

# Recurrent prostate cancer

If your cancer comes back –  
risk and treatment

# Introduction

Many men find that waiting to find out if their cancer has come back is a particularly anxious time for them. This booklet is for men who are worried that their prostate cancer might come back or who have prostate cancer that has recurred after having had one or more treatments. It describes what it is and the treatment options that may be available to you. Each hospital and specialist team will do things slightly differently so use this booklet as a general guide and ask your specialist team for more details about the care you will receive. This booklet also lists other sources of support to help you cope with cancer that has returned.

If your prostate cancer has come back you can speak to a specialist nurse by telephoning our Helpline on 0800 074 8383.

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



The Prostate Cancer Charity Helpline



The Prostate Cancer Charity publications

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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## What does having recurrent prostate cancer mean?

Having recurrent prostate cancer means that your cancer has returned after a period of time after treatment, such as surgery (radical prostatectomy) or radiotherapy. Your cancer may have returned:

- In your prostate gland, if you did not have it removed by surgery.
- In the area where your prostate gland used to be (the prostate bed), if the gland was removed by surgery.
- In other areas of your body such as the lymph nodes or bones. It is much less common for prostate cancer to spread to other areas such as the liver or the lungs.

If your cancer has returned in the prostate gland or in the prostate bed then you may be offered further treatment aiming to cure the cancer. If your cancer has spread to other parts of your body then treatment is usually aimed at controlling the cancer rather than curing it.

## Why does prostate cancer come back?

We do not know exactly why prostate cancer returns, but possible reasons include:

- The cancer was more advanced than the specialist team originally thought. Sometimes the cancer cells are too small in number to be detected by scans.
- Not all of the cancer cells were treated during your first treatment.

We do not know for certain which men will experience a recurrence, but there are some risk factors that affect the likelihood of your cancer coming back. These are described below.

## How do I know if I may be at risk?

Some men are more at risk of a recurrence than others. Your specialist team cannot say whether or not your cancer will return but may be able to tell you about your risk of recurrence. This may be determined by your Gleason score (see page 22) and the stage your cancer had reached when you were diagnosed. If you do not know this information your specialist team will be able to tell you.

The risk of recurrence is:

- **Low**, if your prostate specific antigen (PSA) level at diagnosis was less than 10ng/ml, your Gleason score was less than 7 and your cancer had not spread outside the prostate gland (localised prostate cancer or clinical stage T2 or less).
- **Medium** (or moderate), if your PSA level at diagnosis was between 10 to 20ng/ml or your Gleason score was 7, and your cancer did not appear to have spread outside the prostate (localised prostate cancer or clinical stage T2).
- **High**, if your PSA level at diagnosis was over 20ng/ml or your Gleason score was over 7, or your cancer was outside the capsule of the prostate gland, or into the seminal vesicles (locally advanced prostate cancer or clinical stage T3).

If you would like more information about staging and grading of prostate cancer, please see our Tool Kit fact sheet **How prostate cancer is diagnosed**.

The risk of your cancer coming back is higher if you have been told you have ‘positive margins’ or have been diagnosed with locally advanced prostate cancer after surgery (radical prostatectomy).

If you have had surgery, the tissue removed is looked at by a pathologist (a doctor who studies cells). The pathologist will look at the tissue under a microscope to see what the cancer cells are like and their position in the prostate gland. If cancer cells are found at the edge of the prostate this is described as having ‘positive margins’. If cancer cells have broken through the capsule of the prostate gland, but are not found in the lymph nodes or the bones, then your cancer stage will be changed to locally advanced prostate cancer.

## How do I know if my prostate cancer has come back?

If your cancer has come back, you are unlikely to experience any symptoms at first so it is important to have regular follow up appointments with your specialist team. They can check your progress and monitor the prostate specific antigen (PSA) level in your blood. This will let them see:

- How you are responding to treatment
- Any signs that your prostate cancer has come back

Follow up appointments usually begin at around six weeks to three months after treatment. In the first year after treatment you may have appointments every three or four months. If your specialist team is happy with your progress this may be changed to every six months. Speak to your specialist team if you are concerned about the frequency of your follow up appointments.

