

**Fighting
Prostate Cancer**

A SURVIVAL GUIDE

Dr. Jyoti Shah

Fighting Prostate Cancer – A Survival Guide

First published June 2022

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British Library Cataloguing in Publication Data

A catalogue record for this book is available from the British Library

Medical knowledge is a constantly evolving and changing field. The author has made every effort to ensure the accuracy of the information is published in good faith but cannot accept legal responsibility or liability for any errors or omissions. Readers are strongly urged to contact their doctor for any specific concerns. The information in this book is based on evidence and experience of prostate cancer in men, whilst recognising that the condition may also affect trans women, non-binary people assigned male at birth and some intersex people.

For further information or additional copies, please go to

www.fightingprostatecancer.co.uk

Author and Editor: Jyoti Shah

Front cover concept: Paresh Solanki

Book Design and Production: Toni Barrington, The Magazine Production Company Ltd

Printing: The Magazine Production Company Ltd,

PO Box 2212, Shoreham-by-Sea, West Sussex. BN43 9GB

Published by: Jyoti Shah, Derby & Burton Hospitals Charity (Reg. No. 1061812),

Royal Derby Hospital, Uttoxeter Road, Derby, DE22 3NE.

ISBN: 978-1-3999-2574-7

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FIRST WORDS



When a man in his fifties walked into my clinic with a PSA of nearly 500, it was a tragedy. Not just for him and his loved ones, but for us, as clinicians. He had no idea what PSA was, let alone what such a high result meant. Perhaps this is why he ignored the result for many months. He died within a year of his diagnosis.

This is why I started a campaign to raise awareness of prostate cancer, the most common cancer in men. Although the campaign and this book bear my name, they are the products of many such men; their stories; their lives. Previously a disease that was thought to affect older men, we are seeing men in their 40s and 50s now affected with prostate cancer. We need to do more.

Fighting Prostate Cancer – A Survival Guide is just that – a survival guide to help men understand a little more about prostate cancer and how it is diagnosed. The easy-to-follow language is aimed at men and their families to help them navigate the maze of treatment options that will be made available to them in a constantly changing field, and to appreciate and manage the uncertainties that shroud prostate cancer.

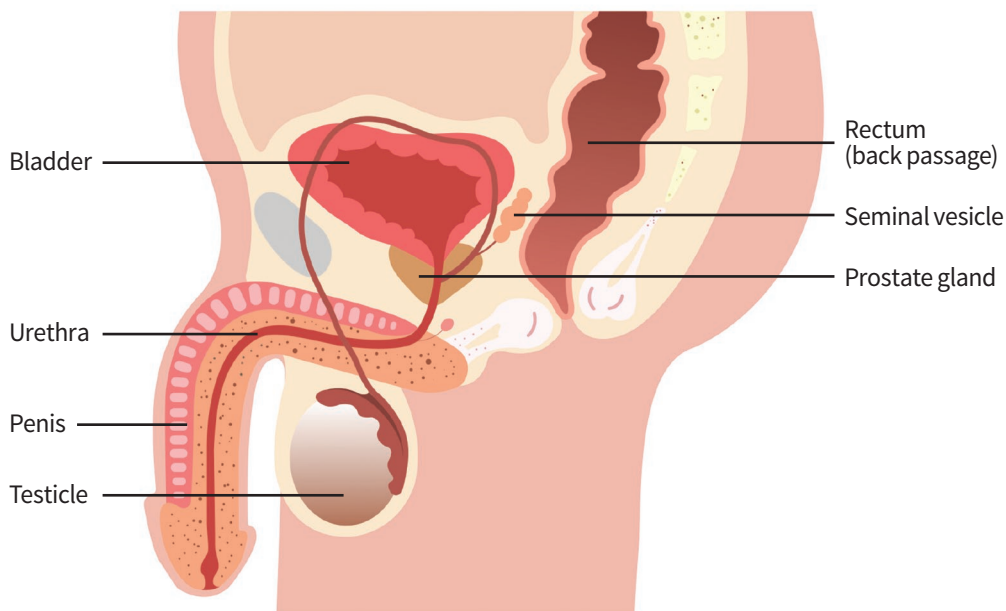
This book stems from the Fighting Prostate Cancer campaign, which has been running since 2016. The campaign started and continues with the unwavering support of Burton Albion Football Club and specifically Chairman, Ben Robinson and his team. There are many other organisations who have helped us along the way, including Burton Mail, Burton Hospital, The Freemasons, Rotary Clubs, Rolls-Royce, and many community organisations such as places of worship to name but a few.

I am very grateful to the authors and my patients who have contributed to this book and to Toni and Dean from the Magazine Production Company Ltd for working their magic. Finally, I would like to thank my very patient husband for simply being my rock.

I hope this guide helps.

Dr. Jyoti Shah
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www.fightingprostatecancer.co.uk



The word prostate seems to derive from the Ancient Greek term “prostates”, which literally means ‘one who stands before’ like a guardian or protector.

What is the prostate?

The prostate is a small gland, which is normally the size of a walnut. It tends to feel soft, smooth and rubbery in consistency and when of normal walnut size, weighs approximately 30 grams. It is part of the male reproductive system.

Who has a prostate?

Men, trans women and people who were assigned male at birth have a prostate. Women do not have a prostate.

Where is the prostate?

The prostate is located deep inside the pelvis just below the bladder and in front of the rectum (back passage). It surrounds part of the urethra (the pipe carrying urine from the bladder). The top of the prostate, nearest the bladder is called the base and the bottom is called the apex.

What does the prostate do?

The most important function of the prostate is to produce fluid called seminal fluid, which is part of the semen. Approximately 20-30% of the fluid in semen comes from the prostate and contains components that help sperm to survive. This includes enzymes, zinc, citric acid and prostate specific antigen (PSA). This is an enzyme that liquifies semen that has thickened after ejaculation, thereby allowing sperm to swim more freely. PSA is made by prostate cells.

What controls the prostate?

Testosterone, which is made in the testicles, controls how the prostate works by giving men a sex drive (libido), an erection and the muscle power for ejaculation. The prostate contains an enzyme called 5-alpha-reductase, which converts testosterone into dihydrotestosterone. The latter is like testosterone but has much stronger and more potent effects.



In 1997, surgeons removed a 2.41 kg prostate with a diameter of 24 cm in a 57 year old man.

Why does the prostate grow?

For most men, the prostate grows as a normal part of the ageing process. This enlargement is called benign prostatic hyperplasia (BPH). Because the prostate surrounds part of the urethra (the pipe through which urine is expelled), an enlarged prostate can squeeze the urethra. This causes the urethra that is inside the prostate to be narrowed, thereby causing some of the common symptoms men experience as they get older. This is covered in more detail later. This growth of the prostate is not cancer.

Some common comparisons to help assess prostate size



Common Questions

Can I live without my prostate?

Yes, a man can live without his prostate. The whole prostate may be removed for cancer or part of it when it is enlarged and causing symptoms

What conditions other than cancer can affect the prostate?

- Benign (non-cancerous) enlargement called BPH
- Prostatitis - infection or inflammation of the prostate

Do biological women have a prostate?

No

How big can the prostate get?

There is no real upper limit

- A small sized prostate has a volume of 30-40ml
- A medium sized prostate has a volume of 40-80ml
- A large sized prostate has a volume greater than 80ml

What is Cancer?

Cancer happens in any part of the body when the cells start to grow uncontrollably. It can start anywhere in the body and spread to other body parts via blood, the lymph system or directly to nearby tissues, such as the bladder. The primary cancer is where the cancer starts. In the case of prostate cancer, the primary cancer is the prostate. When the cancer spreads to other parts, it is called secondary or metastatic cancer.

There are various types of cancer depending on where and in which cell type they start to grow:

- **Carcinoma** – this is a type of cancer that starts in the skin or other internal organ or gland. These tend to be solid cancers and are the most common type of cancer. Prostate cancer is a carcinoma
- **Sarcoma** – this is a type of cancer that begins in the body's support mechanism such as fat, muscles, tendons, joints, blood vessels, lymph, cartilage, or bone
- **Leukaemia** – this is cancer of the blood
- **Lymphoma** – this is a type of cancer that begins in the lymphatic system, which is a network of vessels that drains lymph from tissues into blood. It is part of the immune system

How does cancer spread?

Cancer can spread to lymph nodes near the primary cancer or further afield. These lymph nodes are small, round organs that are part of the immune system and fight infection. In prostate cancer, it can spread to the lymph nodes near the prostate in the pelvis, or higher up in the body.

Cancer can also spread via the blood to distant parts of the body such as bones, liver, or lungs. When cancer spreads it is named from the area it started. For example, if prostate cancer spreads to the bones, then it is not called bone cancer, but instead metastatic prostate cancer.

What causes prostate cancer?

Like a lot of other cancers, the exact cause of prostate cancer is not known. It is most likely due to changes in the DNA of prostate cells, causing them to grow uncontrollably. Experts agree on some risk factors that are associated with the disease, as discussed overleaf.

How common is prostate cancer?

-  Prostate cancer is the most common cancer in men in the UK
-  Approximately 52,300 men are diagnosed with prostate cancer in the UK every year
-  140 men are diagnosed every day in the UK
-  Approximately 1 in 6 men will be diagnosed with this disease in their lifetime
-  34% of all new cancer diagnoses are in men aged 75 years and over
-  About 80% of men aged 80 years or over will have some prostate cancer cells
-  32 men die every day in the UK from prostate cancer
-  Men in their 90s are more likely to die of prostate cancer
-  More than 95% of men diagnosed with prostate cancer will survive for a year or more
-  Almost 78% of men in England survive after being diagnosed with prostate cancer for 10 or more years

(Data from Cancer Research UK 2016-2018)

What are the risk factors for prostate cancer?

• *Being male*

• *Age*

One of the biggest and established risk factors for prostate cancer is age. It is most common after the age of 50, and the risk increases with age. Although the risk of getting prostate cancer under 50 is very low, it is not impossible. Most cases are diagnosed in men over 65

• *Race*

Men of African-Caribbean descent are at much higher risk of prostate cancer than Caucasian men. The exact reason for this is not well understood.

- The lifetime risk of getting prostate cancer is approximately 1:4 in this group
- A black man's risk of prostate cancer increases over the age of 45
- They are more likely to get aggressive disease
- The cancer is more likely to be advanced at the time of diagnosis
- They are more likely to die of prostate cancer

• *Family History*

Men who have relatives with a prostate cancer diagnosis are at higher risk of the disease. Inherited factors are thought to be the reason for prostate cancer in 5-9% of cases. The risk of prostate cancer is not higher if an adoptive parent has prostate cancer, supporting the link with genes.

