About this booklet

This booklet is for men who have recently been diagnosed with prostate cancer. It is your personal guide and explains what prostate cancer is, tests you may have to diagnose it and the treatment options available. It also includes information about sources of support.

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 speak to our Specialist Nurses on our confidential helpline.

There are sections towards the end of the booklet for you to write down any contact details and information that may be helpful to you and your doctor or nurse. We hope that this booklet will help you to get the most from discussions with those involved in your care.

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

- Prostate Cancer UK Specialist Nurse helpline
- Prostate Cancer UK publications

If you would like to know more about anything you read in this booklet, you can call our Specialist Nurses on our confidential helpline.
Contents

About this booklet .............................................................. 2
What is the prostate gland? .................................................. 4
What is prostate cancer? ..................................................... 4
How is prostate cancer diagnosed? ...................................... 7
What do my test results mean? ........................................... 10
What are my test results? ................................................... 15
What are my treatment options? ......................................... 18
Where can I get support? .................................................... 29
Who are my team members? ............................................... 32
Medical words used in this booklet .................................... 34
Follow-up appointments .................................................... 36
PSA levels ........................................................................ 37
Notes ................................................................................. 38
More information from us .................................................. 39
Other useful organisations .................................................. 40
About Prostate Cancer UK .................................................. 42
What is the prostate gland?

Only men have a prostate gland. The prostate 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 job is to make some of the fluid that carries sperm (semen).

What is prostate cancer?

Prostate cancer is the most common cancer in men. Normally the growth of all cells in the body is carefully controlled. As cells die, they are replaced by new ones. 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 may grow more quickly. It sometimes causes symptoms such as problems passing urine. Sometimes the cancer spreads outside the prostate to other parts of the body. The bones are a common place for prostate cancer to spread to, and it may cause symptoms such as bone pain.

About one in nine men (11 per cent) will get prostate cancer at some point in their lives. The following factors may increase your risk of prostate cancer.

• **Age**  
  Prostate cancer mainly affects men over the age of 50 and your risk increases with age.

• **Family history**  
  You are two and a half times more likely to get prostate cancer if your father or brother has been diagnosed with it. You are more at risk if your relative was under the age of 60 when they were diagnosed, or if more than one close relative has prostate cancer.

• **Ethnicity**  
  In the UK, men of black Caribbean or black African descent are three times more likely to get prostate cancer than white men.

• **Lifestyle**  
  We do not know how to prevent prostate cancer but a healthy diet and lifestyle may be important in protecting against it.

For more information about prostate cancer risk, please read our booklet *Know your prostate*. 
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, and you may not necessarily have them in this order.

You can read more about the tests for prostate cancer in our Tool Kit fact sheet, How prostate cancer is diagnosed.

PSA test
The PSA test is a blood test that measures the amount of a protein called prostate specific antigen (PSA) which is produced by the prostate. All men have some PSA in their blood. The level of PSA can be affected by a number of things, including age, an enlarged prostate, infection, vigorous exercise, ejaculation, and prostate cancer.

Digital rectal examination (DRE)
A digital rectal examination (DRE) involves a doctor or nurse feeling the prostate gland through the wall of the back passage (rectum). They will wear gloves and put some gel on their finger to make it more comfortable. They are feeling for any hard or irregular areas that may be a sign of cancer.

Prostate biopsy
During a prostate biopsy, small amounts of tissue are removed from different areas of the prostate gland. These samples of tissue are sent to the laboratory to be checked by a doctor who specialises in looking at cells under the microscope (a pathologist).
A report, called a pathology report, is sent to your doctor explaining what the pathologist has found. Some men also receive a copy of their pathology report. If cancer has been found, the pathology report will provide details, including:
- how many samples contain cancer
- how much cancer is in each sample, and
- your Gleason score (see page 11).

You may have the following tests to find out whether the cancer is likely to have spread outside the prostate.