## Your PSA level

Usually the first sign that your cancer may have returned will be a rise in the level of PSA in your blood. Although the PSA test may not always be accurate at helping to diagnose prostate cancer, regular testing is a very effective way of checking its progress once you have been diagnosed and had treatment.

Your specialist team will monitor your PSA regularly to try and get an accurate picture of how the cancer is responding to treatment. They will look out for changes in your PSA, depending on which treatment you had first:

- **PSA level after surgery (radical prostatectomy)**

After surgery your PSA level should drop to an undetectable level (less than 0.1ng/ml) because the prostate gland, which produces PSA, has been removed. If your cancer has returned there should be a detectable and rising PSA.

- **PSA level after radiotherapy or brachytherapy**

Following radiotherapy or brachytherapy your PSA should drop to its lowest level (nadir) after 18 months to two years (usually to below 1.0ng/ml), although some PSA is still produced. This is because healthy prostate tissue will continue to produce PSA and it does not mean that your cancer has come back. A sign that your cancer may have returned is if your PSA level has risen by 2ng/ml or more above its lowest level. Sometimes men may experience a rise and fall in PSA at around one to two years after treatment. This is called 'PSA bounce' and does not indicate that cancer has returned.

If you have had hormone therapy alongside radiotherapy or brachytherapy, see the next page.

- **PSA level after radiotherapy or brachytherapy with hormone therapy**

Most men are now given hormone therapy before radiotherapy and, very occasionally, before brachytherapy. This means your PSA level should drop to a lower level quite rapidly. It may even be less than 1.0ng/ml by the time you start radiotherapy or brachytherapy. If you continue to have hormone therapy after radiotherapy, your PSA level may continue to fall further.

When you stop hormone therapy your PSA level may begin to rise naturally but a rise of more than 2ng/ml from your lowest level (nadir) may indicate that your cancer has returned.

However, even when there is a rise of more than 2ng/ml from your lowest level your doctor may wish to know how quickly (or slowly) your PSA is rising before deciding on the best course of treatment for you. In this case you may be advised to have your PSA monitored for at least six months before another treatment is considered.

## Other tests

In some cases men may need to have a biopsy to confirm whether prostate cancer has come back. Scans may also be needed (such as a CT, MRI or bone scan) to find out more information. Your specialist team will be looking to see:

- If the cancer is still within the prostate gland (if you have had radiotherapy or brachytherapy).
- If it has spread to other parts of the body.

This process is known as re-staging and is similar to what happens when you are first diagnosed.

If you are having radiotherapy after surgery you may not need any further tests. Again, your PSA level and rate of rise is also taken into consideration when deciding on which tests you will need.

## What treatment options will be available to me?

Treatments for recurrent prostate cancer are called ‘second-line’ or ‘salvage’ treatments. The treatments available to you will depend on several factors including:

- Where your cancer has come back
- Which treatment you have already had
- Your age, your general health and any other medical conditions you may have

The results of tests to re-stage your cancer will also help the doctor to decide which treatments you will be offered. You may not need any further treatment straight away, particularly if your PSA level is rising slowly.

The table overleaf shows the treatment options that may be available to you based on the first treatment you had. If you are unsure if a treatment is suitable for you it is important to discuss your options with your specialist team. If your prostate cancer has spread to other areas in your body (advanced prostate cancer), you will be offered hormone therapy to control your cancer.

First treatment for prostate cancer	Possible second treatment for recurrence of prostate cancer
Surgery	<ul style="list-style-type: none"> <li>• Radiotherapy to the prostate bed (with or without additional hormone therapy)</li> <li>• Hormone therapy</li> </ul>
Radiotherapy	<ul style="list-style-type: none"> <li>• HIFU (high intensity focused ultrasound)</li> <li>• Cryotherapy</li> <li>• Hormone therapy</li> <li>• Very rarely, surgery</li> </ul>
Brachytherapy	<ul style="list-style-type: none"> <li>• Cryotherapy</li> <li>• Hormone therapy</li> <li>• Very rarely, surgery</li> </ul>

If you had brachytherapy as a first treatment, it is unlikely that you will be offered HIFU as a second-line treatment because doctors have found that there is a higher risk that you may develop a fistula (an opening between the urinary system and the bowel).