- The risk is 2.1 - 2.4 times higher in men whose father has/ had prostate cancer
- The risk is 2.9 – 3.3 times higher in men whose brother has/ had the disease
- The risk is 1.9 times higher in men with a second degree relative (grandfather, uncle, or nephew) with the disease
- Those with 2 or more relatives with prostate cancer are almost 4 times as likely to develop the disease
- Prostate cancer is 19-24% higher in men whose mother has/had breast cancer but this link is not true if a sister is affected
- The risk of prostate cancer is considered up to 5 times higher in men who have a BRCA2 gene mutation
- Prostate cancer risk is higher in men with Lynch Syndrome (Hereditary Non-Polyposis Colorectal Cancer, HNPCC) compared to the general population

(Data from Cancer Research UK 2016-2018)

- **Lifestyle**

Although there is no direct link or evidence for this, having a sedentary lifestyle and lack of physical activity is linked to being overweight. This is linked to obesity, which may increase the risk of prostate cancer

- **Obesity (BMI of 30 or more)**

Men who are obese have a higher risk of prostate cancer compared to people with normal weight. Obesity is also linked to getting more aggressive prostate cancer

- **Diet**

A diet that is high in red meat and high in fat may be linked to an increased risk of prostate cancer, particularly one that contains large amounts of animal fat

- **Testosterone**

Although urologists do not believe taking testosterone supplements is linked to an increased risk of prostate cancer, there is a theoretical risk of fuelling latent cancer. Current recommendations are to exclude prostate cancer before initiating testosterone supplementation in men over the age of 40



Common Questions

Can I prevent prostate cancer?

It is not known if there are any preventable risk factors for prostate cancer

Is my risk of prostate cancer higher if I masturbate?

Masturbation has no proven link with prostate cancer

Does having sex affect my risk of prostate cancer?

Sexual activity is not linked to your chances of getting prostate cancer

Does drinking alcohol increase my risk of prostate cancer?

There is no direct link between alcohol and prostate cancer. However, drinking excessive amounts of alcohol may increase weight, and being overweight is linked with more aggressive forms of prostate cancer

Does having a vasectomy increase my risk of prostate cancer?

There is no evidence of a link between vasectomy and prostate cancer

Is smoking associated with prostate cancer?

There is a link between smoking and an increased risk of prostate cancer but there is no concrete evidence for this

Does having sexually transmitted infections increase my risk of prostate cancer?

There is no evidence of a link between diseases like gonorrhoea or chlamydia and prostate cancer

Is there a link between calcium and prostate cancer?

There is some evidence that diets high in calcium may increase the risk of prostate cancer, but it is important to have enough calcium for bone health. If you are in any doubt about your calcium levels, it may be useful to talk to your doctor or a registered dietician

Does finasteride increase the risk of getting prostate cancer?

There is some evidence that the risk of getting prostate cancer is lower in men who are taking finasteride. However, taking finasteride is associated with a slight increase in more aggressive cancers



Dr Adams, working at the London Hospital in 1853 first described prostate cancer during a histological examination. At that time, ironically, given how common prostate cancer is now, he described it as “a very rare disease”.

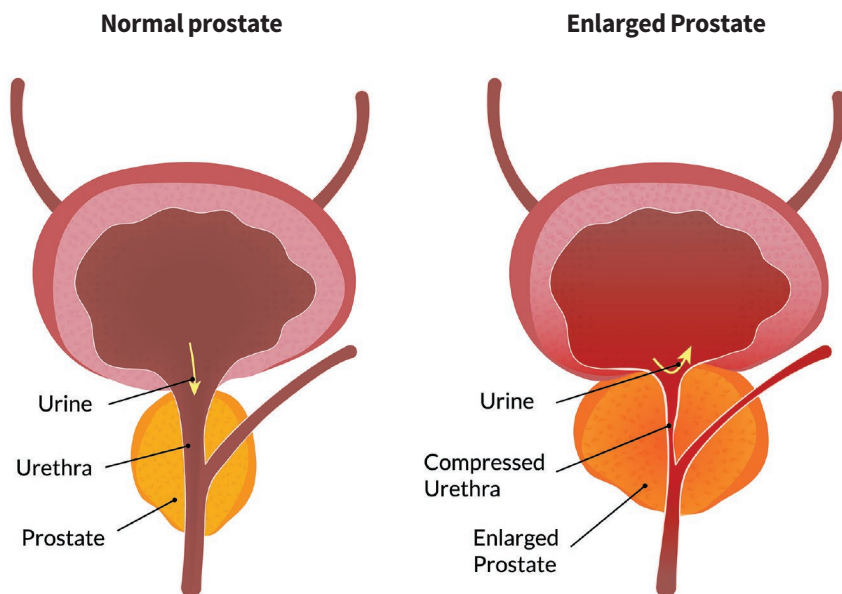
THE SIGNS & SYMPTOMS

3

One of the most common phrases I hear when I tell men they have prostate cancer is “But, I have no symptoms”. If you have just been diagnosed with this disease, you may be asking yourself the same thing – there were no warning signs or symptoms, so how can this be true?

Unfortunately, early prostate cancer does not often cause any problems, which is why it is called a **‘Silent Killer’**. Most prostate cancers start on the outer part of the prostate, which means it must grow quite large before it causes any problems.

As men age, the central part of the prostate, which surrounds the urethra grows. This is called benign prostatic enlargement or hyperplasia (BPH). As it grows, it narrows the urethra, and this is what gives the common symptoms as men get older. This growth is usually benign but can rarely be due to cancer. BPH does not turn into cancer.



Some common symptoms of BPH and occasionally due to cancer include the following:

- Frequent visits to the toilet (frequency)
- Getting up frequently at night (nocturia)
- Difficulty starting to pass urine (hesitancy)
- Decreased force/ weak urinary stream or one that is thin or dribbling
- Urinary stream is not continuous and instead stop and start (intermittency)
- Having to strain to pass urine
- Sense of not completely emptying your bladder
- Need to rush when passing urine (urgency)
- Starting to leak urine before making it to the toilet (urge incontinence)
- Difficulty in having an erection or ejaculating
- Blood in the urine or semen
- Not passing urine altogether (retention)

Other symptoms of prostate cancer can be because of the cancer advancing to nearby areas or spreading further afield, potentially resulting in some of the following symptoms:

- Pain in the back, hips, or pelvis – often because of spread to the bones
- Unexplained weight loss
- Feeling tired
- Kidney failure



Common Questions

If I have no symptoms, how will I know if I have prostate cancer?

Check to see if you are at a higher chance of getting cancer by looking at your risk factors. If you are worried, speak to your doctor about having a prostate examination and a PSA blood test, which is discussed in more detail in the next chapter

Why does prostate cancer not usually cause symptoms?

The prostate has different regions or zones. The following zones make up the prostate, starting from outside to the inside:

- **Peripheral zone** – this is the back of the gland near the back passage (rectum) and most prostate cancers occur in this area (70-80% of all cancers). As this is furthest away from the inside, the cancer needs to grow quite large before it causes symptoms. This is the area that a doctor feels when they examine the prostate with a finger
- **Central Zone** – this surrounds the ejaculatory ducts and only approximately 5% of cancers start here
- **Transition zone** – this surrounds the urethra and grows throughout life. BPH occurs in this area. As this develops, it can narrow the urethra, thereby causing the classical symptoms of ageing men. However, only about 20% of cancers occur here, which explains why symptoms are more common with benign enlargement than with cancer

If I have a large prostate, should I have symptoms?

A larger prostate does not mean you will have bothersome symptoms. Some men with huge prostates have few, if any, symptoms

Can I have BPH and prostate cancer at the same time?

Yes, it is possible for a man to have an enlarged prostate due to benign enlargement as well as cancer



As the prostate is located deep in the pelvis, cancer can go undetected for months or years. Even then, the symptoms may be confused with an enlarged prostate and so prostate cancer is dubbed a 'silent killer'.

What is PSA?

PSA stands for Prostate Specific Antigen. PSA is a protein and is made by both normal prostate cells and by prostate cancer cells. Consequently, it is normal to have some PSA in the blood if you have a prostate. The blood test measures the amount of PSA in the blood.

As men get older, the prostate can grow due to benign enlargement causing the PSA to rise as a normal part of the ageing process.

What is a normal PSA level?

There is no such thing as a normal PSA level. PSA levels vary all the time for many reasons. If you had your PSA checked twice in a day, it is unlikely to be identical on both occasions.

What causes PSA levels to rise?

In general, the higher the PSA result, the higher the chance of having prostate cancer. However, many factors other than cancer can cause PSA levels to be high. This means that a high PSA level does not necessarily mean you have cancer.

- ***An enlarged prostate***

As PSA is made by both normal and cancer cells in the prostate, an enlarged prostate gland will mean there are more normal cells, resulting in more 'normal' PSA being made. Therefore, the larger the size of the prostate, the higher the PSA level that is 'allowed'. Some doctors may use a calculation based on the volume of your prostate to tell you what your predicted PSA level is. PSA levels above the predicted PSA may be of concern requiring further investigations

- ***Prostatitis***

This is an infection or inflammation of the prostate gland. This is not cancer. Prostatitis can cause the prostate gland to swell, often causing symptoms but it can be a silent inflammatory process in some cases. Either way, it frequently causes the PSA levels to rise

- **Urinary Tract infection**

An infection of the urinary tract can cause a temporary spike in the PSA levels, and they can remain high for up to 3 months after an infection. It is best not to have your PSA checked at the time of an infection or for 3 months after an infection. Doing so, can lead to confusion as to whether the rise is significant or not

- **Age**

PSA levels may increase with age. This is usually due to benign growth of the prostate, leading to more normal prostate cells producing more PSA

Many doctors use age reference values:

Age (years)	PSA Level (micrograms/ litre)
Under 40	Clinical Judgement
40-49	2.5
50-59	3.5
60-69	4.5
70-79	6.5
Over 80	Clinical Judgement

(Prostate Cancer Risk Management Programme)

- **Prostate injury**

Injury from a fall or accident can result in a temporary spike in PSA levels

- **Urological procedures**

Insertion of any type of catheter or instrument (cystoscopy) through the penis, past the prostate and into the bladder can result in a temporary increase in PSA levels, for up to 3 months

- **Prostate biopsy**

Having a biopsy of the prostate can also result in an increase in PSA levels for up to 6 weeks

- **Digital rectal examination**

An examination of the prostate can lead to a temporary increase in PSA levels caused by rubbing the prostate and subsequent leakage of PSA into the bloodstream

- **Ejaculation**

An ejaculation within the previous 48 hours can result in a slight rise in PSA levels

- **Vigorous exercise**

Exercise, especially cycling, can lead to rubbing of the prostate and leakage of PSA causing a temporary increase in PSA for up to 48 hours

- **Catheter**

Having a catheter in the urethra can result in high PSA levels

- **Anal sex**

Any prostatic stimulation, including a massage or anal sex can cause PSA levels to rise for up to one week

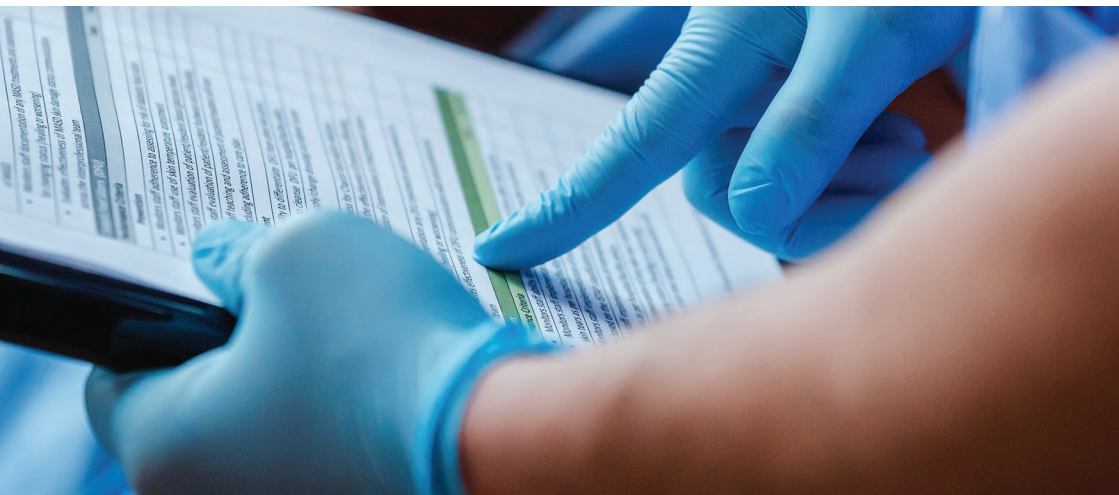
Can anything decrease PSA levels?

