ask the nurse' service on the website and benefits advice.

### General health information

#### Health and Social Care in Northern Ireland www.hscni.net

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

#### Healthtalk

#### www.healthtalk.org www.youthhealthtalk.org (site for young people)

Has information about cancer, and videos and audio clips of people's experiences.

### NHS Choices

The UK's biggest health information website. Also has service information for England.

#### NHS Direct Wales www.nhsdirect.wales.nhs.uk

NHS health information site for Wales.

NHS Inform www.nhsinform.co.uk NHS health information site for Scotland.

#### Patient UK www.patient.co.uk

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

## Counselling and emotional support

#### British Association for Counselling and Psychotherapy (BACP) BACP House, 15 St John's Business Park, Lutterworth LE17 4HB Tel 01455 883 300 Email bacp@bacp.co.uk www.bacp.co.uk Promotes awareness of counselling and signposts people to appropriate services. You can search for a qualified counsellor at itsgoodtotalk. org.uk

#### **Samaritans**

Freepost RSRB-KKBY-CYJK, Chris, PO Box 9090, Stirling FK8 2SA **Tel** 08457 90 90 90 **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.

#### UK Council for Psychotherapy (UKCP)

2<sup>nd</sup> Floor, Edward House, 2 Wakley Street, London EC1V 7LT **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.

### Financial or legal information

#### Benefit Enquiry Line Northern Ireland

Tel 0800 220 674 (Mon–Wed and Fri, 9am–5pm, Thu, 10am–5pm) Textphone 0800 243 787 www.nidirect.gov.uk/ money-tax-and-benefits Provides information and advice about disability benefits and carers' benefits.

#### **Citizens Advice**

Provides advice on financial, legal, housing and employment issues. Find details for your local office in the phone book or on one of the following websites:

England and Wales www.citizensadvice.org.uk

Scotland www.cas.org.uk

#### Northern Ireland www.citizensadvice.co.uk

You can also find advice online in a range of languages at **adviceguide.org.uk** 

#### **Community Legal Advice**

Tel 0845 345 43 45 (Mon–Fri, 9am–8pm, Sat, 9am–12.30pm) Minicom 0845 609 6677 www.gov.uk/ community-legal-advice

Has a list of legal advice centres in England and Wales and solicitors that take legal aid cases. Offers a free translation service if English isn't your first language.

#### Department for Work and Pensions (DWP)

Disability Benefits Helpline 08457 123 456 Textphone 0845 722 4433 Personal Independence Payment Helpline 0845 850 3322 Textphone 0845 601 6677 Carer's Allowance Unit 0845 608 4321 Textphone 0845 604 5312 www.gov.uk/browse/ benefits

Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

#### **GOV.UK**

#### www.gov.uk

Has comprehensive information about social security benefits and public services.

#### The Money Advice Service

Tel 0300 500 5000 (Mon–Fri, 8am–8pm, Sat, 9am–1pm) Typetalk 18001 0300 500 5000 www.moneyadvice service.org.uk Runs a free financial health check service and gives advice about all types of financial matters. Has an online chat service for instant money advice.

Money Advice Scotland Tel 0141 572 0237 www.moneyadvicescotland. org.uk

#### National Debtline (England, Scotland and Wales)

Tricorn House, 51–53 Hagley Road, Edgbaston, Birmingham B16 8TP **Tel** 0808 808 4000 (Mon–Fri, 9am–9pm, Sat, 9.30am–1pm) **www.nationaldebtline.co.uk** A national helpline for

people with debt problems. The service is free, confidential and independent. Personal Finance Society – 'Find an Adviser' service www.findanadviser.org

Use the website to find qualified financial advisers in your area.

#### Unbiased.co.uk

Email contact@unbiased.co.uk www.unbiased.co.uk

On the website you can search for qualified advisers who specialise in giving financial, mortgage, accounting or legal advice.

You can search for more organisations on our website at macmillan.org.uk/organisations, or call us on 0808 808 00 00.

# 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 thirdparty 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 our Senior Medical Editor, Dr Lisa Pickering, Consultant Medical Oncologist, and by our Chief Medical Editor, Dr Tim Iveson, Macmillan Consultant Medical Oncologist.

With thanks to: Mr Christian Brown, Consultant Urological Surgeon; Gill Davis, Specialist Nurse; Helen Johnson, Prostate Clinical Nurse Specialist; Dr James Wylie, Consultant Clinical Oncologist in Urology; and the people affected by cancer who reviewed this edition.

#### Sources

We've listed a sample of the sources used in this booklet. If you'd like more information about the sources we use, please contact us at **bookletfeedback@macmillan.org.uk** 

Kantoff, et al. Clinical presentation and diagnosis of prostate cancer. 2014. www.uptodate.com (accessed June 2014). Mottet, et al. Guidelines on Prostate cancer. European Association of Urology. 2014. National Institute for Health and Care Excellence (NICE) clinical guidelines (CG175). Prostate cancer: Diagnosis and treatment. January 2014. National Institute for Health and Care Excellence (NICE). Transperineal template biopsy and mapping of the prostate. October 2010.

### Can you do something to help?

We hope this booklet has been useful to you. It's just one of our many publications that are available free to anyone affected by cancer. They're 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're there 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.



#### 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

## Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

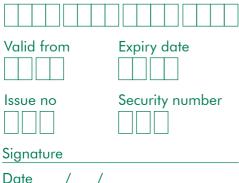
Email

Please accept my gift of £

(Please delete as appropriate) I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support

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

Card number



## Don't let the taxman keep your money

Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

I am a UK taxpayer and I would like Macmillan Cancer Support to treat all donations I have made for the four years prior to this year, and all donations I make in the future, as Gift Aid donations, until I notify you otherwise.

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax in each tax year, that is at least equal to the tax that Charities & CASCs I donate to will reclaim on my gifts. I understand that other taxes such as VAT and Council Tax do not qualify and that Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

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'd rather donate online go to macmillan.org.uk/donate

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 More than one in three of us will get cancer. For most of us it will be the toughest fight we ever face. And the feelings of isolation and loneliness that so many people experience make it even harder. But you don't have to go through it alone. The Macmillan team is with you every step of the way.

We are the nurses and therapists helping you through treatment. The experts on the end of the phone. The advisers telling you which benefits you're entitled to. The volunteers giving you a hand with the everyday things. The campaigners improving cancer care. The community there for you online, any time. The supporters who make it all possible.

Together, we are all Macmillan Cancer Support.

For cancer support every step of the way, call Macmillan on 0808 808 00 00 (Mon–Fri, 9am–8pm) or visit macmillan.org.uk

Hard of hearing? Use textphone 0808 808 0121, or Text Relay. Non-English speaker? Interpreters available. Braille and large print versions on request.

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