Surgery is very rarely performed as a second-line treatment because radiotherapy and brachytherapy affect the nature of the prostate tissue. This makes it very hard for a surgeon to remove it. Some surgeons may occasionally consider this treatment. Speak to your specialist team if you wish to discuss this possibility.

All treatments have side effects, advantages and disadvantages and it is important to discuss these with your specialist team before deciding upon a treatment plan that is best for you.

For more written information or to speak to a specialist nurse call our Helpline on 0800 074 8383.



## Clinical trials

You may be able to take part in clinical trials of new treatments or new combinations of existing treatments. If you would like to know more about clinical trials or any of the treatments mentioned above please read our Tool Kit fact sheets or speak



to a specialist nurse by calling our Helpline on 0800 074 8383.

## When will I be offered treatment?

The timing of second-line treatments will vary from man to man. If the treatment you are offered is aimed at curing your cancer then your treatment (radiotherapy, HIFU or cryotherapy) may begin soon after assessment.

If you are going to have hormone therapy there are several things which will determine how soon you will need treatment such as:

- If your prostate cancer has spread to other areas in your body
- If you have any symptoms from your prostate cancer
- How quickly your PSA level is rising (your specialist team will consider the time taken for your PSA level to double)

Your specialist team may decide to treat your cancer once your PSA has reached an agreed level. Waiting to start treatment may delay the experience of any unwanted side effects of hormone therapy, such as sexual problems, hot flushes and fatigue. If you are concerned about any possible harm caused by delaying the start of treatment, discuss your treatment plan with your specialist team. For more information about the side effects of hormone therapy read our booklet **Living with hormone therapy: A guide for men with prostate cancer**.

### What happens if my cancer comes back after second-line treatment?

If your cancer returns after second-line treatment, such as radiotherapy, HIFU and cryotherapy, you may then be offered hormone therapy to control your cancer.

Other treatments such as oestrogen therapy, steroids (such as dexamethasone) and chemotherapy (such as docetaxel), may be offered at a later stage if your cancer is no longer responding to your first course of hormone therapy.

Some men experience backache or bone pain if their prostate cancer has spread to their bones and you may be offered pain-relieving treatments such as bisphosphonates and palliative radiotherapy in this case.

Not all back pain or bone pain is caused by prostate cancer. Other causes may include arthritis or injury. If you experience pain you should consult your doctor.

## Where can I get support?

Discovering that you have recurrent prostate cancer may understandably cause you, your family and friends some distress. You may need emotional and practical help at this time.


### Friends and family

Some men find all the help and support they need among family and friends. Talking to a partner, friend or relative may help you to cope with your cancer. Telling those close to you how you are feeling will help them to support you in a way that is right for you.

### Your specialist team

Sometimes individual circumstances may mean that you need additional support. Talk to your specialist nurse, doctor or social services about any concerns. Some other organisations which may help you can be found at the back of this booklet.

### One-to-one telephone peer support

If you would like to speak to someone who has been personally affected by prostate cancer you can call our free and confidential  Helpline on 0800 074 8383. A specialist nurse will take a contact phone number for you and a short history of your treatment to date. You will be matched, where possible, with one of our volunteers who may have had similar experiences or treatments. Our volunteers include both men and women whose lives have been affected by prostate cancer either as a patient, partner or other family member.

## Support groups

You might like to be put in touch with your local prostate cancer support group. Support groups can be a great way for you to meet people with similar experiences. These groups are often set up by local health professionals or by people who have experience of prostate cancer. Meetings are usually informal and offer an opportunity to find out about other people's experiences as well as discussing your own thoughts and concerns. Many support groups also welcome partners, friends and relatives. A list of some groups in the UK is available on our website [www.prostate-cancer.org.uk](http://www.prostate-cancer.org.uk) or you can call our Helpline on



0800 074 8383 for more information.