In general, the higher the PSA result, the higher the chance of having prostate cancer. However, many factors other than cancer can cause PSA levels to be high. This means that a high PSA level does not necessarily mean you have cancer.

- Some medications such as Dutasteride or Finasteride can artificially halve the PSA level after 3 or 6 months (respectively), of taking it regularly
- Any prostate cancer treatment will lower the PSA levels
- Some operations such as TURP involve removing some of the prostate tissue, thereby reducing PSA levels after a few months – these are not necessarily operations for cancer but for BPH

How is PSA checked?

This test can be done at a GP's surgery or at a hospital. A sample of blood will be taken and sent to the laboratory within 16 hours of having it taken. You can eat and drink before a PSA blood test as this does not require you to fast. You should get the result within a couple of weeks.





Practicalities of a PSA Test

It is best not to have a PSA blood test in the following circumstances to improve the accuracy:

- Digital rectal examination of the prostate
- Ejaculation within 48 hours
- Vigorous exercise or cycling for 48 hours
- Not receive anal sex or prostate massage for 1 week before
- Prostate or bladder surgery for 3 months
- Urine or prostate infection for 3 months
- Prostate biopsies for 6 weeks to 3 months

How accurate is the PSA test?

The PSA level is not a reliable sign of whether a man has prostate cancer. There is also a lot of conflicting advice about PSA testing. It is therefore used as a guide. Here are some considerations about PSA testing:

- 15% of men with a 'normal' or acceptable PSA level will have prostate cancer
- 1 in 50 men with a 'normal' or acceptable PSA level may have a fast-growing cancer
- 3 in 4 men with a high PSA level for their age may not have cancer
- A single PSA level is not reliable on its own unless it is very high
- A PSA level of > 10 is associated with a 50% chance of having cancer
- A PSA level of > 40 indicates a high chance that there is cancer, and it may have spread
- When the PSA level is > 100, there is a very high chance that there may be spread of the cancer to other parts of the body

Can anything improve the accuracy of PSA levels in the borderline range?

Given the uncertainty of PSA levels, especially when it is only borderline high, the following can be used to help decide if further tests are required:

• **PSA Velocity**

This is a measure of how fast PSA levels are rising. PSA levels tend to rise faster in men with cancer. An increase of 0.75 or more a year is considered a possible indicator of cancer

- **PSA Doubling Time**

This is a measure of how fast the PSA levels double over time. If the PSA level doubles from 2 to 4 over 3-6 months, then this may prompt investigations or treatment

- **PSA density**

This is PSA level divided by prostate volume. The volume is calculated by an ultrasound or an MRI scan of the prostate. A PSA density of 0.15 or higher means that there is a higher suspicion of prostate cancer. This value can be of use in men with larger prostate glands

- **Free PSA**

PSA can attach itself to other proteins in the blood and circulate as bound PSA or circulate free without any attachments. The percentage of free PSA tends to be lower in men who have cancer than in men who do not

- **PSA Age Reference Values**

A borderline high PSA level in a man who is in his 50s is more worrying than the same level in a man who is in his 80s





At my annual blood pressure check at the surgery, I requested my PSA. My GP tried to talk me out of it. My PSA at the age of 62 years came back at 103. I am so glad I insisted on it being done. I had no symptoms but having the PSA saved my life.

Should I have a PSA blood test?

Any man in England over the age of 50 years can have a PSA blood test, but it is important to know the advantages and disadvantages of having it done.

Advantages of a PSA blood test?

- Having a PSA test can pick up prostate cancer before any symptoms develop and at an early stage
- It may be reassuring if your PSA level is 'normal'

Disadvantages of a PSA blood test?

- A high PSA level may cause a lot of anxiety
- Even if the PSA level is acceptable for your age, you may still have cancer. This gives false reassurance
- A high PSA may lead to a many other possibly invasive tests such as biopsies
- A borderline high PSA may need serial tests over a period causing anxiety and uncertainty
- This can diagnose some slow-growing cancers that may never have caused you problems
- You may choose to have treatment you do not need for prostate cancer due to the worry of having a cancer diagnosis - this is known as 'over-diagnosis'

What happens if my PSA level is high?

If your PSA level is borderline high, then your doctor may repeat it after a few months. If it is still high, then you will be referred to a urology department for further investigations.

If your PSA level is very high, you will be referred to a urology department without a repeat blood test.

Common Questions

Do kidney stones affect PSA levels?

Kidney stones without any infection do not affect PSA levels

Can PSA levels distinguish between 'good' cancers and more aggressive cancers?

No

How do I decide if I need a PSA blood test?

Think about your own risk of cancer, the consequences of a cancer diagnosis and treatment, and living with potential side effects of the treatment

My GP will not check my PSA. What should I do?

Men over 50 are entitled to a PSA blood test. However, if you are not in very good health, it may not benefit you to get a PSA blood test done as the diagnosis and treatment may not help you live longer. Ask your GP to explain why they are not recommending a PSA blood test

Why is there no national screening programme for prostate cancer?

The aim of a screening programme is to pick up cancers in men who do not yet have any symptoms and reduce the chance of dying from the disease. The uncertainties and disadvantages of a PSA blood test mean that we do not yet have sophisticated tools to screen men

Is screening recommended for anyone?

If you are at a higher risk of prostate cancer due to your age (over 50), ethnicity (African-Caribbean origin) or family history (one or more close relatives have prostate cancer), then speak to your GP about getting a baseline PSA blood test

At what age should I get my PSA done if my father has prostate cancer?

Ask your GP for a PSA blood test once you are 45

What is the use of PSA after a cancer diagnosis?

The PSA blood test is used to monitor response to treatment after a cancer diagnosis



Before PSA, blood levels of prostatic acid phosphatase (PAP) were used to detect prostate cancer. However, early cases of cancer went undetected as PAP was high in men who already had spread to the bones.

Most men start their prostate journey with their GP because they have some symptoms that are a bother, or because they have requested a prostate blood test, called PSA. This is discussed in more detail in the previous chapter.

Most GPs will consider the following when discussing tests for prostate cancer as there is no single, simple test to detect this disease:

- The index of suspicion
- Signs and symptoms that may be present
- Age
- General health and other illnesses you may have
- 10-year life expectancy

Based on the above and the PSA blood test, the GP may refer you to a urologist in a nearby hospital on an urgent suspected cancer pathway. This may be called a UCR (Urgent Cancer Referral) or 2WW (2 Week Wait). In England, this means that you will be seen as quickly as possible and usually within 2 weeks. Just because you have been referred to a urologist on this urgent pathway, does not necessarily mean that you have cancer.

The urologist may call you for a first consultation, so it is important that your GP has your up-to-date contact details to put on the referral form.

Tests that help make a diagnosis include the following:

- History - enquiry about your signs and symptoms and general health
- An evaluation of your risk factors, such as family history or ethnicity
- Digital rectal examination (DRE) - a test that examines the prostate
- MRI scan
- Prostate biopsies

Digital Rectal Examination (DRE)

- You will need to drop your trousers and underwear but not remove them altogether
- You will need to lie on your left side on an examination table
- Your knees need to be brought up to your chest as much as possible – this may be difficult if you have knee problems, but the doctor will work around this

- The clinician will insert a gloved finger with gel for lubrication on it, into the back passage
- The procedure does not take long and is uncomfortable but not usually painful
- It is normal to feel anxious and/or embarrassed
- A DRE does not damage the prostate
- After the examination, you can get dressed
- You can continue with normal activities after this examination
- The person doing the DRE will discuss the result with you, which can be:
 - Normal – this does not exclude cancer as a DRE does not feel the entire prostate
 - Smooth and enlarged as in BPH
 - Tender, soft or boggy - this may be a sign of an infection or prostatitis
 - Hard and/or knobbly - this may indicate cancer

MRI Scan

An MRI (Magnetic Resonance Imaging) scan uses strong magnetic fields to create detailed images of the prostate. Previously MRI scans were used to assess how far prostate cancer had spread. Now, advances in MRI technology mean that it is standard practice to usually have an MRI scan before having a prostate biopsy. This is because MRI scans, especially using technology called multiparametric MRI scans, give detailed and accurate images of the prostate and can avoid the need for invasive biopsies in a significant proportion of men.

Multiparametric MRI

This is different from standard MRI scans and uses 3 key sequences:

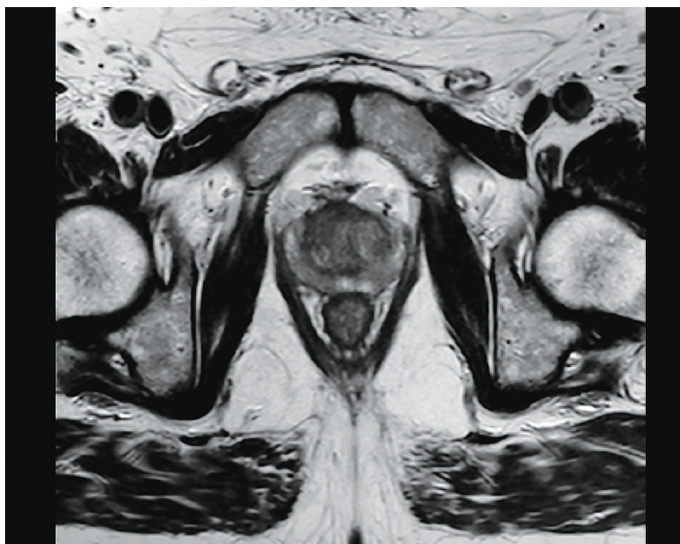
T1 and T2-weighted images – this is the workhorse of a prostate MRI scan and defines the anatomy

Diffusion-weighted images – this measures the movement of water molecules in the prostate

Dynamic Contrast-enhanced images – these sequences are obtained rapidly before, during and after injection of contrast and looks at blood flow in the prostate

What else can an MRI be used for?

As well as using an MRI scan to decide whether a prostate biopsy is required, it can also be used to help guide the biopsy needle, monitor the progress of cancer on an active surveillance pathway, or to assess the extent of cancer just outside the prostate (staging).



MRI scan

When is an MRI not recommended?

Multiparametric MRI scans of the prostate are not routinely recommended in men who are not going to be able to have radical treatment such as surgery or radiotherapy, according to NICE.

How do I prepare for an MRI?

