

Prostate cancer



A guide for
newly diagnosed men


Introduction

This booklet is for men who have recently been diagnosed with prostate cancer. It is your personal guide to diagnosis and treatment, with space for you to record details of your care. The blue shaded areas are for you to write down any contact details and information that may be helpful to you and your specialist team. We hope that this booklet will help you to get the most from discussions with those involved in your care.

You may find it useful to share this information with your partner or family to help them understand more about prostate cancer. If you or those close to you would like to know more about anything you read in this booklet, you can call our specialist Helpline nurses on 0800 074 8383.

The following symbols appear throughout the booklet to guide you to sources of further information:

-  The Prostate Cancer Charity Helpline
-  The Tool Kit information pack

If you would like to know more about anything you read in this booklet, you can call our specialist Helpline nurses on  0800 074 8383.

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Personal details

Name	
Address	
Telephone no.	
Hospital number or sticker	
Local support group	
Any other relevant information	

Who are my team members?

You can use this space to record names and contact details of the members of your multi-disciplinary team (MDT). This is the team of health professionals who will be involved in your ongoing care. Your MDT will discuss your individual diagnosis and agree which treatment options will be possible for you.

We have listed the health professionals who are most likely to be involved in your care, but you may not come into contact with all of them. You are likely to meet more members of your MDT later on when you begin monitoring or treatment. You can find details of how prostate cancer is monitored or treated on page 17.

Key worker (main contact)

Your key worker is your main point of contact. This could be your specialist nurse or another member of your MDT. They help to co-ordinate your care and can guide you to the appropriate team member or sources of information.

Name	
Telephone no.	
Notes	

Specialist nurse

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

Name	
Job title	
Telephone no.	
Notes	

Consultant oncologist

This type of doctor specialises in treating cancer.

Name	
Telephone no.	
Notes	

Consultant urologist

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

Name	
Telephone no.	
Notes	

Other health professionals

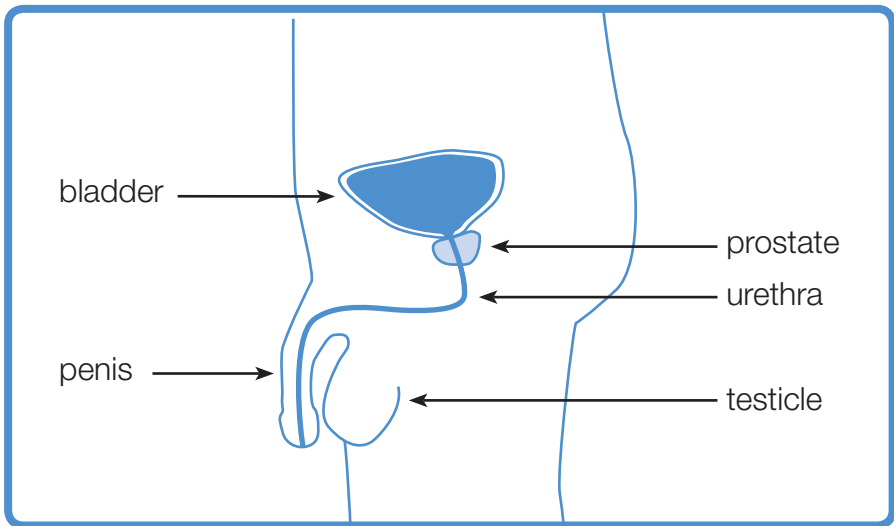
You can record contact details of other health professionals in the space below.

General practitioner (GP)	
Practice nurse	
District nurse	
Other nurses: 1	
2	
3	

 **The Prostate Cancer Charity Support & Information
Specialist Nurses: Helpline 0800 074 8383**

What is the prostate gland?

Only men have a prostate gland. The gland is usually the size of a walnut. It lies underneath the bladder and surrounds the tube that you pass urine and semen through (urethra). The gland's main functions are to make some of the fluid that carries sperm (semen) and to support the neck of the bladder.



