

# Prostate Aware

SIXTH  
EDITION

## UNDERSTANDING PROSTATE CANCER



- Facts and figures
- How to recognise symptoms
- How it is diagnosed
- What treatments are available
- What they involve
- Side effects
- Answers to the most common questions



# Foreword

by **Mr Simon Bott, MD, FRCS (Urol)**  
Consultant Urological Surgeon



I am very happy to recommend this booklet and sincerely hope that you will find it useful. It is intended to help men and their families find out more about prostate cancer. It is important to be aware of all the necessary facts, especially if you have a family history of prostate or breast cancer. Thankfully, men and their partners are becoming more health conscious and this information guide will increase the understanding of this all too common disease, which is more prevalent amongst men than any other cancer.

If you have been unfortunate enough to have been given a diagnosis of prostate cancer, then this booklet is essential reading. It has been written by patients with help from doctors and nurses working in the Surrey, West Sussex and Hampshire Cancer Network who deal with this disease on a daily basis. Prostate cancer is a difficult condition to fully understand and the numerous sources of information can be very confusing. As there may be a number of treatment options, we hope we can assist you to make the right decision. We have tried hard to outline the various options as simply as possible.

The Prostate Project, which funds this publication, feels that Prostate Aware is a good title for this guide as it is a genuine attempt to make men more aware of this potentially treatable disease and to provide essential information in the fight against prostate cancer. The Prostate Project has done a huge amount to improve the care of men with prostate cancer and I thank them for their continuing efforts.

*Cover photo: A researcher at the University of Surrey conducting the simple 'dipstick' EN2 urine test for prostate cancer.*



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# Introduction

Each year in the UK just over 40,000 men are diagnosed with prostate cancer and about 11,000 die of the disease.

It is the most common cancer to affect men. This will be a surprise to many as awareness of the disease is only just starting to pick up, probably because the prostate gland's location and function are a mystery to most people. However, cancer of the prostate can be treated even when it has spread beyond the gland.

In this guide we hope to give some essential information about the prostate gland, how prostate cancer develops, how it can be detected and treated as well as the support available for men and their families following diagnosis.

## The prostate gland

The prostate is a walnut size gland located deep in the pelvis just below the bladder.

The tube draining the bladder, called the urethra, passes through the centre of the prostate to the penis. The prostate is found only in men. It is an essential part of the reproductive system as, along with the seminal vesicle, it helps make nutrients in the form of semen for the sperm. The sperm travels from the testicles to the urethra, where it combines with semen from the seminal vesicles and the prostate.

The prostate gland enlarges after puberty stimulated by rising levels of testosterone, the male hormone. This can sometimes cause problems later in life as a result of a condition called benign prostatic hyperplasia (BPH) where the urethra is squeezed by the

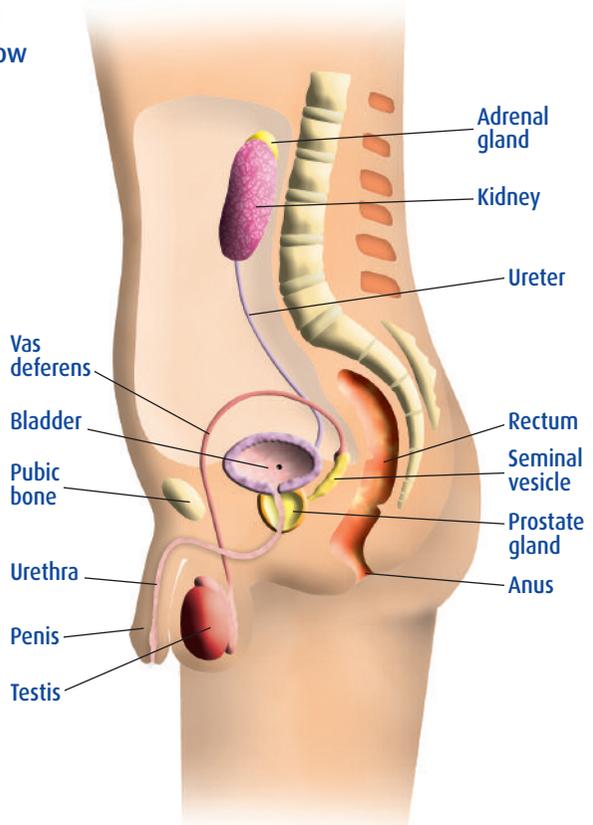


Diagram showing position of the prostate gland

prostate. This may lead to difficulties with urination (especially at night), more frequent urination and on occasion other symptoms.

BPH is different from prostate cancer, although it can share similar symptoms. Treatments available for this non-cancerous problem include drugs to shrink or relax the gland. If symptoms are severe or persist, various surgical options are available to remove prostate tissue or lift and hold it away from the urethra, thus relieving the pressure.

## Prostate cancer

**Prostate cancer is a condition where the cells within the prostate begin to divide and grow in an uncontrolled manner and form tumours.**

Precisely why this happens is not clear. We do know that risk may be increased where there is a family history of the disease or of breast cancer; and there is an increased risk if you are Afro-Caribbean.

Prostate cancer is relatively unusual in men under 50 but by the age of 60 significant numbers of men will have developed some evidence of the disease, with most diagnoses occurring between the ages of 60 and 80. In fact almost all men will have prostate cancer by the age of 80. A diagnosis is not necessarily of immediate concern as most cancers grow very slowly and may cause no harm during a man's natural lifespan. However, some are more aggressive and the earlier they are discovered the better.

If the cancer is localised, meaning it is contained within the gland, there is a wide range of treatment options and a better than 80% chance of a complete cure. If the cancer spreads (metastasises) to other areas of the body, it is said to be advanced and, although not curable, many cases can be controlled with appropriate treatment. It is therefore crucial to detect the disease at as early a stage as possible.