**CT scan**
A computerised tomography (CT) scan uses X-rays to take pictures of the body from different angles. This helps the specialist to see whether the cancer could have spread to the surrounding tissues.

**MRI scan**
Magnetic resonance imaging (MRI) uses magnets rather than X-rays to create an image of your prostate and other tissues to see whether the cancer has spread.

**Bone scan**
A bone scan may show whether any cancer cells have spread from the prostate to the bone. A small amount of a safe radioactive dye is injected into a vein in your arm. After two to three hours, you will have a scan to find any areas where the dye has collected. This can show if prostate cancer cells have spread to your bones.
Before my appointments I find it useful to write down any questions to ask the doctor.

A personal experience
What do my test results mean?

Your doctor will use the results of all the tests you have had to build up a picture of your cancer. This allows them to measure how far the cancer has spread and how quickly it may be growing.

**PSA level**
The PSA test alone cannot diagnose prostate cancer. All men have some PSA in their blood, and the level of PSA naturally rises as men get older. The following figures are a rough guide to ‘normal’ PSA levels, depending on your age. PSA is measured in nanograms per millilitre of blood (ng/ml).

- Up to 3ng/ml for a man aged 50 to 59.
- Up to 4ng/ml for a man aged 60 to 69.
- Up to 5ng/ml for a man aged 70 or over.

A PSA level higher than the normal range for your age may suggest a problem with the prostate. But a normal PSA result does not rule out prostate cancer. Similarly, if your PSA level is only slightly above the normal range for your age, this does not always mean that you have prostate cancer.

There is no upper limit for the PSA level, and some men may have a PSA level in the hundreds or thousands. Having a PSA level this high is uncommon but it is likely to suggest that a man has prostate cancer.

The PSA test is also an effective way of monitoring your prostate cancer after you have been diagnosed or had treatment, and can be used alongside other test results. You will have regular PSA tests as part of your follow-up after treatment.
**Gleason score**

A 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 pathologist may see more than one grade of cancer, so the grades of the most common pattern and the pattern with the highest grade are added together. This gives your Gleason score.

**For example**

If the biopsy samples show that:
- most of the cancer seen is grade 3, and
- the highest grade of cancer seen is grade 4, then
- the Gleason will be 3 + 4, and the Gleason score will be 7.

Most men with prostate cancer will have a Gleason score between 6 and 10. The higher the Gleason score, the more aggressive the cancer and the more likely it is to spread.

- A Gleason score of 6 suggests that the cancer is usually slow-growing.
- A Gleason score of 7 suggests that the cancer may grow at a moderate rate.
- A Gleason score of 8, 9 or 10 suggests that the cancer may grow more quickly.
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 (tumour)
The T stage shows how far the cancer has spread in and around the prostate gland. A digital rectal examination (DRE) can measure this. You may also have an MRI scan to confirm your T stage.

T1
The tumour cannot be felt and can only be seen under a microscope – **localised prostate cancer.**

T2
The tumour can be felt but it is contained within the prostate gland – **localised prostate cancer.**
T3
The tumour can be felt breaking through the capsule of the prostate or into the seminal vesicles – **locally advanced prostate cancer.**

T4
The tumour has spread to nearby organs, such as the neck of the bladder, back passage or pelvic wall – **locally advanced prostate cancer.**

**N stage (node)**
The N stage shows whether the cancer has spread to the nearby lymph nodes. Lymph nodes are part of your immune system and are found throughout your body. The lymph nodes in your groin are near the prostate and are a common place for prostate cancer to spread to.

The N stage is measured using an MRI or CT scan. This stage will only be measured if the result is likely to affect your treatment options.
NX  The lymph nodes were not measured.
N0  The lymph nodes do not contain cancer cells.
N1  The lymph nodes do contain cancer cells.

M stage (metastases)
The M stage shows whether the cancer has spread (metastasised) to other parts of the body, such as the bones. This is measured using a bone scan. Cancer that has spread to other parts of the body is called advanced prostate cancer. 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.