As MRI scanners use strong magnets, they can affect any metal inside the body. If you have any medical implants or devices, try to bring any information on the exact type and manufacturer to your appointments. This will help determine if your device is MRI safe. It is also important that you tell your doctor if you have any of the following:

- Pacemaker or implantable defibrillator used to treat irregular heart rhythms
- Metal clips, pins, plates, screws, rods – often used for treatment of fractures. Most metal objects used in orthopaedic surgery do not pose a risk, but the X-ray staff will need to know
- Cochlear implant used for deafness and is implanted inside the ear
- Nerve stimulator used to treat nerve pain
- Brain aneurysm clips

- Dental fillings and bridges
- Metallic fragments in the eyes – commonly seen in men who work with metal or have had a shrapnel injury. These are very important to check for as they can move or heat up and can cause blindness

If you are unsure about any metal fragments, the X-ray staff may request an X-ray to check before the MRI scan is done.

- Some people may suffer with claustrophobia when having an MRI scan. If you are likely to feel closed in like this, please let the X-ray staff know in advance. Your GP may also prescribe you some medication to help you relax
- You should take all your normal medication before an MRI scan
- Let the X-ray staff know if you have a medication patch on your skin. This may have metal in it or can heat up and cause a burn
- You can eat and drink as normal. No special diet is recommended

What happens before an MRI scan?

- You may need to change into a hospital gown
- All metal objects will need to be removed including watches, piercings, dentures, hearing aids, glasses, phones, and belts
- Empty your pockets of coins and keys
- Remove any credit cards as the scanner can erase the information on the magnetic strip
- Try to empty your bowels before the scan to improve the image quality
- You will also be asked to empty your bladder
- You will have a small tube called a cannula inserted into the back of your hand or into a vein in your arm. This will allow contrast to be injected into the vein. This will usually be gadolinium

What happens during an MRI scan?

- The scanner itself is a large tube surrounded by a circular magnet
- You will need to lie on your back on the scan table and stay very still so as not to create blurry images
- The radiographer will leave the room
- The table will slide into the tunnel
- The scan makes loud tapping noises – you may be given earplugs or headphones to wear. You can ask to listen to music if that helps you



- Some people find it easier to keep their eyes closed during the scan
- You will get an injection of contrast through the cannula
- The scan usually takes about 45 minutes

What happens after an MRI scan?

- The cannula will be removed
- You can eat and drink as normal
- You can drive after an MRI scan
- You can resume normal activities immediately

What are the possible results of an MRI Scan of the Prostate?

The pictures generated from an MRI scan will be looked at by a radiologist, who is an expert at X-ray images. Most scans are reported using the PI-RADS (Prostate Imaging - Reporting and Data System) or Likert scoring systems.

- **PI-RADS 1/ Likert score 1**

Very low – highly unlikely that you have significant prostate cancer or most likely not cancer

- **PI-RADS 2/ Likert score 2**

Low – unlikely that you have prostate cancer that needs treatment

- **PI-RADS 3/ Likert score 3**

Intermediate – this is a borderline result and means that the risk of clinically significant cancer is equivocal or undetermined

- **PI-RADS 4/ Likert score 4**

High – high chance that there is cancer that needs treatment

- **PI-RADS 5/ Likert score 5**

Very high or very suspicious and it is highly likely that there is cancer

What happens after an MRI Scan?

What happens after the scan will depend on the likelihood of there being cancer. When the report suggests a PI-RADS or Likert score 1 or 2, then you are unlikely to need a biopsy.

With a PI-RADS 3 or Likert score 3, you may need a period of monitoring of your PSA, or a biopsy, depending on the index of suspicion for cancer.

If the PI-RADS or Likert score is 4 or 5, then you are likely to need a prostate biopsy.

Prostate Biopsies

Having a prostate biopsy is the logical next step after an abnormal MRI scan. This involves using thin needles to take small samples out of the prostate gland, which are then analysed under a microscope. Usually, an ultrasound is used to guide the needles to the area of concern. There are two main types of biopsies that you may be offered:

- Transrectal ultrasound (TRUS) guided
- Transperineal biopsy

Regardless of the method of taking biopsies, there are some issues with prostate biopsies:

- Missing the cancer – this gives a false negative
- Needing another biopsy if the first one missed picking up a cancer
- Picking up an insignificant cancer, leading to potential overtreatment

Why do I need a prostate biopsy?

- A suspicious area has been picked up on the MRI scan
- Your PSA is high and/ or your prostate feels obviously cancerous, but you have not had an MRI
- You are known to have cancer, which is being monitored and the clinical team want to know if it has progressed or changed in any way
- You will not usually get an automatic prostate biopsy on the basis of PSA alone

Transrectal ultrasound (TRUS) guided

This is one way to remove prostate tissue using thin needles, with an ultrasound probe in the back passage to identify the correct area.

How do I prepare for a TRUS biopsy?

- This is usually done as an out-patient, which means that you will not need to stay in hospital overnight
- Before the procedure, you will need to sign a consent form to give the clinician permission to do the biopsy. You will usually be given a copy of the form you have signed
- You will be checked to see if you have an infection, and if you do, the procedure will be postponed

- If you are taking any drugs that thin the blood, such as warfarin or apixaban, you will be advised to temporarily stop it before the biopsy. You will also be advised when to stop taking the drug. For example, you may be asked to stop clopidogrel 7 days before the biopsy
- You can continue low dose aspirin (75mg)
- Bring a list of your normal medications or a prescription

What happens before a TRUS biopsy?

- You can eat and drink normally before a biopsy
- You may be advised to avoid copious amounts of dairy products (milk/ cheese) before the biopsy
- You can drive yourself to have a biopsy
- If you are on warfarin, your INR level will be checked to ensure it is safe to have the biopsy
- You will be given antibiotics a couple of hours before the biopsy to ensure the levels in your body are highest for optimum protection
- You will be asked to change into a hospital gown and remove your lower clothes
- You will need to provide a urine sample to ensure there is no evidence of infection

What happens during a TRUS biopsy?

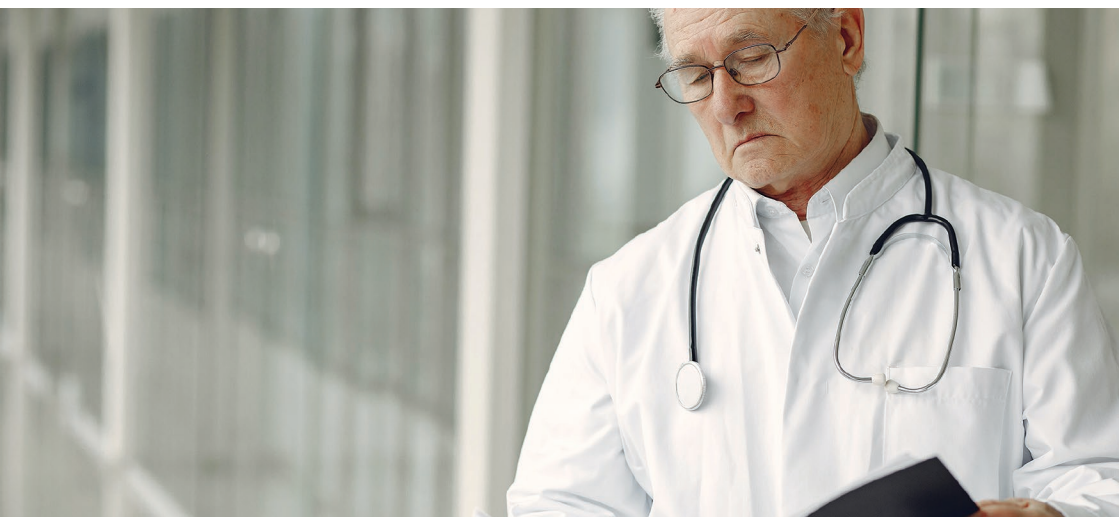
- You will need to lie on your left side like the DRE position
- Your knees must be pulled up to your chest
- A small ultrasound probe is lubricated with gel and inserted into your back passage to show a picture of your prostate on a screen
- The clinician will inject local anaesthetic – this may sting or give the sensation that you need to pass urine
- A long, thin needle is then pushed under vision into the prostate
- Standard TRUS biopsies involve taking 6 samples from each side of the prostate (left and right)
- When the biopsy is taken there is a loud ‘clicking’ sound like a gun firing
- The procedure is generally well tolerated and only takes a few minutes

What happens after a TRUS biopsy?

- After the biopsy, you can eat and drink normally
- The hospital will check that you are emptying your bladder
- Drink plenty of fluids for 24 hours after the biopsy
- You may be given some antibiotics to take for a day or so after the biopsy
- You can drive normally
- You will be advised when to restart any medication that was interrupted before the biopsy, such as clopidogrel

What are the possible side effects of a TRUS biopsy?

- Infection
 - If you feel hot and cold, feverish or have a temperature, you may need to see a doctor or present to an emergency department if you have sepsis
- Blood in the urine for a few weeks
- Blood in the semen for a few weeks
- Blood in the stool for a few weeks
- Retention - unable to pass urine normally requiring a catheter to be inserted. This is usually temporary
- Pain in the back passage for a few days after the biopsy – soaking in a warm bath may help ease discomfort in the back passage



Transperineal Biopsy

This type of biopsy is done by inserting needles through the skin between the testicles and back passage. This is called the perineum. The reasons for having this type of biopsy include:

- Your TRUS biopsy did not pick up cancer, but your doctor thinks you may still have it
- You have an abnormal area in a part of the prostate that cannot be reached by TRUS biopsy
- Your prostate gland is very large

How do I prepare for a transperineal biopsy?

- It can be done under local anaesthetic or a general anaesthetic, which is when you are asleep. This will usually be discussed in clinic with the doctor
- If it is done under local anaesthetic, you can eat and drink normally before the biopsy
- If you have it under a general anaesthetic, you will be advised when to stop food and drink before the biopsy – this is usually 6 hours before
- Take all your normal medications on the day of the biopsy, except any blood thinning drugs – you will be advised when to stop these
- You can continue low dose aspirin (75mg)
- Bring a list of your normal medications or a prescription
- You will need to sign a consent form to give the doctor permission to do the biopsy. You will be given a copy of your form for your records

What happens before a transperineal biopsy?

- You will need to provide a urine sample to check you do not have an infection
- If you have an infection, your biopsy is unlikely to go ahead
- You will be given some antibiotics before the biopsy
- You will need to change into a hospital gown and remove your lower clothes

What happens during a transperineal biopsy?

- You will be asked to lie on your back
- Your legs will be placed in supportive stirrups and your knees bent
- The doctor may use tape to move your scrotum out of the way

- An ultrasound probe covered in gel will be inserted into your back passage to visualise the prostate on a screen
- The perineal skin will be cleaned using an antiseptic solution
- An injection of local anaesthetic will be injected into the perineal skin to numb the area. This may sting for a few seconds, but this will soon wear off
- A long, thin needle will be inserted through the skin into the prostate using the ultrasound as a guide
- If you still feel pain at this point, let the doctor know as you may need more anaesthetic
- A total of 24 - 36 biopsies might be taken
- This process takes 20-30 minutes

What happens after a transperineal biopsy?