## Consulting your GP

As prostate cancer can grow for several years before showing any signs or symptoms, it is important to be aware of the possibility and consult your GP once you are in the relevant age bracket (50-75 years old). A digital rectal examination (DRE) will enable your GP to feel the size, shape and texture of the prostate gland by inserting a gloved finger into your rectum. This examination, while mildly uncomfortable, is usually quick and painless. The feel of your prostate, combined with the results of a blood test to establish the prostate specific antigen (PSA) level and an assessment of any symptoms and medical history, can indicate whether or not prostate cancer is a possibility and therefore requires further investigation.

## Symptoms requiring action

- Frequent need to pass urine, particularly at night
- Delay before urinating and/or interrupted flow
- Pain in passing urine or when ejaculating
- Blood in semen or urine
- Difficulty in getting or keeping an erection
- Nagging pain in the lower back or hip area

However, such symptoms are often associated with non-cancerous conditions such as an enlarged prostate, prostatitis (inflammation of the prostate) and urinary infection.

## The PSA test

PSA is a protein produced only by the prostate gland. It is measured in nanograms per millilitre in the blood and readings can register from less than 1 to over 1000. Readings of below 2 are considered normal in men below 50 rising to 5 in men aged 70+. An elevated level (or if the PSA is rising more quickly than would be expected) can be an indication of prostate cancer. Unfortunately the test is not perfect. Over 60% of men with elevated PSA levels do not have cancer (although the higher the reading the greater the likelihood of cancer being present); and some prostate cancers do not result in an elevated PSA reading.

We feel strongly, however, that as things stand the PSA test is a crucial first line of defence and an important option to consider for all men over 50, or earlier if there is a family history of prostate or breast cancer. The test needs to be repeated as a rising level may indicate a problem. It is important that, in discussion with your GP, you decide whether or not to undergo the test and understand its potential limitations; but many members of our Patient Support Group are glad that they were tested!

## Screening for prostate cancer

All men over 50 have a legal right to a PSA test which can be arranged through their GP, but it is important that they understand the test's limitations as well as its benefits. The desirability of introducing a full national screening programme based on the PSA test has been the subject of much debate. There are concerns that screening may identify many men with clinically insignificant prostate cancer that would never cause a problem during their natural life span; and it is wrong to assume that a negative PSA result can rule out the presence of prostate cancer. On the other hand European studies show that screening can reduce the number of deaths by prostate cancer in screened men.

These studies were carried out many years ago when some of the testing methodologies used now to diagnose prostate cancer were not available. It seems likely that, using today's testing methods, screening for prostate cancer would be even more worthwhile.

A new test, potentially much more reliable than PSA, is currently under trial and is described in greater detail on page 25 of this booklet; if this trial proves successful the screening debate in the UK may be rekindled.

## Referral for further tests

If your PSA level is too high, your prostate gland feels abnormal and/or you have relevant symptoms, your GP should refer you to a urologist (urinary specialist) for further investigation. You may then undergo an MRI scan designed to show any abnormal areas within the prostate and to enable surgeons to direct biopsies (if deemed to be necessary) more accurately.

If there remains a suspicion of prostate cancer after the initial investigation, you are likely to require one of two types of biopsy procedure. A **transrectal ultrasound-guided biopsy (TRUS)** is carried out in outpatients under local anaesthetic. A probe is inserted into the rectum to image the prostate and help guide a needle that is used alongside the probe to take biopsies of potentially malignant tissue. A **template biopsy** requires your admission as a day patient and is carried out with a general anaesthetic. This procedure enables tissue to be taken from deeper in the gland than is the case with a TRUS. The merits and potential side effects of the two options will be discussed with you.

## Grade of cancer

Samples of tissue taken from the prostate by biopsy are analysed by a pathologist. If cancer is found, the pathologist will examine the cell patterns in the tissue and grade them, in a range of 3 to 5, indicating the degree of abnormality and the aggressiveness of the cancer. Grades 1 and 2 are no longer used, so the lowest grade is 3 and the highest is 5. The lower the grade the slower growing the prostate cancer and the less risk there is of the cancer spreading. The grades of the most prevalent and second most prevalent cell patterns are added together to give an overall score with a maximum of 10 for the most aggressive cancers (the so-called Gleason score). As grades 1 and 2 no longer exist the minimum score is  $3+3 = 6$  and the maximum score is  $5+5 = 10$ .

As this can be a bit confusing a new system of grouping prostate cancers (from 1 to 5), based on their Gleason scores, is being introduced to enhance the relevance of the grading system to decisions on treatment. Information on the grade of your cancer will be shared with you, along with an explanation of what it means and its implications.

# Stage of cancer and imaging

The stage means the extent of your cancer. You may need to have further scans such as CT, MRI or a bone scan to determine the stage of your cancer as accurately as possible, i.e. whether the disease has spread to other sites in your body, particularly to the bones. This information will help you and your doctor to decide which treatment would be most appropriate. A brief explanation of the main types of scan that may be used in diagnosis and in assessing the effectiveness of treatment after diagnosis is given below. These procedures, carried out by radiographers, are painless and involve lying still on a couch for a period while images of your internal organs are recorded.

**Magnetic Resonance Imaging (MRI)** produces images of cross-sections of soft tissue (including the prostate and surrounding areas) by utilising magnetic fields created by the machine. The machine can be a bit noisy, but microphone and headphones will enable you to remain in contact with the radiographer throughout the process. MRI scans normally take about half an hour to perform. MRI is particularly good at looking inside the prostate, but it also it can look at other areas of the body.

**Computerised Topography (CT scan)** uses a rotating X-ray beam to take pictures of internal organs and bones from different angles. It is useful in assessing any spread of the disease outside the prostate area, including in the bones. A dye may be injected to enhance the images.