You can read more about how the spread of prostate cancer is measured in our Tool Kit fact sheet, How prostate cancer is diagnosed.

Stages of prostate cancer
• Localised prostate cancer is cancer that is contained within the prostate. You may also hear it called early prostate cancer.

• Locally advanced prostate cancer is cancer that is breaking through the capsule of the prostate or has spread to the area just outside the prostate, including the seminal vesicles, lymph nodes, neck of the bladder or back passage.

• Advanced prostate cancer is cancer that has spread from the prostate to other parts of the body, such as the bones. It is also called metastatic prostate cancer.
What are my test results?

You can use this section with your doctor or nurse to record your test results and next appointments.

PSA level at diagnosis:

Number of biopsy samples taken:

Number of biopsy samples containing cancer:

Gleason score:

T stage at diagnosis:

N stage at diagnosis (if measured):

M stage at diagnosis (if measured):
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

The team of health professionals involved in your care is called a multi-disciplinary team or MDT (see page 32 for more information). They will meet to discuss your test results and treatment options. You will not need to attend this meeting.

Outcome of the 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 36.

Please contact your specialist nurse or key worker (see page 32) at any time if you have any questions or concerns. You can also call our Specialist Nurses on our confidential helpline.
What are my treatment options?

The results of your tests will give you and your doctor a good idea of how your cancer is behaving. A number of things such as the stage of your cancer, your Gleason score and PSA level will affect which treatments you can have. If you have been diagnosed with localised prostate cancer, there may be several treatments available to you. If you have locally advanced or advanced prostate cancer, there may be fewer suitable treatments.

**Localised prostate cancer**

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 so slowly that they do not cause any problems during your lifetime. However, some cancers may be aggressive and spread to other parts of the body. The results of the tests described on pages 7-8 may give some clue as to how your cancer will behave.

There is not an overall best treatment for localised prostate cancer, and each treatment has its own advantages and disadvantages. You will need to think about these when deciding on a treatment.

You can read more about the diagnosis and treatment options for localised prostate cancer in our Tool Kit fact sheet, **Localised prostate cancer**.

**Locally advanced prostate cancer**

Locally advanced prostate cancer is cancer that has spread to the area just outside the prostate gland. Your treatment options will depend on how far the cancer has spread.

Read our Tool Kit fact sheet, **Locally advanced prostate cancer**.
Advanced prostate cancer
Advanced prostate cancer is cancer that has spread from the prostate to other parts of the body. It is also called metastatic prostate cancer. Prostate cancer can spread to any part of the body, but most commonly to the bones. Advanced prostate cancer can cause symptoms, such as bone pain and problems passing urine. It is not possible to cure advanced prostate cancer, but treatments can often keep it under control for several years.

You can read more in our Tool Kit fact sheet, Advanced prostate cancer.

Choosing a treatment
Your doctor or specialist nurse will explain all your treatment options and help you choose the right treatment for you. We have provided a summary of the different treatments on the following pages. Ask your doctor or nurse to tick the options that may be suitable for you. You may not be able to have all of the treatments listed here.

You can read more about each treatment, including how it works and its advantages and disadvantages, in our Tool Kit fact sheets. You can download these from our website or order them by calling our helpline or emailing literature@prostatecanceruk.org. If you would like to discuss your treatment options, you can also call our Specialist Nurses on our confidential helpline.

Your personal preference will be an important factor in deciding which treatment to have. Hearing about your different treatment options can be a lot to take in, especially when you have just been diagnosed. Your doctor may suggest you take time to think things through before coming to a decision.
Make sure you have all the information you need. It can be a good idea to write down any questions you might want to ask at your next appointment. You might find it useful to have someone with you at the consultation, or to make notes that you can read in your own time.