There are three main types of prostate problem that can all cause similar symptoms. These are:

Benign prostatic hyperplasia (BPH)

This is a common problem and is also known as having an enlarged prostate. It mainly affects men over the age of 50. BPH causes the prostate gland to slowly get bigger. In some cases the prostate may press on the urethra, causing problems passing urine.

For more information read our booklet **Enlarged prostate: a guide for men concerned about benign prostatic hyperplasia (BPH)**.

Prostatitis

This can be caused by an infection or inflammation of the prostate gland. It is not a form of cancer.

Prostatitis can cause a wide variety of symptoms, which differ from man to man, including problems passing urine and discomfort, pain or aching in the testicles, urethra, lower abdomen and back. For more information read our booklet on **Prostatitis**.

Prostate cancer

Prostate cancer is the most common cancer in men. Prostate cancer may cause problems passing urine. However, many men with prostate cancer do not have any symptoms at all. Some men may be surprised by their cancer diagnosis because they do not feel unwell.

What is prostate cancer?

Normally the growth of all cells in the body is carefully controlled. As cells die, they are replaced. Prostate cancer can develop when cells in the prostate gland start to grow in an uncontrolled way.

In most cases prostate cancer is a slow growing cancer and it may stay undiagnosed because it never causes any symptoms. However, in some men, the cancer cells can grow quickly and over time they can move outside the prostate. These cells may cause symptoms in other parts of the body, such as bone pain.

How is prostate cancer diagnosed?

Prostate cancer is diagnosed by a number of tests, which are described on the following pages. You may have already had some of these but you may need further tests to find out whether the cancer has spread and how aggressive it is. You may not need to have all of the tests described here.

PSA blood test

The prostate gland makes a protein called prostate specific antigen (PSA). All men have some PSA in their blood and the level can be affected by several factors, including age, infection and some medicines. The amount of PSA is measured in nanograms per millilitre of blood (ng/ml).


The normal level rises with age on a continuous scale, so a man aged 70 will have a higher PSA level than a man aged 50.

A 'normal' PSA test result may be:

- Up to 3.0ng/ml for a man aged 50 to 59
- Up to 4.0ng/ml for a man aged 60 to 69
- Up to 5.0ng/ml for a man aged 70 or over

These values should only be seen as a rough guide.

The PSA test alone cannot diagnose prostate cancer but it can show that there is a problem with the prostate. A normal PSA result does not rule out prostate cancer. Similarly, a high PSA result does not always mean that you have prostate cancer. The PSA test is used together with other tests for diagnosing prostate cancer.

 You can read more about the PSA test in our booklet **PSA and beyond: a guide for men concerned about prostate cancer.**

Digital rectal examination

A digital rectal examination (DRE) involves feeling the prostate gland through the back passage (rectum), using a gloved, lubricated finger. The doctor or nurse is feeling for any hard or irregular areas that may be a sign of cancer.

Prostate biopsy

You may have had a prostate biopsy to remove small amounts of tissue from different areas of the prostate gland. The samples of tissue are sent to the laboratory to be looked at under a microscope. If cancer is found, a report is sent to your specialist, giving details of how many samples contain cancer and how slowly or quickly the cancer may grow or spread in the future.

Trans-rectal ultrasound (TRUS)

TRUS scans use sound waves to make an image of the prostate. This is shown on a screen similar to a small television. The scan allows the specialist to see possible abnormalities and measure the size of the prostate. If you need a biopsy, the TRUS scan is used to guide the biopsy needles.

CT scan

A CT (computerised tomography) scan uses X-rays to take pictures of the body from different angles. This allows the specialist to see any cancer in the prostate gland, lymph nodes and the surrounding area.

MRI

MRI (magnetic resonance imaging) uses magnets rather than X-rays to create a detailed picture of your prostate, surrounding tissues, and nearby lymph nodes.

Bone scan

A small amount of a safe radioactive substance is injected into a vein in your arm. The bones are then scanned to pick up any 'hot spots' where the radioactive substance has collected. These hot spots show where prostate cancer cells may have spread to the bones.

i For further information on the tests described here, read our Tool Kit fact sheet **How prostate cancer is diagnosed**.