A **bone scan** may be used as prostate cancer can sometimes spread to the bones. A small amount of radioactive material is injected, and then photographs taken by a gamma camera some two hours later. The images show up any hot spots on the bone. These may be caused by cancer or other conditions such as arthritis, so the images require careful interpretation.

The scans and diagnostic tests will be used to decide what stage any cancer has reached which, along with the grade of cancer, is of critical importance in assessing prognosis and deciding on treatment. The T stages relate to the spread of the tumour in and around the prostate and are outlined below in simplified form. Each T stage can be sub-divided to reflect the extent of spread.

**T1** – The cancer is so small that it cannot be felt on rectal examination and can only be identified under a microscope.

**T2** – Early prostate cancer where the tumour can be felt on rectal examination but is still confined to the prostate gland.

**T3** – Locally advanced cancer where the tumour has spread outside the prostate and may have invaded the seminal vesicles (glands behind the bladder).

T4 – Late stage cancer. The tumour has spread to involve surrounding tissues such as the rectum, bladder or muscles of the pelvis. There may be more distant secondaries (metastases or ‘mets’).

Additional staging includes the N stage that measures the extent to which the cancer has spread to the pelvic lymph nodes (part of the immune system) and the M stage, referring to metastasis or the degree to which the cancer has travelled out of the immediate area of the prostate to other parts of the body such as the bones.

## Treatment options

A number of factors will determine treatment options available to you including your age and the stage and grade of your cancer. In 2014, NICE recommended three curative treatment options, (radical surgery, brachytherapy and external beam radiotherapy). These seem to offer patients the same chance of cure but individuals may be better suited to one treatment over another. For those patients with advanced cancer, where complete cure is not an option, the treatment and support regime will be designed to keep the disease in check, alleviate symptoms, maintain quality of life and maximise the period over which you can lead a normal and productive life.

New treatments and enhancements of existing treatments are coming on stream on a regular basis. Often these are designed to target the cancer more accurately while minimising damage to healthy tissue, so reducing side effects. Inevitably new developments will take place after this edition of the booklet has been published, and it is important that you are made aware of all the options by your consultant.

## Management and treatment of early prostate cancer

### Active surveillance

Do not be surprised if your consultant recommends having no immediate treatment and embarking on a regime of active surveillance. This is suitable for men with small localised and less aggressive cancers that are unlikely to spread. In such cases a slow growing cancer may not cause any problems during your lifetime and active surveillance can mean avoiding or at least delaying treatment with its possible associated side effects. It is important that the prostate has been accurately and extensively assessed before you undertake this option. Patients under active surveillance are closely monitored with PSA tests, digital rectal examinations and MRI scans at appropriate intervals. If the cancer shows signs of progressing your consultant will discuss with you the options for curative treatment.

## Watchful waiting

This option is usually offered to older men in cases where the disease may grow so slowly that it will not cause significant symptoms or to men whose health does not allow them to undergo invasive treatment. The aim is to keep an eye on the cancer over the long term and offer palliative (as opposed to curative) treatment if problems do develop. Monitoring activity through PSA tests and digital rectal examinations may not be as frequent as in the case of active surveillance. Should symptoms start to occur or if the disease starts to spread more quickly than expected, then hormone treatment (see page 13) is a likely option.

## Radical surgery

This involves the total removal of the prostate gland under general anaesthetic in an operation called a Radical Prostatectomy. It is done where diagnostic tests suggest that all of the cancer can be completely removed along with the prostate gland. This may involve conventional open surgery but most surgeons are now using laparoscopic (keyhole) or robotic surgery (both of which involve cutting and manipulating tissue through tiny incisions). Recovery from keyhole surgery is much faster than is the case when the area being operated on is completely opened up and less time is therefore spent in hospital and convalescence.

During surgery you will be fitted with a temporary catheter through which your urine will drain. This will normally be removed 10-14 days after the operation. Tissue that has been removed will be sent to pathology for analysis to check whether the cancer has been completely removed. If any cancer is found outside the prostate or a significant risk of recurrence is identified, then you may be offered further treatment such as radiotherapy or hormone treatment.

## Radiotherapy: 2 options

### 1. Brachytherapy

This is a one-stage treatment for early prostate cancer in which tiny radioactive seeds are implanted directly into the cancerous prostate gland through delivery needles under ultrasound control. The needles are passed through the skin behind the scrotum. A real time planning computer monitors the procedure to ensure that the desired radiation dose is given to the cancerous parts of the gland while the surrounding structures are spared. By delivering radiation directly into the prostate, the side effects can be minimised and patients rapidly return to their normal activities. The procedure is performed under general anaesthetic and may be a day case or involve an overnight stay in hospital.

## 2. External beam therapy

This involves directing high-energy radiation at the tumour from outside the body. Modern technology (Conformal 3D or Intensity Modulated Radiotherapy) uses a computer to 'shape' the radiotherapy beams to a more exact shape of the prostate, minimising the amount of healthy tissue that receives radiation. Fiduciary markers (tiny pieces of metal) may be inserted into the prostate under local anaesthetic. These markers, along with the planning (CT) scan that takes place before treatment, help ensure that the radiotherapy beams are precisely focused on the area needing treatment. External beam radiotherapy may also be used if the cancer has spread outside the gland. Hormone therapy (see page 13) is usually given to men undergoing this treatment.

Treatment is usually daily (Monday-Friday) for 4-8 weeks. To maximise effectiveness and reduce side effects, you are likely to be asked to ensure that your bowels have moved and that your bladder is full before each treatment. This will be explained to you by a radiographer at the planning stage. If anything about the process is unclear, do not hesitate to ask for further explanation and advice at any stage in the process.