Each treatment has side effects, and will affect each man differently. You may not get all of the side effects. It is important that you think about the side effects and how you would cope with them when deciding on a treatment. We have included some information about side effects here. You can find more detailed information in our Tool Kit fact sheets.

The first treatment you have may affect which treatments you can have in the future, if you need further treatment. Speak to your doctor or nurse about this.

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

“The range of treatments was a bit bewildering, and it was only when I had my follow-up appointments that we started to whittle down those which were relevant to me.”

A personal experience
Treatment options

Localised prostate cancer

- Active surveillance
- Watchful waiting
- Surgery (radical prostatectomy)
- External beam radiotherapy
- Brachytherapy (either permanent seed or high dose rate)
- Cryotherapy (as part of a clinical trial)
- High intensity focused ultrasound (as part of a clinical trial)

Locally advanced prostate cancer

- Hormone therapy
- Watchful waiting
- External beam radiotherapy with hormone therapy (and sometimes with high dose rate brachytherapy)
- Surgery (radical prostatectomy) with hormone therapy and/or external beam radiotherapy. This is less common and you may be offered it as part of a clinical trial.

Advanced prostate cancer

- Hormone therapy
- Pain-relieving drugs to treat pain
- Palliative radiotherapy to treat symptoms
- Bisphosphonates to treat symptoms
- Chemotherapy to treat symptoms
Active surveillance
Prostate cancer may be slow growing and, for many men, may never progress or cause any symptoms. Active surveillance is a way of monitoring prostate cancer. It aims to avoid or delay unnecessary treatment for localised prostate cancer and so avoid the side effects that can be caused by treatment.

Active surveillance involves monitoring your cancer with regular tests, rather than treating it straight away. The aim is to find any changes which suggest that the cancer may grow. If tests show that your cancer may be growing, you will be offered treatment with surgery (radical prostatectomy), radiotherapy or brachytherapy, with the aim of getting rid of the cancer completely.

You can read more, including the advantages and disadvantages, in our Tool Kit fact sheet, Active surveillance.

Watchful waiting
Watchful waiting is a different way of monitoring prostate cancer that is not causing any symptoms or problems. The aim is to monitor the cancer over the long term. It is generally suitable for men who have other health problems so may not be fit enough for treatments such as surgery or radiotherapy. It may also be suitable for older men whose cancer is unlikely to cause problems during their lifetime or shorten their lifespan.

If you choose watchful waiting, you will not start treatment unless you get symptoms, such as problems passing urine or bone pain. You may then be offered hormone therapy (see page 26) to manage these symptoms. Watchful waiting involves fewer tests than active surveillance.

You can read more about watchful waiting, including the advantages and disadvantages, in our Tool Kit fact sheet, Watchful waiting.
If you are offered active surveillance or watchful waiting, make sure you are clear which approach you are being offered. These terms are not always used in the same way. Other terms that you may hear to describe either active surveillance or watchful waiting include ‘active monitoring’ and ‘wait and see’. Because active surveillance and watchful waiting are two quite different approaches to treatment, ask your doctor to explain exactly what they mean.

**Surgery (radical prostatectomy)**

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

However, surgery may be an option for some men with locally advanced prostate cancer. This is not very common as it may not be possible to remove all the cancer cells that have spread outside the prostate. You may be offered surgery as part of a clinical trial. You may have hormone therapy or a course of radiotherapy following surgery.

The main side effects of surgery are problems controlling when you pass urine (urinary problems) and difficulty getting and keeping an erection (erectile dysfunction). Symptoms may improve over time, and there are treatments available to help manage these side effects.

You can read more about surgery, including the side effects, in our Tool Kit fact sheet, **Surgery: radical prostatectomy**.
External beam radiotherapy (EBRT)
This treatment uses high energy X-rays to destroy the cancer cells. EBRT is often used together with hormone therapy and is suitable for men with localised prostate cancer. It is also suitable for some men with locally advanced prostate cancer.