- You will be asked to pass urine after the biopsy. The nursing team will check that you are emptying your bladder and that you do not need a catheter
- You will be asked to get dressed
- Some people feel lightheaded after the biopsy, so you may need to take things slowly
- You may need to wear a pad in your underwear as the skin punctures may bleed or leak
- If you have the biopsy under local anaesthetic, you should be able to drive yourself home the same day
- If you have had a general anaesthetic, you may need to be in hospital for a few hours until you have fully recovered
- You will not be able to drive yourself home if you have had a general anaesthetic. You will need someone to pick you up
- You will be advised when to restart any medication that was stopped before the biopsy
- You may need further antibiotics – if so, please complete the course
- Drink plenty of non-alcoholic fluids for at least 24 hours after a biopsy
- Do not receive anal sex for at least 1 week after the biopsy

What are the side effects of a transperineal biopsy?

- A transperineal biopsy has a much lower risk of infection than a TRUS biopsy
- You may notice blood in the urine – this is usually mild
- Blood in the semen can last up to 3 months after a transperineal biopsy
- Some men experience temporary erectile dysfunction for up to 2 months
- Bruising of the perineal skin is usually mild and settles by itself after a few days
- Occasionally the swelling in the prostate makes it difficult to pass urine. Stopping altogether is called acute urinary retention. This may require a temporary catheter

Are there any other diagnostic tests?

- **PCA3** – this is a urine test. PCA3 is a protein made by normal prostate cells but there is more of it if a man has prostate cancer. This is still a research tool and helps decide if a biopsy is needed. This is not widely used on the NHS
- **Prostate Health Index (PHI)** – this combines 3 blood tests (total PSA, free PSA and proPSA) and is likely to be most useful in men where the total PSA result is only mildly elevated. This is an indicator of whether a man should proceed to biopsy. It is not widely available on the NHS
- **4KScore** – this is a new blood test and it is not available in the NHS. It is used to assess the risk of aggressive prostate cancer using 4 prostate specific biomarkers

Prostate Biopsy Results

Biopsy samples are sent to a laboratory where they are analysed under a microscope by a histopathologist. This process can take up to 2 - 3 weeks and the results can be:

- **Positive** – there is cancer
- **Negative** – there is no cancer
- **Suspicious** – the cells contain some abnormal areas but there is no cancer. These can be called PIN or ASAP
 - **PIN** – Prostatic Intraepithelial Neoplasia – abnormal changes in the prostate cells but no cancer. If there is high grade PIN, you may need a repeat biopsy in future
 - **ASAP** - Atypical Small Acinar Proliferation – there are some cells that seem to be cancerous but there is not enough to be certain there is cancer. A repeat biopsy is indicated at some point in the future

Gleason Grade

If the prostate biopsy is positive and cancer has been detected, then the histopathologist will analyse the samples to see how aggressive they are. The cancer cells are compared to normal, healthy prostate cells under a microscope. If the cancer cells look very different and are significantly abnormal compared to healthy cells, then they are considered aggressive.

If the cancer cells are relatively like healthy prostate cells, then they are considered less aggressive. This helps determine the Gleason Grade or Gleason Score, which is the most common system used to grade prostate cancer.

Each sample of prostate cancer cells is given a grade from 3 to 5 based on the aggressiveness, as described above. The higher the grade, the more aggressive the cancer and the more likely the cancer is to spread outside the prostate.

The overall Gleason score is worked out by adding 2 Gleason grades. The first number is the most common grade seen in all the samples. The second is the next most common grade in the rest of the samples.

For example, if the most common Gleason grade is 4, and the second most common grade is 5, then the overall Gleason score is $4+5=9$. This combined score is also classified as the Grade Group:

- **Gleason score $3+3=6$ or Grade Group 1** - *these cancers tend to be very slow growing*
- **Gleason score 7 ($3+4$) or Grade Group 2**
- **Gleason score 7 ($4+3$) or Grade Group 3**
- **Gleason score 8 ($4+4$ or $3+5$ or $5+3$) or Grade Group 4**
- **Gleason score 9 or 10 ($4+5$ or $5+4$ or $5+5$) or Grade Group 5** - *these cancers grow quickly*



My Gleason score was 7, which means moderately aggressive, with 6 being mild, and 8-10 highly aggressive. What I didn't realise was $4+3$ is worse than $3+4$, even though the score is the same.

Common Questions

Does a DRE affect urination?

It is normal to feel the urge to pass urine during a DRE. Some men also experience leakage of a few drops of urine – this is nothing to worry about, and results from pressure on the prostate

Does an MRI scan use radiation?

An MRI scan is painless, safe and does not involve any radiation

Does the contrast injection cause any side effects?

It is common to feel a flushing sensation when the contrast is injected, but this is usually only for a minute or two. Some people can feel sick, get a rash, experience headaches or dizziness. These tend to be mild and only last for a short time

How do I know which type of biopsy I should have?

This will depend on the location of the suspicious area on the MRI, the size of your prostate gland and the overall risk of infection. Your urologist will advise you on what is the best technique to get the best results

When can I have anal sex after a TRUS and biopsy?

You should wait for 2 weeks after a biopsy before you receive anal sex, to allow the biopsy tracts to heal

Will the blood in my semen after a biopsy affect my partner?

Blood in the semen after a biopsy can last for many months and will not cause any harm to your partner

How long does it take to get the results after a biopsy?

It can take up to 2-3 weeks

What is a false – negative prostate biopsy?

Sometimes no cancer is picked up on the biopsy samples. This can be because the area with cancer has not been sampled, leading to a false-negative result

What if my prostate biopsy result is negative?

If the suspicion of cancer is low (PSA density less than 0.15; PSA velocity less than 0.75 per year; no family history) then you will be discharged back to your GP. Your doctor may be advised to repeat the PSA every few years. Your GP should be given guidelines on when you need to be sent back to a urologist for further investigations



The day I got my diagnosis

To be perfectly honest the actual order of events is a bit of a blur.

There was so much to take in. So many emotions. So many unanswered questions.

My Surgeon sat down with me and my wife and told me that my PSA was high.

It was well above the upper limit.

I had done some reading. Everything talked about a PSA above 10 being bad.

No-one told you what a PSA above 50 meant.

In my head I immediately felt this must be at least five times as bad.

I started crying. I don't really remember what I was told after that.

I cried because I thought I would never see my children graduate.

Never see my daughter married.

Never see my grandchildren.

At this moment I had not had my prostate biopsies, nor had I had any scans to look for spread, so, it was understandable (in retrospect) why I was told nothing about likely outcomes (or perhaps I was - who knows, as I said, it was all a bit like listening underwater).

Strange emotions were going through me.

The overwhelming one was shame. I was ashamed that I had this disease which might mean I couldn't look after my family, after all, that was my job.

I was ashamed to tell my friends.

My wife had different emotions.

She was angry. Angry with me. In her mind the PSA was high because I had delayed seeing the doctor.

Over the next few weeks, I bottled everything up inside. It was my problem.

I would deal with it.

Then, one day, a friend asked me what was wrong. This was not the first time someone had asked. I would smile and say, 'nothing is wrong' and they would ask no more.

This time was different.

He physically pinned me to the wall and told me he would not let me go until I told him what was wrong.

I cried, we hugged and I told him everything.

From that moment on things were easier.

I talked about things to my close friends. I joked about the treatment and the complications.

It's good to share

Mark (age 54 at diagnosis)

People react very differently to being told they have cancer. There is no right or wrong way. Your feelings are normal for you. Many men feel overwhelmed and out of control. Others feel angry and naturally most men worry about the future. This chapter focuses on practical tips when you have been told that you have cancer.

Emotional and Wellbeing Tips

- Talking to others
 - At a chosen suitable moment, consider discussing your diagnosis with loved ones. You can support each other, and your diagnosis may affect them as much as it does you. They, too, will be worried, angry, and upset
 - Express your feelings – cry if you need to. There is no shame
- Do not blame yourself for your cancer diagnosis – anyone can get prostate cancer and there is nothing you could have done to avoid it
- Ask for help if you need it. One example is to ask a loved one, friend or neighbour to drive you to your appointments so that you do not need to worry about driving, parking or being late because you cannot find a space to park in
- Ask for help around the house with shopping, cooking, or cleaning if you need it
- Keep doing things you like to do, such as having an afternoon nap, a walk with nature, listening to music. It is key to do things that make you feel better and more relaxed
- Keep a journal or a diary of how you feel – it is sometimes easier to see things when they are written down
- Try to stay active – it is important to be physically fit for your cancer treatments
- Eat healthy, well-balanced foods. Eat regularly
- Avoid drinking excessive alcohol to cope with what has happened
- Find out what makes you relax. This could be meditation, breathing exercises or listening to music
- Do not be afraid to ask for more formal help through your GP with talking therapies, such as counselling. Some people find talking to a stranger in a one-to-one confidential and safe environment incredibly helpful
- There may be local prostate cancer support groups, which help patients and their partners. The hospital team will know about any such groups in your local area

Practical Tips

- Take someone with you to appointments
 - You may wish to take a partner, friend or relative to your clinic appointments, and especially at the one where you will receive your test results. This may help you remember what was discussed
- Get the facts
 - Once you have overcome the initial shock of the diagnosis, it is important to obtain as much information about your cancer as possible. Use reliable and trustworthy sources. Your specialist or CNS will signpost you
- Ask the doctor for copies of clinic letters that are sent to your GP
- Keep a file of all your letters
- You may wish to take a list of questions that you want to ask with you to your appointments
- Consider keeping a calendar or diary as a way of monitoring your appointments with various professionals – it can be hard to keep track. Alternatively, this could be on a smartphone

Financial Tips

- If you want to return to work, then ask your specialist how feasible this is. This will depend on what treatment you need.
 - You may need to discuss your diagnosis with your workplace or boss, especially if you need time off for appointments and treatments
 - You may not be able to return to your normal work - perhaps your job needs to change temporarily
 - You may need to change or reduce your working hours
- Some people may come across as unsupportive or it may feel like they are avoiding you. Often, this is not the case. Most people mean well but don't know what to say to you
- **Help with finances**
 - You may be able to get help with travel costs associated with hospital appointments and this depends on where you live. Talk to your specialist or CNS about this
 - You may be entitled to some benefits or grants. Most hospitals will have a Macmillan Cancer Centre and they can provide you with further guidance about this



- People being treated for cancer can get an exemption certificate that allows them to get free prescriptions for all medicines
 - Your doctor will give you an application form for a medical exemption certificate
 - This entitles you to free NHS prescriptions
 - It is valid for 5 years or until your 60th birthday and then needs to be renewed

Who do I need to tell?