## Recently developed treatments

New treatments are also available where only the part of the prostate containing the cancer is treated – these are called focal therapies. They are minimally invasive resulting in short hospital stays with speedy recovery times; and they enable precisely targeted treatment of the cancerous tissue in the prostate, leaving areas of the prostate that do not have cancer in them untreated, thus reducing potential side effects.

There are several ways of treating part of the prostate but we don't yet know which is the best. We have most information about focal **HIFU (High Intensity Focused Ultrasound)**. This uses focused high frequency ultrasound waves delivered with a probe through the wall of the back passage to heat and destroy cancerous tissue in the prostate; the probe is surrounded by a cooling balloon to protect the back passage. Alternatively the cancer can be killed by freezing it using **Cryosurgery**. Here, argon gas is passed through needles into the prostate to freeze and destroy the cancer cells. Focal treatment can also be performed using conventional radiotherapy and even brachytherapy, though these options have only recently been used in the focal setting so we have less long-term information on them. Both HIFU and cryosurgery treatments are also sometimes used if cancer comes back after radiotherapy.

## Side effects

All radical/curative treatments carry the risk of side effects. These include impotence (loss of erections), incontinence (leakage of urine) and bothersome urinary symptoms. Some of these will wear off but some may be long term. It is important that you discuss the relative risks of these with your urologist, and/or members of the multi-disciplinary team looking after you (which will include a clinical nurse specialist, oncologist, etc.). It is very important not to rush into any form of treatment (seek a second opinion if need be) and to consider the pros and cons of each procedure.

**Although your consultant(s) may recommend a course of treatment, the final decision remains YOURS, with help and support from spouse or partner and those closest to you. It is important to ensure you are told about and understand all available treatment options so that you can make an informed decision based on the benefits and risks associated with each.**

## Recurrence

Recurrence is usually indicated by a rising PSA or, for the minority of prostate cancers that do not affect PSA levels, other tests or symptoms. Tests such as MRI, CT, bone scan and/or a further biopsy will indicate if the recurrence is local or distant from the pelvis or prostate. It may not be necessary to initiate further treatment straightaway and this will depend on the results of the tests and speed of change in the PSA.

Should the prostate cancer recur after curative treatments there are several options available. For example, recurrence after external beam radiotherapy may be treated by cryotherapy or HIFU, after brachytherapy by radical prostatectomy or cryotherapy and recurrence after surgery can be treated by external beam radiotherapy. These treatments can only be used if the recurrence is localised to the prostate and has not spread elsewhere. If the recurrence is not localised to the prostate, hormone therapy is usually used.

# Management and treatment of advanced prostate cancer

Where the cancer has advanced beyond the prostate complete cure is not possible; but there are a number of options available that can control the cancer, reduce tumours and enable the patient to live a full and active life for many years.

## Standard hormone therapy

The prostate gland and prostate cancer are under the influence of testosterone, the male sex hormone, which drives the tumour to grow and spread. By blocking the body's production of testosterone, or preventing its action, hormone therapy may greatly reduce the cancer's capacity to grow. When the cancer has spread away from the prostate, usually going to either the lymph nodes or bones, hormone therapy can be effective at shrinking the tumour and reducing the side effects of the disease. It will often keep the cancer in check for a number of years. This can be assessed by keeping an eye on the PSA blood test.

Hormone therapy is also often used in conjunction with external beam radiotherapy as for some cancers it improves their response to the radiotherapy. In these circumstances, patients typically have hormone therapy for 3 months prior to the radiotherapy starting and may continue with the medication for between three months and two years.

There are two basic types of hormone therapy. **Anti-androgens**, delivered daily in tablet form, do not stop the production of testosterone, but block its effects on the prostate. An **LH-RH analogue** comes in the form of a slowly dissolving pellet that is usually injected every month or three months to prevent the production of testosterone by the testicles (Prostap and Zoladex are drugs commonly used for this purpose). The injection is straightforward and can be given at a GP's surgery or is sometimes self-administered. It is common for anti-androgens to be prescribed for a short period before Prostap or Zoladex are injected.

Possible side effects from the treatment with hormones include weight gain, hot flushes, tiredness, mood change, reduced sex drive and loss of erection. Some patients may experience tenderness in the breast area and in rare cases some degree of breast enlargement. It is important to discuss the relative effectiveness of different hormone treatments and the likelihood of possible side effects with your consultant or clinical nurse specialist.

## Newer hormone therapy

Two newer forms of hormonal treatment are now available and may be given after the standard hormone therapies. These are Abiaterone or Enzalutamide. Both these treatments block the effects of testosterone inside the prostate cancer cell. They are effective but have more side effects so careful monitoring is required with more frequent hospital visits.

## Chemotherapy

Chemotherapy involves the administration of powerful drugs that poison the cancer cells with the aim of slowing the growth of the cancer and shrinking tumours. We now know that in some instances it is beneficial to receive this as soon as prostate cancer has spread outside of the prostate gland. In this instance chemotherapy is usually given with hormone treatment. Alternatively chemotherapy is given after hormone therapy if the PSA readings start to rise.

The commonly used chemotherapy drug for patients with prostate cancer is Docetaxel, which is administered through a drip in up to ten outpatient sessions lasting for an hour or so, with three-week intervals between each session. It is often used in conjunction with a steroid such as Prednisolone, taken daily in pill form to enhance the effectiveness of the treatment and help reduce side effects. Hormone treatment may be continued in parallel.

Chemotherapy affects some healthy cells as well as attacking the cancer. Side effects and their severity vary from patient to patient but can include nausea, indigestion, hair loss, mouth ulcers, fatigue and reduction in red and white blood cells. These days careful monitoring and the use of drugs to mitigate their impact mean that side effects tend to be less significant than in the past and many patients will experience little more than bouts of fatigue (which tend to become more of a problem towards the end of treatment). However, because the reduction in white cells compromises the immune system, any infections should be reported to your doctor immediately so that they can be dealt with. Your blood count, liver and kidney functions will be checked before each treatment cycle.