## Spiritual issues

Some men find that being diagnosed with recurrent prostate cancer also raises issues that may affect their religious faith or spiritual wellbeing. If this happens you may feel the need to discuss your concerns with your faith leader or spiritual adviser. You may wish to speak to a hospital chaplain who can be contacted through your specialist team.

## Counselling

It can sometimes be difficult to speak to those close to you because you do not want to upset them, or you may find it hard to show your emotions. Some people find it easier to talk to someone they do not know. Counsellors are trained to listen and can help you to understand your feelings and find your own answers. Your GP may be able to refer you to a counsellor or you can see a private counsellor. There are different types of counselling available. To find out more contact the

British Association for Counselling and Psychotherapy on 0870 443 5252 or visit [www.bacp.co.uk](http://www.bacp.co.uk).

## Who are my team members?

You can use this space to record names and contact details for 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 likely to be most involved, but you may not come into contact with all of these.

### Key worker

Your key worker is your main point of contact. They help to co-ordinate your care and guide you to the appropriate team member or source of information.

<b>Name</b>	
<b>Telephone no.</b>	
<b>Notes</b>	

## Specialist nurse

You may have a urology, uro-oncology or prostate cancer specialist nurse as part of your MDT. They can answer questions you may have about your cancer and your care.

<b>Name</b>	
<b>Telephone no.</b>	
<b>Notes</b>	

## Consultant oncologist

This type of doctor specialises in treating cancer.

<b>Name</b>	
<b>Telephone no.</b>	
<b>Notes</b>	

## Consultant urologist

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

<b>Name</b>	
<b>Telephone no.</b>	
<b>Notes</b>	

## Other health professionals

You can record contact details of other health professionals in the space below. For example these might include a radiographer, pharmacist, dietician, sexual dysfunction clinician, continence nurse or physiotherapist.

<b>Name</b>	<b>Contact details</b>

## Questions to ask your specialist team

What is the risk of my prostate cancer coming back?

How will I know if my cancer returns?

Which second-line treatment(s) will be available to me?

What are the side effects of this treatment?

What are the chances of successfully controlling the cancer with this treatment?

What follow-up will I need after treatment?

Are there any clinical trials which I could take part in?

Who can I contact if I or my family have any further questions or concerns?





## Glossary

For more medical words please read our Tool Kit fact sheet

**i** **A to Z of medical words.**

### Bisphosphonates

A group of drugs which may be used by men with prostate cancer that has spread to the bones. They do not treat the cancer but may help with symptoms.

**i** Tool Kit fact sheet - **Bisphosphonates.**

### Chemotherapy

Drugs used to destroy cancer cells. This type of treatment may be used to treat prostate cancer that has spread outside the prostate gland and is no longer responding to hormone therapy. Men with an earlier stage of prostate cancer may be offered chemotherapy as part of a clinical trial.

**i** Tool Kit fact sheet - **Chemotherapy.**

### Cryotherapy

A treatment that uses freezing and thawing to destroy cancer cells. This is a newer type of treatment for prostate cancer and you may be offered it as part of a clinical trial or national study. Also known as 'cryosurgery' or 'cryoablation'.

**i** Tool Kit fact sheet - **Cryotherapy.**

### Fistula

An abnormal opening between two parts of the body that may be caused by injury, infection, or inflammation, or may be created during surgery. This is a rare complication of some treatments for prostate cancer, where a hole forms between the back passage and the tube that carries urine through the penis.

The main symptoms of this condition are watery diarrhoea with or without gas in the urine. In severe cases major surgery might be needed to correct the leak.

## Gleason grade

Cancer cells in a biopsy sample are given a Gleason grade to show how active they are. The cells are given a grade of between 1 and 5. Non-aggressive cells are grade 1 and the most aggressive are grade 5. The most common type of cells found is graded first. Then the same is repeated with the second most common type of cells. The two grades are added together to give a Gleason score.

## Gleason score

A scale that shows how aggressive a cancer is. The Gleason score is worked out by adding together the Gleason grades of the two most common types of cell in a biopsy sample. Gleason scores run from 2 to 10. The higher the score, the more aggressive the cancer. Very few men with prostate cancer have Gleason scores of less than 6.