Side effects of EBRT include urinary problems, bowel problems such as passing loose watery stools (diarrhoea), problems getting an erection, and tiredness. Symptoms may develop during treatment and improve over time. However, some men may get side effects later on which may develop several months or years after treatment. There are treatments available to help manage side effects.

You can read more, including the side effects, in our Tool Kit fact sheet, External beam radiotherapy.

Brachytherapy
This is an internal radiotherapy treatment, which involves putting a source of radiation into the prostate. There are two types of brachytherapy – permanent seed brachytherapy and high dose rate brachytherapy.

Permanent seed brachytherapy involves implanting tiny radioactive seeds into the prostate. This is an option for men with localised prostate cancer.

High dose rate brachytherapy, also called temporary brachytherapy, involves putting a source of radiation into the prostate gland for a few minutes at a time. This treatment is less common and may be used to treat localised prostate cancer. It may also be an option for some men with locally advanced prostate cancer.
Brachytherapy may be 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.

You may have hormone therapy to shrink the prostate for a few months before starting either type of brachytherapy.

Side effects of brachytherapy include problems passing urine, problems getting and keeping an erection, and tiredness. Men who have permanent seed brachytherapy may also get bowel problems, although these tend to be mild. Side effects may improve over time, and there are treatments available to manage them.

You can read more about brachytherapy, including the side effects, in our Tool Kit fact sheets, **Permanent seed brachytherapy** and **High dose rate brachytherapy**.

**High intensity focused ultrasound (HIFU)**

HIFU uses ultrasound to heat and destroy cancer cells in the prostate. It is not widely available in the UK, but may be available as part of a clinical trial. We do not know very much about how effective it is in the long term compared to other treatments. It may be a suitable option if you have localised prostate cancer. It may also be used to treat cancer that has started to grow again after radiotherapy.

The side effects of HIFU include problems passing urine and sexual problems including difficulty getting an erection. Side effects may improve over time, and there are treatments available to manage them.

You can read more about HIFU, including the side effects, in our Tool Kit fact sheet, **High intensity focused ultrasound**.
Cryotherapy
Cryotherapy uses freezing and thawing to destroy the prostate cancer cells. We do not yet know very much about how effective this treatment is in the long term. It is not widely available in the UK but may be available as part of a clinical trial.

Cryotherapy may be suitable for men with localised prostate cancer. It may occasionally be suitable for some men with locally advanced prostate cancer. However, it is more commonly used to treat men whose cancer has started to grow again after radiotherapy or brachytherapy.

The most common side effect of cryotherapy is problems getting or keeping an erection. Some men also get urinary problems after cryotherapy. These side effects may improve over time. There are treatments available to manage them.

You can read more about cryotherapy, including the side effects, in our Tool Kit fact sheet, Cryotherapy.

Hormone therapy
Prostate cancer needs the male hormone testosterone to grow. Hormone therapy stops testosterone from reaching the cancer or reduces the production of testosterone, causing the cancer to shrink.

Hormone therapy will treat all prostate cancer cells, wherever they are in the body. It will not cure prostate cancer but it can usually keep the cancer under control for several years. It is the standard treatment for locally advanced and advanced prostate cancer.
There are three main types of hormone therapy for prostate cancer. These are:

- injections to stop the production of testosterone (LHRH agonists and antagonists)
- tablets to stop the testosterone reaching the cancer cells (anti-androgens)
- surgery to remove the testicles (orchidectomy).

The side effects of hormone therapy are caused by lowered testosterone levels. They can include:

- loss of sex drive and problems getting and keeping an erection
- hot flushes
- tiredness (fatigue)
- swelling and tenderness in the breast area (gynaecomastia)
- weight gain.

You may not get all of these side effects, and there are ways to manage them. The risk of getting each side effect depends on a number of factors, including which hormone therapy you are taking and how long you take it for.