After the chemotherapy cycle has finished you will receive check-ups at intervals to be agreed with your consultant. In many cases the treatment remains effective for a considerable time. If the cancer starts to grow again, treatment with Docetaxel will not be repeated but other forms of chemotherapy may be considered.

## Clinical trials

Clinical trials play a critical role in finding more effective ways to diagnose, treat and prevent diseases. The objective is to find out whether or not new tests or treatments produce better results than the current standard treatment. With regard to prostate cancer, there are a number of clinical trials being carried out at any one time. Do ask your consultant about them or go onto websites mentioned in this booklet.

It can be a difficult decision whether to take part in clinical trials but there can be benefits as you will be closely monitored, receive care from some of the best specialists in the field and even ongoing monitoring and care once the trial is completed.

Usually a trial will be organised where half the patients get a new treatment while the other half (the control group) continue with the current standard treatment so that comparisons can be made. The treatment you receive is usually allocated randomly and you may not know whether you are in receipt of the new treatment or are in the control group. In other types of trial different combinations of treatment may be tried or you may be asked to undergo regular blood or urine tests, for example to see if new markers or tests for prostate cancer are better than PSA. In this latter sort of study your treatment will not be affected.

## Diet and Lifestyle

**There are several factors that can increase your risk of getting prostate cancer.** Some, such as genetic make-up, increasing age, an African Caribbean background or a family history of prostate cancer/breast cancer, are beyond your control. But there are others, in particular diet and lifestyle, where you can bring benefits to your health such as reducing your risk of heart disease, diabetes and cancer. Men in the Western world have higher rates of cancer than men living in Far Eastern countries such as Japan and China. Researchers think that this may be due to the Western diet as cancer rates have increased in men who have migrated from Japan to the USA.

There is evidence emerging from research that some foods may slow down the growth of prostate cancer or reduce the chance of the cancer returning after treatment. However, the exact link between diet and prostate cancer and the extent to which certain foods may increase or decrease risk is unclear. Finding reliable information on healthy eating can be a confusing task.

## Some suggestions for you to draw on

Taking all the evidence together and advice that patients have received from their doctors and nutritionists, we suggest considering the following ideas as part of a balanced healthy diet:

### **Eat at least five portions of fruit and vegetables each day.**

Different fruits and vegetables contain differing nutrients some of which have properties (e.g. anti-oxidants, anti-inflammatories) helpful in combatting cancer. That is why, in order to cover all the bases, experts suggest that you try to include the following “rainbow of colours” in the fruit and vegetables you eat:



The following table suggests some foods that you may wish to eat or add to your diet:

What should I eat more of?	What does it do?	How do I include it in my diet?
Fruit and vegetables	Reduces your risk of cancer and other medical problems	Eat at least 5 portions each. Try to include a “rainbow of colours” in your diet
Cruciferous vegetables	May reduce your risk of getting prostate cancer	Eat more cabbage-like vegetables such as broccoli, cauliflower, cabbage, Brussels sprouts, bok choy and kale
Lycopene	May reduce your risk of prostate cancer and slow down its spread	Lycopene is found in tomatoes (particularly cooked and processed tomatoes), watermelon, pink grapefruit, guava, papaya
Green tea	May protect against development and growth of prostate cancer	Try drinking green tea in place of any hot drinks you have throughout the day
Oily fish	Fats in oily fish may help prevent prostate cancer developing and growing	Eat fresh, canned or frozen oily fish two or three times a week. Examples of oily fish are sardines, pilchards, mackerel, salmon, tuna (fresh or frozen only) and shrimp
Soy	May reduce the risk of prostate cancer	Choose traditional forms of soy, such as tofu, miso and tempeh, available from supermarkets and health food shops
Pulses	May reduce the risk of prostate cancer	Include more beans, peas and lentils in your diet
Whole grains	May reduce your risk of several cancers, including prostate cancer	Whole grain foods include brown bread, whole grain cereals, whole grain pasta

*The above has been reproduced from the Fact Sheet on ‘Diet and Prostate Cancer’ produced by the Prostate Cancer Charity.*

Other pointers towards a healthy diet include:

- **Include some protein, like fish, skinless chicken and pulses**
- **Eat a low-fat diet**
- **Reduce or avoid intake of full fat dairy products**
- **Reduce consumption of red and processed meat**
- **Avoid barbecued meat (and fish) or meat grilled or fried at very high temperatures**
- **Cut down on sugar and salt**
- **Drink six to eight glasses of water each day. Avoid sugary or fizzy drinks**
- **Limit alcohol to 2 units a day**

The best approach, if making dietary changes, is to do so on a gradual and selective basis that you are confident can be sustained.

## **Professional dietary advice for cancer sufferers**

If you have any concerns about weight, or have any other queries regarding your diet, you should discuss them with your consultant, GP or nurse specialist. They may refer you to specialist dieticians who can advise you on any aspect of food and help match your nutrition to your specific needs. You may be referred to a dietician as part of your treatment or you can ask to be referred to one.

## **Supplements**

There are some circumstances where your doctor may recommend supplements, for example calcium if you are on hormone therapy in order to help protect the bones. However, in most cases you should be able to get all the nutrients you need by eating a balanced diet. Nutrient-rich whole foods contain substances like fibre, vitamins and minerals that are needed for good health. Although some of these substances are available as supplements, scientists cannot always be sure that we get the same benefit if we consume nutrients in this form. Research also shows that taking high doses of supplements can be harmful. You may wish to consult with your doctor if you are considering taking supplements.