- Existing Insurance policies – most insurance companies like to know if your health has changed since you took out your insurance. If you do not tell them, it may affect any claims you make
- You should tell your life insurance even if it predates your cancer diagnosis
- You do not need to tell the DVLA unless your condition or treatments affect your driving. However, it is useful to update your car insurance provider in case you are subsequently involved in a vehicle accident
- It may be harder or more expensive to take out life or health insurance
- You do not need to tell your credit card company about your cancer diagnosis if you can still make your payments
- You cannot take out your state pension early but if you have a private pension, then you may be able to retire early depending on the rules
- You do not need to tell your existing mortgage provider unless you are struggling with your repayments
- If you are struggling with energy costs due to your cancer diagnosis or treatments, talk to your energy provider to explore different tariffs, access to grants or getting your name on a list of people who need extra support
- Consider updating your affairs and writing a will

Support for partners

Although prostate cancer affects men, a cancer diagnosis can also affect partners and families. It is natural for loved ones to feel fear, worry, anxiety and feel out of control. Here are some of the tips that have worked for other partners:

- Recognise your own emotions as natural. You may want to speak to someone about what you are going through – this may be friends who are impartial or perhaps those going through a similar situation. Would you benefit from counselling?
- You may feel empowered if you learn more about prostate cancer from reliable sources

- Try to attend appointments with your partner
- Yoga, meditation, or a walk may help manage stress
- Eat regular and balanced meals – encourage your partner with cancer to do the same
- Take regular exercise – this may help combat tiredness, which accumulates if your partner with cancer is getting up frequently at night to go to the bathroom
- Try practical measures to help your partner, such as booking aisle seats in aeroplanes or sitting in the back row of a cinema. This helps with bathroom visits
- Try to be open about how you feel and keep the lines of communication open to encourage your partner with cancer to talk
- It may help to write your emotions in a diary
- Being diagnosed with prostate cancer and the subsequent side effects of treatments can result in changes to your sex life. Although your partner may have difficulty achieving an erection, you may feel less desirable, unsatisfied, angry, and even guilty for feeling such emotions. Try to be open with your partner and explore alternative ways of being intimate
- You do not have to do everything. Ask family, friends, or neighbours for help



THE ENDLESS WAITING

I am in the midst of the personal and family crisis that hits when, from the start the threat of cancer looms. At the start, when only slight indications and issues are known, the wait is full of hope, full of a strange reality that resonates as this could just be a false indication, a strange anomaly, a mistake!

Waiting is then not difficult or indeed stressful. The wait to the next stage is slow and sleepy and there is no hurry. All is quite, quite, normal.

Gradually you move on to the next stage of diagnosis. Things are becoming a little clearer and yet more worrying, but still, initially there is a sense that enough is surely known to be able to move to treating something?

Waiting has just become a bit more tense, a bit more questioning,

But, it seems, more has to be known to ascertain greater clarity, and so the wait must go on. How far has this demon called cancer travelled? The following scans are weeks apart, followed by further weeks of waiting for results or consultations.

Why cannot someone speak to me, why must everything be so formal, be so slow? Why must I wait?

Nevertheless, the days and weeks in between the waits are free, they are full of some good days, normal days, and yet nights beginning to be full of doubt and anxiety. The waiting becomes the norm, and strangely everything is fine.

An odd reality fills in the cracks, the waits.

Things are not so bad after all. Or are they?

So, the wait goes on still further, as now further tests need to seek even more clarity.

All that you want now is for a full picture to be painted. All you want now is for something to be done, for treatment to be started, for a start and for an end. Your patience is now being stretched, but you feel helpless.

By this time not just friends and family are aware of what is going on, but the extended wait has allowed your acquaintances and the wider community to hear your news. People are kind and gentle and caring and that brings its own warmth and comfort, but all within an endless unknowing.

And so, the wait goes on. However, the time in between waits shortens and suddenly professional health care people are talking to me and wanting me to talk to them. Yet at the same time the anxiousness increases for you and everyone around you because you sense the waiting is coming to an end maybe, and what will happen then?

This is the worst time. This is the worst of the waits so far; the tummy is in knots and your head is never at rest....and that feeling is quite normal. That is the thing to remember. Others have been here before you and these feelings of anxiousness are normal, and the best way to address them is to talk to whosoever will listen.

But be assured, whilst you wait others are busy. They are busy on yours and many others behalf, and eventually the wait is over. And at last the diagnostics are complete, you will have a very short wait for an outcome.

You know what you now face, and very quickly you know how it is to be dealt with and rectified.

The waiting period is incredibly short now and full of information and options. It has now become a time when it is your decisions which are the ones that count and you move into action quickly, because you wish to wait no longer.

The final wait is the lead up to your treatment date. It should be filled with information, with communication and with preparation.

Always remember, waiting can provoke impatience, stress and anxiety, and in turn, anxiety also makes waits seem longer than they actually are, and stress makes us feel worse than we actually are or should be.

“It is so hard to be patient in these times of confusion and worry, but we all must try, and keep faith in those who have our best interests at the heart of everything they do.”

In Japan, there is a concept known as “ma”. It refers to a gap, a pause, a wait or a negative space between things. “Ma” recognises that negativity and tries to fill it with positive thoughts or at least not let negative spells absorb us. It is tricky to be patient, but it is better for our being if we can, even at these difficult moments.

Chris Wood

What is Staging?

Staging refers to how far the cancer has spread. This is usually determined by various scans and the need for which scans depends on:

- Your PSA results at the start
- The type of cancer you have been diagnosed with - also called the Gleason Grade

How is the stage recorded?

The stage of your cancer is commonly classified using the TNM system, which is as follows:

T – how far the cancer has spread near the prostate

N – tells you whether the cancer has spread to the lymph nodes

M – this is about whether the cancer has spread to other parts of the body

Clinical Staging

Sometimes the extent of the cancer is determined by the urologists' physical examination of the prostate.

- T1a – the cancer cannot be felt but is found incidentally after an operation to the prostate (usually for BPH) in less than 5% of the tissue sent to the laboratory
- T1b – the cancer cannot be felt but has been found incidentally after a prostate operation in more than 5% of the tissue sent
- T1c – the cancer cannot be felt but has been detected after a needle biopsy
- T2 – the cancer is only in the prostate but can be felt when the prostate is examined, in:
 - T2a – one half or less than one side of the prostate
 - T2b – more than one half of one side of the prostate but not both sides
 - T2c – cancer can be felt on both sides of the prostate
- T3 – the cancer has spread outside the prostate to one seminal vesicle (T3a) or both seminal vesicles (T3b)
- T4 – the cancer has spread to tissues near the prostate, such as rectum or bladder

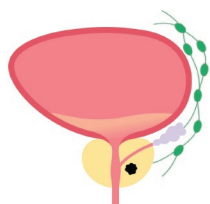
The Number Staging System

Stage I – the cancer is small and only within the prostate

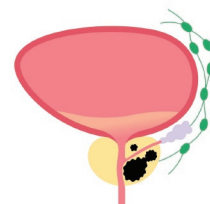
Stage II – cancer may be in one or both sides of the prostate but not outside the prostate

Stage III – the cancer has spread beyond the prostate to nearby lymph nodes or seminal vesicles

Stage IV – the cancer has spread to other places such as bones – this is called metastatic cancer



Stage I



Stage II



Stage III



Stage IV

The Cambridge Prognostic Group Classification (CPG)

• CPG 1

- Gleason score 6 and PSA < 10 and Stage T1 – T2

• CPG 2

- Gleason score 3+4=7 or PSA 10-20 and Stage T1 -T2

• CPG 3

- Gleason score 3+4=7 and PSA 10-20 and Stage T1-T2
- Gleason score 4+3=7 and Stage T1 – T2

• CPG 4 – any ONE of the following:

- Gleason score 8
- PSA > 20
- Stage T3

• CPG 5 – TWO or more of the following:

- PSA > 20
- Stage T3 or T4
- Gleason score 8 or 9 or 10

Where can prostate cancer spread to?

Any cancer can spread to any other part of the body, near or far, but there are some common patterns. Prostate cancer commonly spreads to bones and lymph nodes.

Localised or organ confined prostate cancer – refers to cancer that is with the prostate.

Locally advanced prostate cancer – the cancer starts to spread just outside the prostate such as through the capsule (outer skin of the prostate); seminal vesicles; lymph nodes in the pelvis; bladder or rectum (back passage).

Advanced or metastatic prostate cancer – this is when the cancer has spread much further afield either through the blood or lymph system.

What staging scans are used for prostate cancer?

MRI scan – discussed in chapter 5

CT scan

Bone scan

PET scan



CT Scan

A CT (computerised tomography) scan uses X-rays to produce thin slices of the body, like slices of a loaf of bread. These are put together by a computer to build up a 3-dimensional picture of the inside of the body. The main reason for using CT scans in prostate cancer is to see if the cancer has spread to other parts of the body such as lymph nodes or other organs. A CT scan is not as good as an MRI scan to visualise the prostate itself.

How do I prepare for a CT scan?

CT scans do not require much preparation.

- You may be asked to stop eating and drinking 4 hours before the procedure
- You can drink clear fluids in this time as it keeps you well hydrated prior to having contrast (dye). Clear fluids include see through drinks such as tea, black coffee, or ginger ale. Alcohol is not included in this list
- Continue taking all your normal medications. Let the X-ray staff know if you are taking metformin
- The X-ray staff will check that you have had blood tests for your kidney function within the previous 3 months. This is because your kidneys need to be working well to get rid of the contrast that will be given for the scan. If this is not available, they will take blood urgently before starting the scan
- Please let the X-ray staff know if you are allergic to shellfish or iodine

What happens before a CT scan?

- Upon arrival, you may be asked to change into a hospital gown
- Jewellery and other metal objects such as belts will need to be removed as they interfere with the images
- You will have a small tube called a cannula placed into a vein in your arm or hand
- If you are not allergic to the contrast (dye), then this will be injected into the cannula. This allows certain areas to be seen clearer

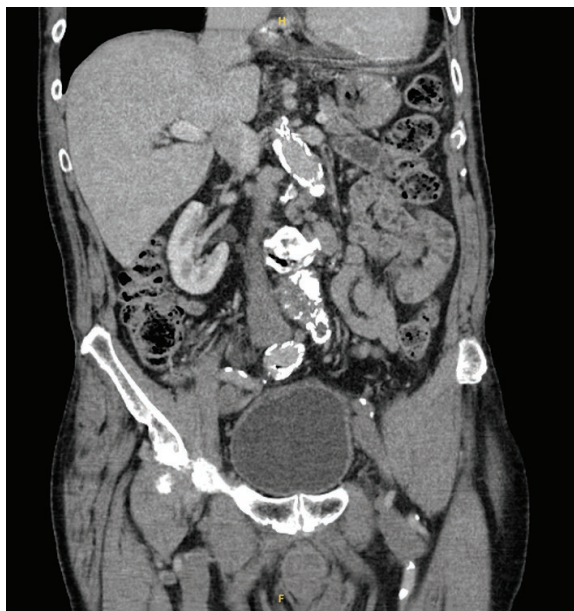
What happens during a CT scan?

- The CT scan machine is shaped like a large doughnut, and it is unusual to feel claustrophobic in a CT scanner
- You will be asked to lie on your back on a table and this table moves in and out of the scanner

- The radiographer will leave the scan room, but they can see you through the window at all times and you can speak to them through the intercom
- You will need to stay still otherwise the images can be blurry
- The machine can be quite loud as it rotates around you
- You may be asked to hold your breath for about 10 seconds
- A CT scan usually takes 15-30 minutes

What happens after a CT scan?

- You can eat and drink as normal
- You may be asked to stay in the department for about half an hour if you have had contrast injected to make sure that you feel well before you leave
- Your cannula will be removed
- You can drive home and return to work
- You should aim to drink at least half a litre of fluids after the scan to stay hydrated (due to the contrast)



CT scan

Common Questions

What is the difference between a CT scan and a CAT scan?