**i** Tool Kit fact sheet – **How prostate cancer is diagnosed.**

## HIFU (high intensity focused ultrasound)

A treatment that uses ultrasound to heat and destroy cancer cells. HIFU is a fairly new treatment for prostate cancer and you may be offered it as part of a clinical trial or national study.

## Hormone therapy

Cancer specialists use hormone therapy to stop testosterone from reaching the prostate cancer cells. There are three main types of hormone therapy using surgery, injections or tablets.

**i** Tool Kit fact sheet - **Hormone therapy**.

## Lymph nodes

Small bean shaped structures that are part of the body's lymphatic system, which helps the body to fight disease and infection. Also known as lymph glands.

## Margins (positive and negative)

When the prostate gland is removed by surgery it is sent to a laboratory for testing. If cancer cells are found at the edge of the gland this is described as positive margins. If cancer cells are not found at the edge this is described as negative margins.

## Multi-disciplinary team (MDT) or specialist team

The team of health professionals or specialists involved in your care. The team may include a specialist nurse, a consultant oncologist, consultant urologist, consultant pathologist and a consultant radiologist.

## Oestrogen

A female sex hormone that may be used as a type of hormone therapy for men with advanced prostate cancer by controlling testosterone levels.

**i** Tool Kit fact sheet – **Hormone therapy**.

## Palliative radiotherapy

Radiotherapy given to help control symptoms and pain caused by cancer, rather than treating the cancer itself.

 Tool Kit fact sheet – **Palliative radiotherapy**.