## **An active lifestyle**

Exercise protects against some cancers and other diseases. Recent research, at Surrey University and elsewhere, suggests that a higher level of physical activity may help to reduce your risk of aggressive prostate cancer and it is strongly recommended by most medical professionals. For men on some hormone treatments, regular exercise can help to reduce bone thinning (osteoporosis) and also help to maintain a healthy weight. Also exercise can have an important psychological impact in lifting mood and helping men cope with the side effects of treatment. It is recommended that you try to include 30 minutes of moderate exercise as part of your daily routine; but that is not always possible and any exercise is better than none.

## Learning that you have prostate cancer

Being told that you have got cancer can be a life-changing event. Your emotions may vary between despair, fear, anger and denial. The first reaction may be “Why me?” It may be difficult to focus on the many decisions you have to make about which treatment to undergo and when to begin that process. However, any reluctance in dealing with the disease should be banished: you need to remain positive. Most importantly, you have to ask your consultant the relevant questions. It is worth noting down any questions you have, as well as any significant developments in symptoms or side effects, for use when you see the consultant; it is very easy to forget important points. Where possible, we suggest that you take your partner, a family member or a friend with you when you go for a consultation, as it will not be easy to remember everything that is said – also as a way of involving your partner/family in what is going on. You should receive a copy of the letter sent after your consultation from the consultant to your GP, which will also help remind you of what was discussed with you.

## Some useful questions

- What stage (extent) is my cancer?
- What grade (how aggressive) is my cancer?
- What is the prognosis?
- What further tests do you advise and when will they happen?
- How long will I have to wait for the results and who sends them to me?
- Will you tell me what the results mean?
- Who will be the doctor in charge of my case or is there a team? Who is in the team and what are their roles?
- How can the clinical nurse specialist help me?
- What treatment options are available for my type of cancer?
- What are the benefits and possible side effects from the treatment you would recommend?
- How long have you been practising this form of treatment, with what results?
- How will I know if the treatment has been successful?
- What happens if I decide not to have any treatment?
- Are there any local prostate cancer patient support groups?



# Answers to some common questions

## • Do we know the cause of prostate cancer?

We do not know why some men get prostate cancer and others do not. As it is a growing phenomenon in the West, there may be a link with the Western lifestyle. There are a number of theories, but no real proof yet of what causes prostate cancer.

## • Could I have prostate cancer despite having no symptoms?

Yes, you could. It is not uncommon for prostate cancer to be found during regular health checks despite patients having no symptoms whatever. This further emphasises the importance of asking your GP for a PSA test once you reach 50 or even earlier if there is a family history of the disease.

## • Is time of the essence?

Prostate cancer, diagnosed at an early stage, may not grow rapidly at all. In such circumstances there may be plenty of time to consider and identify the right treatment. But in the event that it is an aggressive tumour or the disease is not diagnosed until a later stage, treatment needs to begin as soon as possible. Early diagnosis to establish the extent and nature of the cancer is important.

## • Where can I find out more about the disease?

This booklet provides a useful summary of prostate cancer. If you want to get more information, there are many organisations (see page 23) that provide more detailed advice and also free helplines manned by specialist nurses or volunteer prostate cancer patients.

## • Will I pass the cancer to others, and will my family inherit it?

While we do not know the cause of the cancer, it is not infectious and cannot be passed from one person to another through sexual intercourse or in any other way. Prostate cancer can however be inherited. Several genes have been identified which may make a man more susceptible to developing the disease. In other words, if you have a brother or father with prostate cancer, or a close female blood relative with breast cancer, then you are more likely to develop the disease than other men.

## • Is prostate cancer likely to affect my day to day life?

Prostate cancer can affect some men more than others, depending on the stage and severity of the disease. However, most patients with prostate cancer continue to be active at work, at home and in their social life and this is encouraged.

## • Will the disease affect my sex life?

Prostate cancer itself generally does not affect your sex life, except in the advanced stages. However, the treatment can lead to loss of erection. There are many treatments available to overcome this problem, including tablets, injections and vacuum devices which initiate an erection. Hormone treatment can also affect your sex drive as it reduces the level of testosterone.

## • What if the cancer is already outside the prostate gland?

Sometimes at diagnosis, the cancer is found to have already spread outside the prostate gland and so cannot be cured by treatments to remove or treat the prostate. Some cancers grow very slowly and do not require treatment so a process of active surveillance is recommended. In other cases hormone therapy may be started, sometimes along with chemotherapy.

## • What about other treatments?

Research is taking place around the world on developing new treatments for prostate cancer. These include new hormone treatments, chemotherapy, drugs that reduce the blood supply to the cancer, immunotherapy, oncolytic ('cancer killing') virus therapy, vaccine treatments and gene therapy. Royal Surrey County Hospital and Frimley Park Hospital have research projects and you may be asked to become involved in them. The Charity also helps fund research at the Oncology Group at the University of Surrey.

## • What is the role of local prostate cancer support groups?

Local support groups offer confidential non-medical information and support based on the experiences of fellow sufferers. This information can be provided on the phone or face-to-face or at regular meetings. There is a local support group serving prostate cancer patients at Frimley Park Hospital, the Royal Surrey County Hospital (including St Luke's Cancer Centre) and private hospitals throughout Surrey (see page 22).

## • What is the role of the Clinical Nurse Specialist?

A Clinical Nurse Specialist can play a vital role in your journey by acting as the link with the medical team looking after you. He/she can offer individualised information and support tailored to your own needs. Find out who he or she is!

# Role of the Clinical Nurse Specialist

The work of Clinical Nurse Specialists (CNS) can vary from hospital to hospital but they have a fundamental role in the provision of ongoing care and support for men and their families following diagnosis of prostate cancer.