How is the growth and spread of prostate cancer measured?

Your specialist team will use the results of all the tests you have had to build up an overall picture of your cancer. This allows them to measure how far the cancer has spread and how quickly it is growing.

Gleason score

A specialist in the laboratory (pathologist) will look at your biopsy samples under the microscope. If a sample contains cancer it is 'graded' to show how active the cancer is. The pathologist looks at the pattern made by the cancer cells and gives that pattern a grade from 1 to 5. This is called Gleason grading.

The grades of the two most common patterns seen in the biopsy samples are then added together to give a Gleason score out of 10.

For example

If the biopsy samples show that:

- most of the cancer cells seen are grade 3

- the second most common type of cell seen is grade 4
- then the Gleason will be 3 + 4, and the Gleason score will be 7.

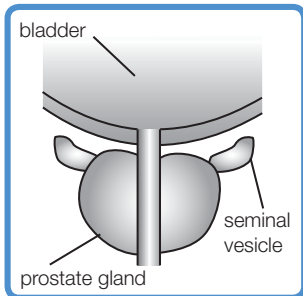
The higher the Gleason score, the more aggressive the cancer and the more likely it is to spread. Gleason scores run from 2 to 10. However, most men with prostate cancer will have a Gleason score between 6 and 10.

Staging

Staging is a way of recording how far the cancer has spread. The most common method is the TNM (Tumour-Nodes-Metastases) system.

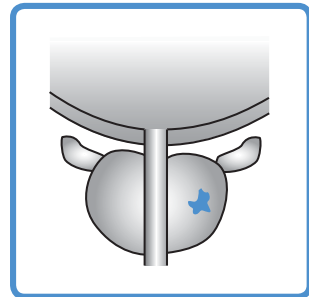
T stage

The T stage shows how far the cancer has spread in and around the prostate gland. This is measured by a digital rectal examination (DRE). You may also be offered a MRI scan to confirm your T stage.



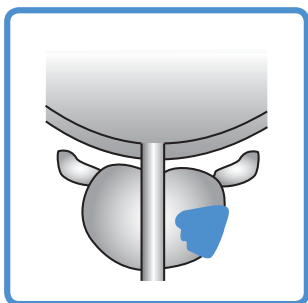
T1

The tumour cannot be felt and can only be seen under a microscope –
localised disease



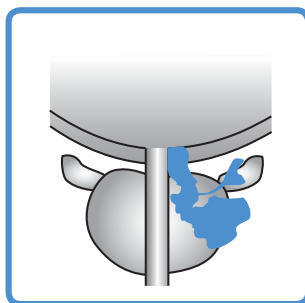
T2

The tumour can be felt but it is contained within the prostate gland –
localised disease



T3

The tumour can be felt breaking through the capsule of the prostate – **locally advanced disease**



T4

The tumour has spread to nearby organs, such as the bladder neck, back passage or pelvic wall – **locally advanced disease**

N stage

The N stage shows whether the cancer has spread to the nearby lymph nodes. This is measured using an MRI or CT scan. This stage may not be measured if the result is unlikely to affect your treatment options.

- NX** The lymph nodes were not measured
- N0** The lymph nodes are not seen to contain cancer cells
- N1** The lymph nodes contain cancer cells

M stage


The M stage shows whether the cancer has spread (metastasised) to other parts of the body, such as bone. This is measured using a bone scan. This stage may not be measured if the result is unlikely to affect your treatment options.

- MX** The spread of the cancer was not measured
- M0** The cancer has not spread to other parts of the body
- M1** The cancer has spread to other parts of the body

PSA

The PSA test is not a perfect tool for diagnosing prostate cancer. However, once you have been diagnosed with prostate cancer, your PSA level becomes a useful and reliable way of monitoring cancer activity, alongside other test results.