You can read more about hormone therapy, including the side effects and how to manage them in our Tool Kit fact sheet, **Hormone therapy**, and our booklet, **Living with hormone therapy: A guide for men with prostate cancer**.
Treatments to relieve the symptoms of advanced prostate cancer

If you have been diagnosed with advanced prostate cancer and are having problems with symptoms such as bone pain, there are treatments to manage these.

- Palliative radiotherapy uses a low dose of radiotherapy to shrink the cancer and relieve symptoms.
- Bisphosphonates are drugs that treat pain caused by cancer that has spread to the bones.
- Chemotherapy uses anti-cancer drugs to kill the cancer cells. This slows the growth of the cancer and can help control symptoms.
- Pain-relieving drugs can help relieve pain such as bone pain.

You can read more about these in our Tool Kit fact sheets, Treating prostate cancer after hormone therapy, Radiotherapy for advanced prostate cancer, Bisphosphonates, Chemotherapy and Pain and advanced prostate cancer.

Clinical trials

Clinical trials are a type of medical research study that aim to find new improved ways of preventing, diagnosing, treating and controlling illnesses. If you would like to find out about taking part in a prostate cancer clinical trial ask your doctor or specialist nurse.

You can read more about this in our Tool Kit fact sheet, A guide to prostate cancer clinical trials.
Where can I get support?

A diagnosis of cancer can be a frightening and overwhelming experience, and men respond in all kinds of ways. You might feel shocked or angry. You may be concerned about the future and how a diagnosis of prostate cancer will affect your life and your loved ones. It can be difficult and stressful trying to make a decision about your treatment. There is no right or wrong way to feel, and you may find that your feelings change over time. Your family may also find this a difficult time and may need some support. This section may be helpful for them.

Talking about it

Many men find that talking about their cancer can help them to cope. Some men find that talking to a partner, friend or relative can help. However, some men find it difficult to share their feelings with someone close to them and prefer to talk to someone else.

You and those close to you can speak to one of our Specialist Nurses by calling our confidential helpline. They can help you to understand your diagnosis and the emotional effects of cancer. You may also find it helpful to talk to your nurse, doctor or GP about how you are feeling. If you would like some more support, they may be able to put you in touch with a counsellor.

Asking questions can help you understand what is happening, and may help you feel more in control. You may find it useful to write down any questions you have to take along to your appointments. Our Tool Kit fact sheets list some suggested questions that you may wish to ask your doctor or nurse.
Talking to someone affected by prostate cancer
You and your family may find that talking to someone with similar experiences helps. Our support volunteers are all men and women personally affected by prostate cancer. They are trained to listen and offer support over the telephone. Call our Specialist Nurses on our confidential helpline to arrange to speak to a volunteer.

If you have access to the internet, you and your family can join our online community on our website at prostatecanceruk.org You can share your experiences with other men and their families. There are also prostate cancer support groups across the country, where you and your family can meet other people affected by prostate cancer. You can find details on our website or ask your nurse.

There is more information about dealing with the emotional impact of prostate cancer and support for partners and families in our booklet, Living with and after prostate cancer: A guide to physical, emotional and practical issues.

Practical support
You may find that making changes to your diet gives you more control over your body and is something that you can do for yourself. Eating a healthy, balanced diet and being physically active will benefit your overall health and may be helpful in slowing down the growth of the cancer. Diet and physical activity may also help you cope with the side effects of treatment and any feelings of anxiety. You can find out more about this in our Tool Kit fact sheet, Diet, exercise and prostate cancer.

If you live in England and are having treatment for cancer, including treatment for the symptoms of cancer or treatment for the side effects of a cancer treatment, you are entitled to free prescriptions. You will need to apply for a medical exemption certificate.
Ask your doctor for a FP92A form. Once you have filled out the form, your doctor will need to sign it, and you will be sent the certificate. You can find out more about free prescriptions at NHS Choices. If you live in Scotland, Wales or Northern Ireland, all prescriptions are free.