The CNS work closely with the hospital consultants and other members of the medical team and will often be the first point of contact that men will have with the hospital once referred by their GP. They will continue to be available for advice and support from referral through to diagnosis and during subsequent investigation and treatment. In addition to arranging appointments and tests and carrying out results and review clinics, many CNS complete advanced training to acquire the skills necessary to undertake prostate examination and biopsy.

Patients coming to hospital for the first time or after they have been diagnosed with prostate cancer are often very worried and apprehensive. They are looking for reassurance as well as information and advice about their specific areas of concern. The CNS is a key link between the patient, the medical team and any local prostate cancer support group to ensure that patients and their family have access to the help and support they need during such a life-changing event.

There are professional Prostate Cancer Specialist Nurses at both the Royal Surrey County Hospital (01483 571122) and at Frimley Park Hospital (01276 604604) who are happy for you to get in touch.



**Nikki Pereira**  
Clinical Nurse Specialist  
Frimley Park Hospital



**Donna Higgins**  
Clinical Nurse Specialist  
Royal Surrey County Hospital



**Michele Pietrasik**  
Clinical Nurse Specialist  
Royal Surrey County Hospital

## Support Group

**Being newly diagnosed with prostate cancer can be very traumatic.**

Doctors are experienced in telling people they have got cancer, but only people who have experienced cancer have a real understanding of how sufferers and their families feel about being told. Men can be reluctant to talk about medical conditions or to seek help and support, even when faced with such a life-changing experience. However, many men (and their families) find they gain much comfort, confidence and encouragement from talking to others who are either living with or have been cured of prostate cancer.

There is a patient-led support group working with Frimley Park Hospital, the Royal Surrey County Hospital and private hospitals in Surrey. We:

- Offer confidential non-medical information and support based on our own experiences to men, their partners and families affected by the disease
- Seek to raise awareness of the consequences of prostate cancer in our area to encourage others to seek early diagnosis
- Hold quarterly evening meetings where we invite specialists to talk to us about relevant topics. There are also lunch meetings
- Give talks to a wide range of local groups about our personal experiences of prostate cancer and about our work
- Have displays in shopping centres and at local events to promote awareness of prostate cancer and the work we do
- Talk to and support individuals and members of their families who would like to know more about what it is like to live with the condition

Any contact with us is treated in strictest confidence, and we respect people's wishes to have as much or as little contact with us as they want. We are aware that there is a need for help and support for partners of men with prostate cancer who can be affected greatly and play a vital role in helping sufferers deal with the disease. All our meetings are open to family and friends and there are usually several partners at each meeting. The group has the full support and backing of the medical profession.

We have a free patient support helpline open so if anyone close to you is suffering from prostate cancer or you would just like to have a confidential chat about the disease, please call **0800 0355 302** and ask for contact details of your nearest support group, or email [supportgroup@prostate-project.org.uk](mailto:supportgroup@prostate-project.org.uk)

Further information about the Support Group, with dates of forthcoming meetings and events, can be found on the Prostate Project website:

[www.prostate-project.org.uk](http://www.prostate-project.org.uk)

## Other useful links

### **Prostate Cancer UK:**

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

A national campaigning organisation that supports men with prostate cancer. Its 'Toolkit' can be accessed through the 'Publications' section of its website and provides excellent well-presented information about many aspects of prostate cancer and its treatment.

### **Macmillan Cancer Support:**

[www.macmillan.org.uk](http://www.macmillan.org.uk) Info line: 0808 8080000

Provides information on Macmillan nurses and the help that they can offer to improve the lives of people affected by cancer.

### **NHS Choices:**

[www.nhs.uk](http://www.nhs.uk)

Website for NHS offering a search facility for many aspects of prostate cancer including information on hospitals. Also [www.cancerscreening.nhs.uk](http://www.cancerscreening.nhs.uk) for men concerned about prostate cancer who are looking for balanced information on the risks involved.

### **PCaSO Prostate Cancer Support Organisation:**

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

Based in Sussex, Hampshire and Dorset, it provides free and confidential help, support and information to anyone concerned about prostate cancer. Its 'Prostate Cancer Information Booklet', produced by patients and accessible through its website, contains useful and quite detailed information.

### **The Prostate Cancer Support Federation:**

[www.tackleprostate.org](http://www.tackleprostate.org) Helpline: 0800 0355302

Organisation of UK-wide local prostate cancer support groups that acts and speaks for prostate cancer patients and their families.

### **The Prostate Cancer Centre:**

[www.prostatecancercentre.com](http://www.prostatecancercentre.com) Info line: 0845 3707000

Provides a single referral point for specialists on the treatment of prostate cancer and provides comprehensive advice and information.

### **The Prostate Brachytherapy Centre:**

[www.prostatebrachytherapycentre.com](http://www.prostatebrachytherapycentre.com). Info line: 0845 5050560

Website of the Brachytherapy Centre at the St Luke's Cancer Centre, Guildford. Providing comprehensive up-to-date information on prostate brachytherapy, including patient information booklets and videos that can all be downloaded.

### **The Fountain Centre:**

[www.fountaincentre.org](http://www.fountaincentre.org) Tel: 01483 406618

A charity for cancer patients, families and carers in the St Luke's Cancer Centre at the Royal Surrey County Hospital – offering drop-in facilities, advice, counselling and a wide range of complementary therapies.

# Facts about the Prostate Project

The Prostate Project is a Registered Charity established in 1998.

We pride ourselves on being run entirely by volunteers and on keeping administration costs below 4%. Based in Guildford, we support the Royal Surrey County Hospital, St Luke's Cancer Centre, Frimley Park Hospital and the Oncology Research Group at the University of Surrey.

Our involvement, support and fundraising have been significant factors in the Royal Surrey County Hospital being widely recognised as a 'Centre of Excellence' in the treatment and diagnosis of the disease. The medical team at the four locations (some of whom are Trustees) are intimately involved with the Charity and work closely with their non-medical colleagues. We want to maintain the contribution we make and keep spreading the word about the value of early diagnosis as a key to improved cure rates. All our work has one ultimate goal – to bring direct benefits to prostate cancer sufferers and their families.