You may be asked to have a PSA test before your follow-up appointments, so that your specialist team knows how the cancer is behaving. It can take a couple of weeks for the PSA test results to arrive.

 You can read more about the measures described here in our Tool Kit fact sheet called **How prostate cancer is diagnosed**.

What are my test results?

You can use this section with your specialist team to record your test results and next appointments.

Number of biopsy samples taken:

Number of biopsy samples containing cancer:

T stage at diagnosis:

N stage at diagnosis (if measured):

M stage at diagnosis (if measured):

PSA level at diagnosis:

Date of bone scan (if needed):

Results of bone scan:

Date of MRI scan (if needed):

Results of MRI scan:

The cancer is (please tick):

- localised** – contained within the prostate gland
- locally advanced** – spread to the area just outside the prostate gland
- advanced** – spread to other parts of the body

Outcome of the multi-disciplinary team (MDT) meeting and suggested plan:

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

- Urologist
- Specialist nurse
- Oncologist
- Other

You can record details of future appointments on page 26. Please contact your specialist nurse or key worker at any time if you have any questions or concerns. You can also contact The Prostate Cancer Charity specialist nurses by calling our



confidential Helpline on **0800 074 8383**.

What are my treatment options?

The results of the your tests will give you and your specialist team a good idea of how your cancer is behaving. However, the test results are just a guide to how the cancer may be treated. Remember that your team are treating you as an individual and your personal choices are important when deciding on treatment.

In most cases there is no urgency to decide which treatment you want to have, and your team may suggest you take time to think things through before coming to a decision.

There may be several treatment options available to you. Both your personal preference and a number of other factors such as the stage of your cancer, your PSA level and Gleason score will affect which of these treatments you can have. There is not an overall 'best' treatment and each treatment has its own advantages and disadvantages. Your doctor or specialist nurse

will explain which options are suitable for you and help you to choose your treatment. Ask them to tick the treatment options that may be suitable for you on the following pages. You may not be able to have all of the treatments listed here. Do not be afraid to ask questions and if you need more time to think about the treatment options, just ask.

Research trials, known as clinical trials, are carried out to try and find better treatments for cancer. If you would like to find out about taking part in a clinical trial, ask your doctor or specialist nurse. You can read more about this in our **Clinical trials** Tool Kit fact sheet.

The following information describes treatments for men with newly diagnosed prostate cancer. Men who have had prostate cancer for some time may have different treatments and combinations of treatment.

You can find out more about what each treatment involves and what the side effects may be by reading our **Tool Kit** fact sheets and by calling our confidential Helpline on 0800 074 8383.

Cancer that has not spread

Prostate cancer that has not spread outside the prostate gland (localised cancer) can behave in different ways. Many localised cancers are not aggressive and grow too slowly to cause any problems in your lifetime. However, some cancers may behave aggressively and spread to other parts of the body.

When you are first diagnosed, it is often difficult to tell whether your cancer is aggressive or not. The results of the tests described on pages 11 to 13 may give some clue as to how your cancer will behave. These results are important to help

you and your specialist team decide on the best treatment for you. If you have a slow growing cancer that is not likely to cause you any problems in your lifetime, you may not want to have a treatment that may cause severe side effects. Your specialist team will discuss the advantages and possible side effects of your treatment options with you.

Watchful waiting

Watchful waiting is way of monitoring cancer and is generally suitable for men who may not benefit from treatments such as surgery or radiotherapy. This may include older men whose cancer is unlikely to cause problems during their lifetime or men who have other serious health problems.

The aim is to monitor the cancer over the long term rather than to cure the cancer. If you choose watchful waiting, you will not start treatment until you get symptoms, such as problems passing urine or bone pain. You may then be offered hormone therapy to control the cancer. The advantage of this approach is that you will not experience any of the side effects that can be caused by treatment.

Active surveillance

Many prostate cancers are not life threatening because they are small and slow-growing. Active surveillance is a relatively new way of monitoring prostate cancer. It aims to avoid unnecessary treatment in men with less aggressive cancer and so avoid the side effects that can be caused by treatments. It also aims to detect cancers that are starting to behave more aggressively and to treat them before the cancer spreads and while it is still possible to get rid of the cancer completely.