You can read more about practical issues of prostate cancer, such as work and money, in our booklet, *Living with and after prostate cancer: A guide to physical, emotional and practical issues.*
Who are my team members?

You can use this space to record the names and contact details of the team of health professionals who will be involved in your ongoing care. You may hear them called your multi-disciplinary team (MDT). Your MDT will discuss your individual diagnosis and agree on which treatment options would be suitable for you.

We have listed the health professionals who are likely to be most 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 treatment or monitoring.

**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.

<table>
<thead>
<tr>
<th>Name</th>
<th>Telephone no.</th>
<th>Notes</th>
</tr>
</thead>
</table>

**Main contact (key worker)**

Your main point of contact may be called your key worker. 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.

<table>
<thead>
<tr>
<th>Name</th>
<th>Telephone no.</th>
<th>Notes</th>
</tr>
</thead>
</table>

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

<table>
<thead>
<tr>
<th>Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>Telephone no.</td>
</tr>
<tr>
<td>Notes</td>
</tr>
</tbody>
</table>

Consultant oncologist
This type of doctor specialises in treating cancer.

<table>
<thead>
<tr>
<th>Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>Telephone no.</td>
</tr>
<tr>
<td>Notes</td>
</tr>
</tbody>
</table>

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

General practitioner (GP)
Practice nurse
Other health professionals

You could also call our Specialist Nurses on our confidential helpline.

You can find out about your local support group from your nurse or on our website.

Details of your local support group:
Medical words used in this booklet

Our Tool Kit fact sheet, *A-Z of medical words*, explains more words that you may hear or read when you are finding out about prostate cancer.

**Gleason grade**
A grading system which shows how aggressive prostate cancer is likely to be. Cancer patterns in a prostate biopsy sample are given a grade. Cells that are not aggressive are grade 1 and the most aggressive are grade 5.

**Gleason score**
Your Gleason score is worked out by adding together the Gleason grades of the most common cancer pattern and the pattern with the highest grade in the biopsy samples. The higher the Gleason score, the more aggressive the cancer and the more likely it is to spread. Most men with prostate cancer will have a Gleason score of between 6 and 10.

**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. Also called lymph glands.

**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 specialist nurse, a consultant oncologist and a consultant urologist.

**Oncology**
The diagnosis and treatment of cancer.

**Prostate specific antigen (PSA)**
A protein that is produced by the prostate gland. It is normal for all men to have a small amount of PSA in their blood. A raised PSA level can be due to a variety of reasons, including age, infection, an enlarged prostate and prostate cancer.

**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.
Follow-up appointments

You can use this section to record any appointments you have with your doctor, nurse or other health professional.

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Contact name</th>
<th>Location</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**PSA levels**

You may like to use this page to record the results of your PSA tests. If you need more space, you can order PSA record cards by calling Prostate Cancer UK on 0800 074 8383.

<table>
<thead>
<tr>
<th>Date</th>
<th>PSA level</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Date</th>
<th>PSA level</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Notes
More information from us

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.

Leaflets and booklets
Other leaflets and booklets about prostate cancer can be ordered free of charge from Prostate Cancer UK.

To order publications:
• Call us on 0800 074 8383
• Email us at literature@prostatecanceruk.org
You can also download and order all of our publications from our website at prostatecanceruk.org

Call our Specialist Nurses
If you want to talk about prostate cancer or other prostate problems, call our Specialist Nurses in confidence. You can also email the nurses using the contact form on our website. Visit prostatecanceruk.org and click on ‘support’.

Speak to our Specialist Nurses
0800 074 8383*
prostatecanceruk.org

* Calls are recorded for training purposes only. Confidentiality is maintained between callers and Prostate Cancer UK.
Other useful organisations

**British Association for Counselling and Psychotherapy**
www.itsgoodtotalk.org.uk
Telephone: 01455 883300
Provides information about counselling and details of therapists in your area.