## Why are we different to other charities

We focus directly on our excellent regional hospitals. We are linked to a key Health University which has a 5 star rating and have funded the creation of a dedicated research team at the University. We bring together inputs from patients, medical experts and researchers in deciding on our priorities and on how to increase the impact of our work and funding on outcomes for patients, for example securing shorter lead times for diagnosis and treatment.

## The continuing aims of the Project are:

- To increase the awareness, particularly among men, of the existence of prostate cancer, its symptoms and its potential adverse effects
- To encourage wider recognition of the symptoms of the disease and swifter action in seeking GP advice
- To fund state of the art equipment, facilities and specialist staff to support urologists in achieving early diagnosis and rapid treatment
- To push forward the boundaries of knowledge about prostate cancer by initiating a world-class programme of research
- To help fund the building of a world-class NHS Urology Centre at the Royal Surrey County Hospital
- Or in one sentence:

**Giving men a better chance of beating prostate cancer**

# Prostate Project Foundation research

**In 2006 the Prostate Project provided 50% of the start-up funding for a new Chair of Urological Oncology at the University of Surrey.**

This provided the perfect opportunity to develop a ground-breaking team of researchers in the diagnosis and treatment of prostate cancer.

Since then significant additional funding from both the Charity and the University has enabled Professor Hardev Pandha and his 24-strong team to achieve results of international significance. The team combines the knowledge, expertise and skills of four clinicians (oncologists) and eight scientists. They receive dedicated and essential support from technicians, data managers, nurses and PhD students, and have strong links with the local Royal Surrey County Hospital and St Luke's Cancer Centre.

Since its inception Professor Pandha's team has had over 190 peer-reviewed papers published in key scientific media, which has led to world-wide collaborations – University of California, Cornell Medical School, University of Leeds, Mayo Clinic, Royal Marsden London, and others. The team also has in place a wide variety of important clinical trial programmes testing novel cancer therapies and diagnostic tools.

The team's research has included the invention of targeted therapies for cancer such as the HXR9 molecule that kills only cancer cells, leaving normal cells untouched. The group is a leading centre in the pioneering research into the development of cancer vaccines (immunotherapy) and the use of viruses to kill cancer cells (virus therapy).

The team has also developed a novel diagnostic biomarker, a protein called Engrailed-2 (EN2), which can detect prostate cancer in men when found in small urine samples. This raises the prospect of a relatively cheap, easy-to-administer test for prostate cancer that could be far more reliable than the current 30-year-old PSA test (see page 6). It is undergoing a multi-centre clinical trial programme at local hospitals, part funded by the Prostate Project.

The Prostate Project has provided critical funding for the team, purchasing vital pieces of equipment and supporting PhD students, clinical trial nurses and senior scientists. We are hugely proud of what they are achieving.



# Notes

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This booklet is published and distributed free of charge by The Prostate Project. Contributions to defray our costs would be most welcome.

The Prostate Project, Purbecks, Grosvenor Road, Godalming, Surrey GU7 1NZ

Tel: 01483 419501 Freephone Helpline: 0800 035 5302

Email: [info@prostate-project.org.uk](mailto:info@prostate-project.org.uk)

Website: [www.prostate-project.org.uk](http://www.prostate-project.org.uk)

Registered Charity No.1078523



## giving men a better chance of beating prostate cancer



**John Davies**  
Consultant Urological Surgeon,  
Royal Surrey County Hospital



**Chris Eden**  
Professor of Urology,  
Royal Surrey County Hospital



**Robert Laing**  
Consultant Oncologist,  
Royal Surrey County Hospital



**Stephen Langley**  
Professor of Urology,  
Royal Surrey County Hospital



**Bruce Montgomery**  
Retired Consultant Urologist,  
Frimley Park Hospital



**Prof. Hardev Pandha**  
Chair of Urological Oncology,  
University of Surrey

*“We are delighted to be part of this  
very productive prostate cancer charity.*

*Please continue to support the Prostate Project as  
their work is vital to us maintaining our hospitals as  
‘Centres of Excellence’ and to our clinical research”*



## We are here to help you

We have a free patient support helpline open so if anyone close to you is suffering from prostate cancer or you would just like to have a confidential chat about the disease, please call **0800 0355 302** and ask for contact details of your nearest support group.

If you want to speak with any person involved with our Support Groups, just ring Reg or Maggie Swaden on 01483 425626 (mobile 07833 198155) or Mac Derwig on 01483 811878 (mobile 07971 855195). Or email: [supportgroup@prostate-project.org.uk](mailto:supportgroup@prostate-project.org.uk)

### Prostate Cancer Nurse Specialists

There are Prostate Cancer Nurse Specialists at the Royal Surrey County Hospital (Tel: 01483 571122) and also at Frimley Park Hospital (Tel: 01276 604604), who can give advice and support to patients and their families.

## FINAL NOTE – IT IS IMPORTANT TO DISCUSS YOUR CONCERNS ABOUT PROSTATE CANCER

- WITH YOUR GP
- WITH YOUR FAMILY AND FRIENDS
- WITH SUPPORT ORGANISATIONS

**THANK YOU SO MUCH FOR SUPPORTING THE PROSTATE PROJECT**



The Prostate Project, Purbecks, Grosvenor Road, Godalming, Surrey GU7 1NZ Tel: 01483 419501  
Freephone Helpline: 0800 035 5302 Email: [info@prostate-project.org.uk](mailto:info@prostate-project.org.uk) Website: [www.prostate-project.org.uk](http://www.prostate-project.org.uk)  
Registered Charity No. 1078523