If you choose this option, you will have regular PSA tests. You may also need to have further biopsies after a period of time to check for any changes in the way your cancer is behaving. If there is any sign that the cancer is growing more quickly, you will be offered active treatment with surgery (radical prostatectomy), radiotherapy or brachytherapy.

What is active monitoring?

You may hear another term called 'active monitoring'. This is not always used in the same way and you may hear it used to describe either watchful waiting or active surveillance. Because these are two quite different approaches to treatment, make sure you ask your specialist to explain exactly what they mean by 'active monitoring' if they use this term.

Radical prostatectomy

This is an operation to remove the whole prostate gland. There are several types of operation: traditional open surgery; laparoscopic (keyhole) surgery and robot-assisted surgery. This treatment is usually only suitable for men with localised prostate cancer.

External beam radiotherapy

This treatment uses high energy X-rays to destroy the cancer cells. It can be used to treat localised and locally advanced prostate cancer. Radiotherapy is often used together with hormone therapy and is suitable for men with localised and locally advanced prostate cancer.

Brachytherapy

This is an internal radiotherapy treatment. There are two

types of brachytherapy – permanent and temporary. Permanent brachytherapy involves implanting tiny radioactive seeds into the prostate. This treatment is used to treat localised prostate cancer.

Temporary brachytherapy, also called ‘high dose rate’ brachytherapy, involves inserting a source of radiation into the prostate gland for a few minutes at a time. This treatment is less common and may sometimes be used to treat localised or locally advanced prostate cancer. It is used together with external beam radiotherapy to give higher doses of radiation to the whole gland as well as to the area just outside the prostate. In a small number of cases, your doctor may suggest you have hormone therapy for a few months before starting either type of brachytherapy.

HIFU

HIFU uses ultrasound to heat and destroy the prostate gland. This is a fairly new treatment in the UK. It is usually used to treat cancer that has started to grow again after treatment with radiotherapy. It may be available as a first treatment in some NHS centres or through private healthcare. Most HIFU treatments are carried out as part of a clinical trial. We still do not know very much about how effective this treatment is in the long term.

Cryotherapy

Cryotherapy uses freezing and thawing to destroy the prostate cancer cells. It is suitable for men newly diagnosed with localised prostate cancer but it is more commonly used to treat men whose cancer has started to grow again after having radiotherapy or brachytherapy. We still do not know

very much about how effective this treatment is in the long term. You may be offered cryotherapy as part of a clinical trial.

Cancer that has spread outside the prostate gland

If your cancer has spread to the area just outside the prostate gland (locally advanced cancer) or to other parts of the body (advanced cancer), you will need a treatment that works on the cancer wherever it is in the body. Most of the treatments described on the previous pages only treat cancer that is contained within the prostate gland.

Hormone therapy is the standard treatment option for cancer that has spread. It will treat all prostate cancer cells, whether they are in the prostate gland or have spread to other parts of the body. Depending on the stage of your cancer, you may be offered radiotherapy alongside hormone therapy.

Hormone therapy

Prostate cancer needs the hormone testosterone to grow. By stopping testosterone from reaching the cancer, hormone therapy can cause the cancer to shrink. Hormone therapy will not cure prostate cancer but it can keep the cancer under control for several years. It works wherever the cancer is in your body and may help to control symptoms such as bone pain and problems passing urine.

There are three main types of hormone therapy treatment for prostate cancer. These are:

- Surgery to remove the testicles (orchidectomy)
- Injections to stop the production of testosterone
- Tablets to block the effects of testosterone

Other treatments

A very small number of men with locally advanced prostate cancer may be suitable for a different treatment such as radical prostatectomy or high dose rate (HDR) brachytherapy. However, these treatments are not as well established for this stage of cancer. You can ask your doctor if either of these treatments may be suitable for you.