**Cancer Black Care**
www.cancerblackcare.org.uk
Telephone: 020 8961 4151
Provides information and support to all people affected by cancer and raises awareness of cancer in black and minority ethnic communities.

**CancerHelp UK**
http://cancerhelp.cancerresearchuk.org
Freephone: 0808 800 4040 (9am-5pm, Mon-Fri)
Part of Cancer Research UK, CancerHelp provides information about all types of cancer and a database of cancer clinical trials.

**Carers UK**
www.carersuk.org
Advice line: 0808 808 7777
Provides information and advice for carers including signposting to support groups.

**Citizens Advice**
www.citizensadvice.org.uk
Provides free information and advice on financial, legal and other issues. You can find contact details of your local Citizens Advice Bureau on their website or in the phone book.
Healthtalkonline
www.healthtalkonline.org
Watch, listen to, or read personal experiences of men with prostate cancer and other medical conditions.

Macmillan Cancer Support
www.macmillan.org.uk
Freephone: 0808 808 00 00 (9am-8pm, Mon-Fri)
Provides practical, financial and emotional support for people with cancer, their family and friends.

Maggie’s Cancer Caring Centres
www.maggiescentres.org
Telephone: 0300 123 1801
Cancer information and support centres throughout the UK where people affected by cancer can drop in to access information and support services.

National Institute for Health and Clinical Excellence (NICE)
www.nice.org.uk
Telephone: 0845 003 7780
Provides guidance on treating ill health, including guidelines for prostate cancer.

NHS Choices
www.nhs.uk
Provides information and advice about medical conditions, and information on NHS health services in your area.

UK Prostate Link
www.prostate-link.org.uk
Guide to reliable sources of prostate cancer information.
About Prostate Cancer UK

Prostate Cancer UK fights to help more men survive prostate cancer and enjoy a better life. We support men by providing vital information and services. We find answers by funding research into causes and treatments and we lead change, raising the profile of the disease and improving care. We believe that men deserve better.

At Prostate Cancer UK, we take great care to provide up-to-date, unbiased and accurate facts about prostate cancer. We hope these will add to the medical advice you have had and help you to make decisions. Our services are not intended to replace advice from your doctor.

References to sources of information used in the production of this booklet are available at prostatecanceruk.org

This publication was written and edited by:
Prostate Cancer UK’s Information Team.

It was reviewed by:
• Debra Gray, Uro-oncology CNS, Darlington Memorial Hospital, Darlington
• Anup Patel, Chairman of Clinical Studies Committee of EAU Research Foundation, and Scientific Chair of Endourology Society
• Sean Vesey, Consultant Urological Surgeon, Southport and Ormskirk NHS Hospitals Trust and Royal Liverpool and Broadgreen University Hospitals Trust, Southport
• Karen Wilkinson, Urology Nurse Specialist, St Bartholomew’s and the London NHS Trust, London
• Prostate Cancer UK Specialist Nurses
• Prostate Cancer Voices
Donate today – help others like you

Did you find this information useful? Would you like to help others in your situation access the facts they need? Every year, 40,000 men face a prostate cancer diagnosis. Thanks to our generous supporters, we offer information free to all who need it. If you would like to help us continue this service, please consider making a donation. Your gift could fund the following services:

- £10 could buy a Tool Kit – a set of fact sheets, tailored to the needs of each man with vital information on diagnosis, treatment and lifestyle.

- £25 could give a man diagnosed with prostate cancer unlimited time to talk over treatment options with one of our specialist nurses.

To make a donation of any amount, please call us on 020 8222 7666, visit prostatecanceruk.org/donations or text PROSTATE to 70004*. There are many other ways to support us. For more details please visit prostatecanceruk.org/get-involved

*You can donate up to £10 via SMS and we will receive 100% of your donation. Texts are charged at your standard rate. For full terms and conditions and more information, please visit prostatecanceruk.org/terms