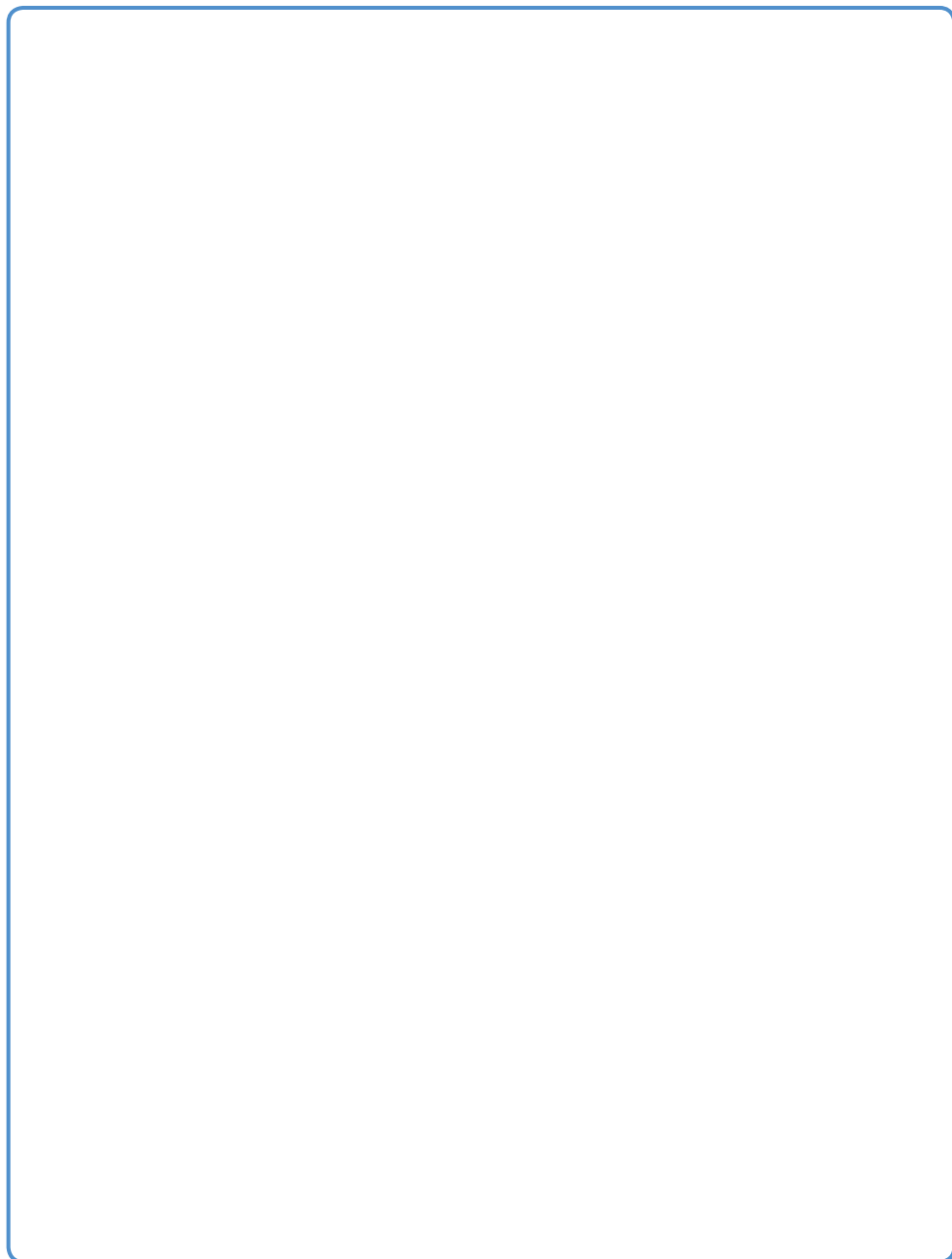
## Seminal vesicles

Two glands which are about 5cm long situated next to the prostate gland and bladder. They provide some of the fluid which makes up semen.

## Steroids

A type of drug used to control swelling and inflammation. Steroids may be used for advanced prostate cancer to help reduce inflammation in areas where the tumour has spread.

## My notes



# The Prostate Cancer Charity

This booklet is available from our free and confidential Helpline on 0800 074 8383 or visit our website at [www.prostate-cancer.org.uk](http://www.prostate-cancer.org.uk) for more information. Our Tool Kit fact sheets are also available and include an A – Z of Medical Words which explains some of the words and phrases used in this booklet.

## Free and confidential Helpline

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



You can also send a query to the Helpline by using our email contact form. Visit [www.prostate-cancer.org.uk](http://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](mailto: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](http://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 Counselling Trust

[www.cancercounselling.org.uk](http://www.cancercounselling.org.uk)

Edward House, 2 Wakley Street, London, EC1V 7LT

Telephone 020 7843 2292 (answerphone for out of office hours enquiries)

Counselling services for anyone affected by cancer either face-to-face or over the telephone.

### Cancer Research UK Clinical Trials

[www.cancerhelp.org.uk](http://www.cancerhelp.org.uk)

61 Lincoln's Inn Fields, London, WC2A 3PX

Freephone 0808 800 4040

Mon – Fri 9am – 5pm

Information about current clinical trials for cancer.

### Macmillan Cancer Support

[www.macmillan.org.uk](http://www.macmillan.org.uk)

89 Albert Embankment, London SE1 7UQ

Freephone 0808 808 0000

Practical, emotional and financial support for people with cancer, family and friends. Information about cancer, its treatment and living with cancer. Please note Macmillan Cancer Support has now merged with Cancerbackup.

## **Maggie's Cancer Caring Centres**

[www.maggiescentres.org](http://www.maggiescentres.org)

Maggie's Centres, 8 Newton Place, Glasgow G3 7PR

General enquiries Tel: 0131 537 2456

Support centres accross the UK.

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.

## **Marie Curie Cancer Care**

[www.mariecurie.org.uk](http://www.mariecurie.org.uk)

89 Albert Embankment, London SE1 7TP

Telephone: 020 7599 7777

Marie Curie run hospice centres throughout the UK and provide a nursing service for patients in their own home day and night, free of charge.

References to sources of information used in the production of this booklet are available on our website: [www.prostate-cancer.org.uk](http://www.prostate-cancer.org.uk)

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**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 already been given 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.

**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**

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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](mailto: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](http://www.prostate-cancer.org.uk)



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A charity registered in England and Wales (1005541)  
and in Scotland (SC039332)

THE  
**PROSTATE**  
CANCER CHARITY