There are also treatments available which can help to reduce symptoms caused by the cancer, including palliative radiotherapy, and a group of drugs called bisphosphonates.

What support is available to me?

Men respond in all kinds of ways to being diagnosed with prostate cancer. You might feel shocked, frightened or angry. You may not believe that you have got prostate cancer – if you feel well, you may think that the doctor has made a mistake. It is not unusual to feel stressed by the need to make a decision about your treatment.

Asking questions is one way of feeling more in control. You may find that it helps to write down your questions to take along to your appointments. Our Tool Kit fact sheets list some suggested questions that you may wish to ask your specialist team.

Some men find that altering their diet gives them a sense of control over their body and the cancer. Eating a balanced diet that may be helpful to the prostate is something you can do for yourself. You can find out more about this by reading our Tool



Kit fact sheet on **Diet and prostate cancer**.

It is not always easy to talk about cancer and how being

diagnosed is affecting you. Talking to a partner, friend or relative may help you to cope better and make any decisions about your treatment easier to deal with. By helping people close to you to understand your feelings and concerns, they can find a way of supporting you in a way that is right for you.

If you, and those close to you, would like to share experiences and support with others affected by prostate cancer you can ask your specialist team if there is a support group in your area. We can put you in touch with people who have been affected by prostate cancer – call our confidential Helpline on



0800 074 8383 for details. If you have access to the Internet, you can sign up to our message board at www.prostate-cancer.org.uk.

You can always contact your specialist nurse or a member of your MDT if you have any questions or concerns. They can help you to come to terms with your diagnosis and can talk through the emotional effects of cancer. They may be able to put you in touch with a counsellor if you need further support. You, and those close to you, can also speak to a specialist nurse by



calling our confidential Helpline on 0800 074 8383.

Glossary of medical terms

Biopsy

The removal of small samples of tissue to be looked at under a microscope.

Gleason score

Scale that shows how aggressive a cancer is by looking at the most common patterns of cancer cells in biopsy samples. When cancer is found in a biopsy sample it is given a grade and the two most common grades are added together to give a Gleason score.

Lymph nodes

These are part of the body's immune system. The lymph nodes in the groin and pelvic area sit close to the prostate gland and are a common place for prostate cancer to spread to.

Metastasis

The spread of cancer from the prostate gland to other parts of the body. Cancers that have spread are called 'metastases' or 'secondaries'. A cancer that has spread is said to have 'metastasised'.

Multi-disciplinary team (MDT)

The team of health professionals involved in your care. The team may include a key worker, a specialist nurse, a consultant oncologist and a consultant urologist.

Oncology

The diagnosis and treatment of cancer.

PSA

Prostate specific antigen. A kind of protein, called an enzyme, that is produced by the prostate gland and is present in the blood stream.

Urology

The diagnosis and treatment of diseases of the urinary system, which includes the prostate gland.

Uro-oncology

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

The Prostate Cancer Charity

The Prostate Cancer Charity is the UK's leading charity working with people affected by prostate cancer. We fund research, provide support and information, and we campaign to improve the lives of men with prostate cancer. Our vision is a world where lives are no longer limited by prostate cancer.

Free and confidential Helpline

If you have any questions about prostate cancer, call our confidential Helpline to speak to a specialist nurse.



Free and confidential Helpline
0800 074 8383*
Mon - Fri 10am - 4pm, Wed 7pm - 9pm

You can also send a query to the Helpline by using our email contact form. Visit **www.prostate-cancer.org.uk** and click on 'support' for details of how to contact the Helpline.

The Tool Kit

The Tool Kit information pack contains fact sheets that explain how prostate cancer is diagnosed, how it is treated and how it may affect your lifestyle. Each treatment fact sheet also includes a list of suggested questions to ask your doctor.

To order your copy:

- Call us on **0800 074 8383**
- Email us at **literature@prostate-cancer.org.uk**

You can also download all of the Tool Kit fact sheets from our website at **www.prostate-cancer.org.uk**

*Calls are free of charge from UK landlines. Mobile phone charges may vary. Calls may be monitored for training purposes. Confidentiality is maintained between callers and The Prostate Cancer Charity.