They are both the same thing. CT stands for computerised tomography. CAT stands for computerised axial tomography

Is a CT scan radioactive?

Yes, a CT scan exposes you to some radiation, but they are generally safe and only use a small amount. The dose for a CT scan of the abdomen and pelvis is equal to about 7 years of background radiation if done with and without contrast

Is the contrast medium safe?

Contrast medium contains iodine. It can make you feel flushed or leave a metallic taste in the mouth when injected. Occasionally, people have a minor and rarely, a more serious allergic reaction. Please keep a note of this if you find that you are allergic to the contrast so that it is not given again

Is a CT scan painful?

A CT scan is painless, non-invasive, fast and simple



The first clinical CT scan was used in 1971 in Atkinson Morley Hospital, Wimbledon to scan a patient's brain. The scanner was invented by Sir Godfrey Hounsfield, a biomedical engineer and the first doctor to use it was Dr James Ambrose.

Bone Scan

This is a nuclear medicine scan that uses a radioactive drug injected into a vein and shows abnormalities in your bones. In the context of prostate cancer, a bone scan is done to see if the cancer has spread to the bones.

How do I prepare for a Bone Scan?

- You will not need to restrict your diet in any way before a bone scan. You can eat and drink normally
- If you are taking any over the counter medications containing bismuth, please let the X-ray staff know. These drugs, such as Pepto-Bismol, are used for stomach upsets
- If you have had a barium scan within 4 days, please let the X-ray staff know as both bismuth and barium can interfere with the radioactive drugs given for bone scans

What happens before a Bone Scan?

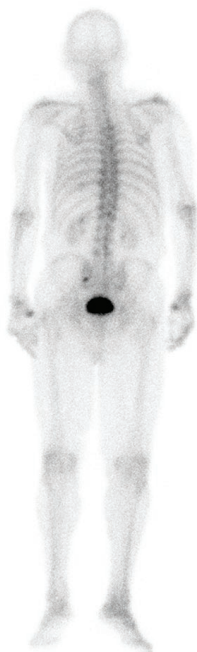
- You will be asked to arrive up to 4 hours before the actual scan
- You will have a small cannula inserted into a vein in your arm or the back of your hand
- A radioactive liquid called a tracer will be injected through the cannula
- Whilst the drug travels through the body, you will need to wait 2-3 hours
- You can ask to leave the department whilst you are waiting
- During this time, you should drink at least 1.5 litres of water to flush the drug around the body
- If you need to use the toilet, you may be asked to use separate toilets from others due to the radioactive drug that has been injected
- You will be asked to remove any metal items such as belts or jewellery. You will also need to remove glasses

What happens during a Bone Scan?

- The scan can be done with you either sitting, standing, or lying down on your back
- The gamma camera will be brought quite close to you to take the images. The camera will not touch you
- You will be asked to remain still so that the images are not blurred

What happens after a Bone Scan?

- You should be able to go home after the bone scan
- The cannula in your hand or arm will be removed
- Drink plenty of fluids for the next 24 hours after a bone scan
- You can drive yourself after a bone scan
- Keep an arm's length away from children or pregnant women for the rest of the day to avoid exposing them to radiation



Bone scan



Damaged areas in bones collect the injected tracer and appear dark on bone scans. These areas are called 'hot spots' but do not necessarily mean the cancer has spread. Sometimes arthritis or fractures can look like hot spots.



Common Questions

How long does a bone scan take?

Whilst the scan itself takes up to an hour, you will be at the hospital for several hours

What else can a bone scan show?

A bone scan is sensitive to any changes in bone turnover and so can diagnose fractures, arthritis, Paget's disease, or infection of the bones (osteomyelitis)

Is a bone scan painful?

A bone scan does not cause any pain. It may be uncomfortable to be in the same position for up to an hour

Can I travel abroad after a bone scan?

You may still have minute doses of radiation in your body after the scan, which can be picked up by sensitive airport radiation monitors. Take your bone scan appointment letter with you to show the staff that any activation is due to the drug that has been injected

Are there any risks to having a bone scan?

You may get a small bruise where the cannula was placed, but this will settle. Some of the radioactive drug may leak outside the vein, causing some irritation, swelling or pain. This, too, will settle

What is the radiation dose I will receive from a bone scan?

The radiation dose is very small and about the same as a CT scan. It is similar to the amount that you get from the environment in 2 years. This is not considered dangerous

How long does the radiation dose last in my body?

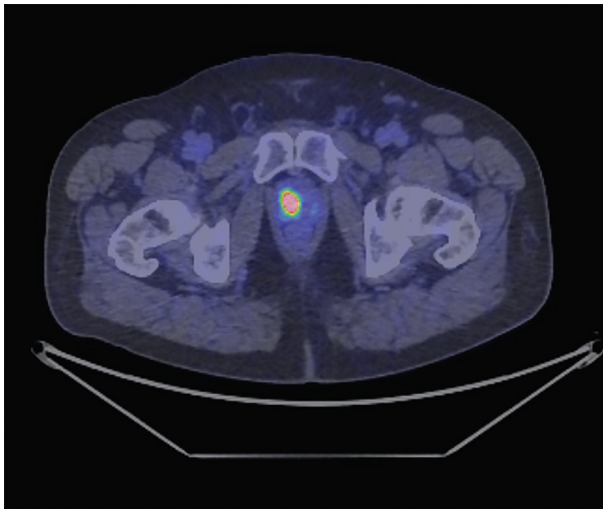
The radioactive drug is removed from the body through urine and will be mostly gone within 24 - 48 hours



Bone scans might be indicated if your PSA level is > 10; your Gleason score is > 7; if you have bone pain or if your cancer is locally advanced.

PET Scan

PET is short for Positron Emission Tomography and is a type of scan that uses a radioactive drug and is combined with a CT scan to obtain 3-dimensional images of the whole body. The images analyse areas where the radioactive drug builds up and helps to localise prostate cancer cells. It is a painless scan.



PET scan

Why do I need to have a PET scan?

- To accurately assess how far the cancer has spread
- In men who have a PSA reading that is rising after initial treatment to determine if the cancer has come back, and if so, where

What are the different types of PET scans?

- Choline C-11 PET uses a special radioactive drug called Choline C-11
- PSMA PET is prostate-specific membrane antigen PET, which is a relatively new technique. It uses PSMA that is linked to a radioactive drug called Fluorine-18

Preparing for a PET Scan

- These scans are usually done as an out-patient and therefore you will not need to stay in hospital overnight

- You will need to stop eating 4 - 6 hours before your appointment time
- It is important to arrive on time as the radioactive drugs only work for a short period of time
- You can drink as much water as you want
- Please take all your routine medicines unless you have been told otherwise
- Please let the X-ray staff know if you are claustrophobic

When you arrive in the X-ray Department

- Staff will confirm your name and hospital number
- Occasionally the X-ray staff may need to do some blood tests, such as your kidney function tests

What happens before a PET scan?

- You may be asked to change into a hospital gown
- You will need to remove any jewellery or metal objects such as belts
- A small intravenous cannula will be placed into a vein in the arm or hand
- The radioactive drug will be injected into the cannula
- You will be asked to wait 1-2 hours whilst the drug spreads through the body

What happens during a PET Scan?

- The machine is shaped like a doughnut, and you will need to lie on your back on the exam table. The radiographer will position you correctly
- The X-ray staff will leave the scan room, but they will be able to see you. You can still talk to them through the intercom
- You will be asked to remain still or perhaps even hold your breath for a few seconds
- The couch will move in and out of the machine
- The actual scan takes 30 - 40 minutes to take the relevant images

What happens after a PET Scan?

- You may be asked to wait a few minutes on the exam table whilst the X-ray staff check the images
- The radiographer will remove the cannula after the scan
- You will be able to go home the same day

Common Questions

Is the procedure safe?

Yes, a PET scan is safe. You will be exposed to a small amount of radiation, which is equal to about 8 years of average background radiation exposure

Is a PET scan painful?

A PET scan is not painful but can be uncomfortable as you need to remain still. Some people can feel stiff during or after a PET scan

Are there any side effects?

You may get some bruising where the cannula was inserted into your arm or hand. There is a slight chance of the radioactive drug leaking outside the vein, which may cause a little irritation. It is rare to get an allergic reaction to the injected drug. If you experience any swelling, difficulty breathing or weakness, please tell the X-ray staff immediately

Is the radiation dose safe?

The dose you receive from the drug is very small and goes away very quickly

Can I travel abroad after a PET scan?

Yes, you can travel abroad after a PET scan, but the small amount of radiation may be picked up by the ultra-sensitive scanners at the airport. It may be worth taking your PET scan appointment letter with you

Do I need to avoid anything after a PET scan?

You should avoid close contact (at least an arm's length away) with babies or pregnant women for 6 hours after the scan due to the radiation

How long does it take to get a result?

The images will be analysed by an X-ray consultant (radiologist) who is an expert in PET scans and the report will be sent to your consultant



Cancer stage is important. It's about where the cancer is in your body and how much cancer there is. This is key to getting the correct treatment.

What is an MDT meeting?

An MDT (Multidisciplinary Team Meeting) is a meeting of a group of professionals from several clinical disciplines who meet regularly to make decisions regarding treatment of individual patients with cancer.

The MDT places patient's needs and wellbeing at the centre of their care, to ensure that they offer the highest quality treatment pathway, based on the best evidence available. Essentially MDTs are key decision-making forums for the management of patients with cancer, with the emphasis on collaboration between different specialties.

Several things are considered to arrive at the best treatment plan:

- The type of cancer
- The size of cancer
- Whether your cancer has spread
- Your general health and medical background
- National guidelines for managing your cancer

Why are MDTs in place?

MDT meetings are considered the 'gold standard' in the UK for patients with cancer. These meetings started in the 1990s to improve the quality of cancer care and to improve survival rates in the UK. They were also established to ensure that care is consistent with the best available evidence. The main aims are:

- Timely diagnosis and treatment of patients with cancer
- Patient care is evidence-based
- Continuity of care
- Information exchange and regular communication between all those involved in looking after patients with cancer
- Streamline resources for best management
- Opportunity for learning and education to keep doctors up to date with best practice
- Identify patients who are eligible for research in clinical trials

Who attends the MDT meeting?