More information

Cancer Black Care

www.cancerblackcare.org

Telephone 020 8961 4151

Provides information and support to people with cancer from black and minority ethnic communities.

Cancer Counselling Trust

www.cancercounselling.org.uk

Counselling service Helpline 020 7843 2292

Provides free specialist counselling for people affected by cancer, their friends and family.

Carers UK

www.carersuk.org

Carers line 0808 808 777 10-12am & 2-4pm, Wed & Thurs

Provides information and advice for carers including signposting to support groups.

Citizens Advice

www.adviceguide.org.uk

For information and advice on financial help, including travel costs and prescriptions. You can find contact details of your nearest service in your local phone book.

Healthtalkonline

www.healthtalkonline.org

Watch, listen to, or read personal experiences of men with prostate cancer and other medical conditions.

'Going for a' website

www.goingfora.com

Virtual hospital from the Royal College of Radiologists.

Interactive information on cancer treatment and scans. Includes descriptions from both staff and patients.

Macmillan Cancer Support

www.macmillan.org.uk

Freephone Cancerline 0808 808 00 00 Mon-Fri 9am-8pm

89 Albert Embankment, London SE1 7UQ

Information on practical and financial issues of living with cancer as well as emotional support.

Maggie's Cancer Caring Centres

www.maggiescentres.org

General enquiries Tel: 0131 537 2456

Cancer information and support centres located in several towns and cities around the UK where people affected by cancer can drop in to access information and support services.

UK Prostate Link

www.prostate-link.org.uk

This website guides you to reliable sources of prostate cancer information.

The Prostate Cancer Charity funds research into the causes of, and treatments for, prostate cancer. We also provide support and information to anyone concerned about prostate cancer. We rely on charitable donations to continue this work. If you would like to make a donation, please call us on 020 8222 7666.

The Prostate Cancer Charity makes every effort to make sure that its services provide up-to-date, unbiased and accurate facts about prostate cancer. We hope that these will add to the medical advice you have had and will help you to make any decisions you may face. Please do continue to talk to your doctor if you are worried about any medical issues.

References to sources of information used in the production of this booklet are available at www.prostate-cancer.org.uk

Reviewed by:

- Hashim Uddin Ahmed, MRC Clinical Research Fellow and Specialist Registrar in Urology, University College London
- Jim Catto, Consultant Urological Surgeon, Royal Hallamshire Hospital
- Debbie Gray, Uro-Oncology CNS, Darlington Memorial Hospital
- Patricia McClurey, Specialist Nurse, Prostate Cancer, James Cook University Hospital, Middlesburgh
- Clare Moynihan, Medical Sociologist & Senior Research Fellow, The Institute of Cancer Research: Royal Cancer Hospital
- Phil Reynolds, Radiographer, Guy's Hospital, London
- Bruce Turner, Uro-oncology Nurse Practitioner, Homerton University Hospital NHS Foundation Trust
- The Prostate Cancer Charity Support and Information Specialist Nurses
- The Prostate Cancer Charity Information Volunteers

Written and edited by: The Prostate Cancer Charity Information Team

The Prostate Cancer Charity

First Floor, Cambridge House, 100 Cambridge Grove,
London W6 0LE

Email: info@prostate-cancer.org.uk

Telephone: 020 8222 7622

Fax: 020 8222 7639

The Prostate Cancer Charity Scotland

Unit F22-24 Festival Business Centre, 150 Brand Street,
Glasgow G51 1DH

Email: scotland@prostate-cancer.org.uk

Telephone: 0141 314 0050



Free and confidential Helpline

0800 074 8383*

Mon - Fri 10am - 4pm, Wed 7pm - 9pm

Website: www.prostate-cancer.org.uk

Endorsed
by:



* Calls are free of charge from UK landlines. Mobile phone charges may vary. Calls may be monitored for training purposes. Confidentiality is maintained between callers and The Prostate Cancer Charity.