The Urology MDT has a set of core members. Other specialists may join the team from time to time, but the typical team includes:

- A Lead Clinician, who is a Urology Consultant, who takes responsibility for the Urology Cancer services at the hospital
- Urology Consultants who specialise in performing the type of operations that may be needed to treat your condition and have specialist knowledge of your condition and the various treatments
- Medical Oncologist who is a doctor who specialises in treating cancer with chemotherapy and other cancer drugs. Oncologists also advise on further testing, monitoring, or drug treatments
- Clinical Oncologist who is a doctor who specialises in treating cancer with radiotherapy, chemotherapy and other cancer drugs
- Histopathologists who are a team of doctors who examine tissue samples (biopsies) under the microscope and help reach a diagnosis
- Radiologists are a team of doctors who review and report images such as X-rays, Ultrasound, MRI, CT and PET scans to help make a diagnosis. They also advise on further tests that may be required or best scans for monitoring cancers
- MDT Coordinators provide administrative support and prepare information for the weekly meetings. They also chase outstanding results to prevent any diagnostic or treatment delays
- Research Nurses / Trial Coordinators are trained nurses who may contact you and offer you the choice to enter a clinical trial, if appropriate
- Urology Navigators provide a link between patients and clinical staff ensuring that each patient's cancer journey is as streamlined as possible. The navigator will also offer holistic needs assessments (HNA) to all cancer patients
- Urology Clinical Nurse Specialist (CNS)/ Keyworker. Your CNS is also known as your Keyworker and takes a key role in coordinating your care with different members of the MDT, ensuring you have the advice and support you require. You will usually meet your CNS at the time of your cancer diagnosis
- The extended team comprises of:
 - Palliative care specialists
 - Chaplains
 - Clinical Psychologists
 - Stoma Nurses

How often does the meeting take place?

An MDT meeting usually takes place once a week. You will need to check with your local hospital what day they hold their urology MDT.

How are patients discussed at the MDT meeting?

Any member of the urology team can refer patients for discussion at the MDT meeting. It is usually the urologist or oncologist who will give the MDT coordinator names of patients they wish to discuss. However, occasionally radiologists may wish to discuss specific scans or the pathologist, certain biopsy results. The MDT agenda is prepared by the coordinator and there is usually a cut-off day and time.

Other teams may also request urology MDT discussion and need to complete an MDT referral form and the specific question they would like an answer to, as well as a list of any scans that they would like to be reviewed in the meeting.

What gets discussed at the MDT?

- All new cancer diagnoses
- All histology (biopsy samples) whether they are cancer or benign
- All scans related to a cancer diagnosis

It is important to understand that results cannot be given to patients until they have been reviewed and ratified at the MDT meeting.

How soon will my results be discussed?

Once your results are ready, they will be discussed in the next MDT meeting. This could mean having to wait up to a week depending on the day the results are made available and when the meeting is held.

What happens after the MDT meeting?

Depending on the results of the MDT you will be informed of the outcome of the meeting in one of the following ways:

- Face to face in clinic
- Over the telephone
- In writing

Documentation will also be sent to your GP informing them of the outcome of the meeting. You will usually be sent copies of letters written about your care to other professionals. You will also be informed of local and national support services about your condition.

How soon after the MDT will I get my results?

This will vary from a day to a few weeks.

Can patients attend the MDT meetings?

Many other patients are discussed in the MDT meetings and therefore patients cannot attend for reasons of confidentiality. If you have a specific view that you would like the meeting to discuss, your clinical team / CNS can represent your views.



Common Questions

How are patients referred to an MDT?

Patients can be referred to the MDT at any time, either at the initial stages of diagnosis, when there are significant changes, or when further options for treatment need to be considered

Are MDT decisions documented?

The MDT coordinator usually documents each patient's decision on a computer system. A summary of each outcome is then circulated to members of the MDT. Each consultant may keep a record of the discussion in the patient's notes so that they can have access to the discussion when the patient is reviewed, rather than have just the outcome decision available

Who do I contact if I have not heard back from the hospital?

You should contact the specialist nurse or your consultant's secretary for an update on your care plan. They may not give you results over the telephone. It is unlikely that your GP will have heard anything if you have not



I was relieved and reassured that so many clinicians with such expertise were meeting to discuss my case. But do the timings have to be so rigid? I had a scan on Tuesday but the MDT was held on Wednesday afternoon so I waited over a week for the scan to be discussed. The frustrations and anguish of the wait to us patients, be it a day or a fortnight, should never be underestimated.

What is Active Surveillance?

Many men with low-risk prostate cancer that has not spread are unlikely to come to any harm or decrease their life expectancy from their cancer. Such men may never need any treatment for their cancer as it is so slow growing or 'lazy'. Men with low-risk cancer have the same survival benefit as those men treated with surgery or radiotherapy.

Early treatment can lead to unnecessary side effects affecting quality of life. Instead, doctors may recommend monitoring or observation for men with these types of cancers and defer any treatment should the cancer gets worse.

Active surveillance is therefore a strategy of regular, close monitoring of the cancer. The intent is still 'cure'.

Who can be on active surveillance?

Some of the characteristics that help decide if active surveillance is a reasonable alternative to active treatment options (surgery, radiotherapy or brachytherapy) include:

- The cancer is small
- The cancer is confined to the prostate
- PSA blood test is usually less than 15
- The Gleason score is 6 or 7, suggesting that it is slow growing
- If the cancer starts to grow, then you can still have an operation or radiation with the aim of cure
- There are no symptoms
- You can do your everyday activities without concern about the cancer spreading
- You understand the benefits and risks of your decision to be monitored

What other factors are considered for active surveillance?

• Age

Younger men tend to live longer with their cancers, and therefore there is a higher chance that the cancer may progress. Although young men can be managed with active surveillance, they require long term follow-up

- **General health**

You need to be fit enough to have other curative treatments such as radiotherapy or surgery, should it be required in future

- **Family history**

There may be a higher risk of prostate cancer getting worse in men with a strong family history. However, such men can still safely be offered active surveillance

- **Personal preference**

- **Ethnicity**

Are there any risks of active surveillance?

- The main risk of active surveillance is that the cancer can grow significantly or perhaps spread. This may limit treatment options in future. This is rare if you are monitored closely by a specialist
- Some men feel anxious about having a cancer diagnosis but not being treated. Other men feel anxious about the uncertainty of their cancer status
- Frequent medical appointments

What happens with active surveillance?

On an active surveillance pathway, you can expect regular appointments to monitor the cancer. There is no internationally agreed time frame. At each visit, tests may include:

- An examination of the prostate to assess any possible change or growth of the cancer
- PSA blood test
- MRI scan of the prostate - if there is concern about any clinical change or rising PSA, then the cancer may be reassessed with an MRI scan
- Repeat prostate biopsy - this will usually only be done if the MRI scan suggests a change in the cancer characteristics. The biopsy will justify if it is safe to stay on active surveillance or move to active treatment options



Low-risk prostate cancer is usually slow growing. The chances of the cancer spreading or dying from the cancer 10 years after diagnosis is very low.

Example of an active surveillance protocol

Year 1:	PSA every 3-4 months
At 12 months:	Examination of prostate
12-18 months:	Consider an MRI scan
Year 2:	PSA every 6 months and an examination of the prostate every 12 months
	This should continue every year until active surveillance ends

(NICE: 2019)

When does active surveillance stop?

- At any time when a man starts to feel uncomfortable about living with cancer
- Patient preference to move to active treatments such as surgery or radiotherapy
- Change in other health conditions limiting lifestyle, quality of life or life expectancy
- Moving to watchful waiting
- A repeat biopsy shows that the cancer grade has changed
- An MRI scan shows that the cancer volume has increased



Common Questions

What is the difference between active surveillance and watchful waiting?

Both approaches have emerged over the past few decades after extensive medical research, showing that men with early, localised prostate cancer can delay treatment, especially older men. The key focus with active surveillance is deferring treatment until it is necessary but with the intent still on cure. Watchful waiting tends to be observation for older men, who have limited life expectancy. The focus is on quality of life

Is active surveillance the same as no treatment?

No, it is an observation strategy to treat the cancer if it is required in future

Is there an internationally agreed protocol for active surveillance?

No. There are guidelines that have been developed by many groups with areas of agreement such as, active surveillance should be the preferred strategy for men with low-risk prostate cancer. However, there is no agreement on eligibility or follow up strategy

Is there anyone who cannot be on active surveillance?

Men who have locally advanced prostate cancer or CPG 4/5
(see staging chapter)



Initially I thought all cancers require chemotherapy. It took a while for me to get my head around not having any actual treatment. The potential side effects of the various treatments weighed heavily in my decision process. Today life continues - 3 years after the dreaded diagnosis. Now I laugh; I relax; but I watch my cancer closely.

What is watchful waiting?

Watchful waiting is a form of monitoring prostate cancer without treating it. It is often used for men who are older and who have cancer that is slow growing and unlikely to alter their natural survival.

It can also be used for men who are too sick with other life-threatening illnesses to benefit from treatment. The monitoring is less aggressive and less intense than with active surveillance protocols. The aims are to maintain quality of life and to watch the cancer until it spreads to other places or if it starts to cause symptoms. At that point, patients may opt to start treatment to slow the growth of the cancer.

Why is watchful waiting used?

- To avoid risks of treatments and any side effects
- Avoid repeated tests and biopsies
- To control the cancer but not necessarily cure it

Who can be on watchful waiting?

- Men who do not want treatment or have no symptoms from their cancer
- Men who cannot have treatment
- Men with other life-threatening medical illnesses
- Cancer that is localised
- Men with slow-growing cancers
- In men with cancer that has spread after discussion – usually to avoid further detrimental side effects of treatments

What does watchful waiting involve?

- Regular monitoring, either with a urologist or your GP, usually of your PSA blood test and your symptoms – this may be every 6-12 months
- Fewer tests than active surveillance
- You may need scans to assess if the cancer has spread but most men do not require invasive biopsies



What symptoms should I look out for?

- Bone Pain
- Difficulty passing urine
- Deteriorating kidney function
- Blood in your urine
- New back pain – either central or located to one side
- New swelling in your legs, especially if only one leg is involved

If you develop any of the above, your doctor may start you on hormone therapy to help control the cancer. Without any signs that the cancer is getting worse, you can stay on monitoring.



My urologist told me that I was more likely to die with the cancer than of it. That was enough to get on with life rather than suffer with side effects of unnecessary treatment.



What is a radical prostatectomy?

Surgery for your prostate cancer is called a radical prostatectomy. Prostatectomy means removal of the prostate and radical means it is removed whole along with its adjacent organs, the seminal vesicles. If you imagine the prostate being Mickey Mouse's head, then the seminal vesicles are his ears. The whole lot is removed, hence the term radical.

What are the different types of surgery?

Removing the prostate and seminal vesicles (radical prostatectomy) can be done by the surgeon in a number of ways:

- Open radical prostatectomy - using his hands only and a cut in the belly
- Laparoscopic radical prostatectomy - using keyhole instruments (look like chopsticks with instruments on the ends to cut and grasp, etc)
- Robot-assisted radical prostatectomy - using a surgical robot

Please note that robot-assisted means that the surgeon is still in control and moving the robot to do the operation, and the robot is not doing the operation on its own. It's a bit like playing golf with a fancy new driver. It's still you that hits the ball 300 yards not the driver itself.

Which is best - open, laparoscopic, or robot-assisted?

That depends on the surgeon. Some surgeons are very skilled in open or laparoscopic surgeries and can get great outcomes for patients using those techniques. However, most surgeons are not, and the robot-assisted technique works best as it helps the surgeon to operate better. The robot gives the surgeon more precision and better vision, and if a surgeon can both feel and see better, then this is generally going to result in better outcomes for their patients.

But, going back to the golf analogy, if you give me a fancy driver, I will still hit the ball less far and less straight than if you give Tiger Woods a wooden club. Hence, the optimal situation is to have the best equipment in the hands of the best expert. That is, a highly skilled robotic surgeon.

Who can have a radical prostatectomy?

- Men who have prostate cancer confined to the prostate or just outside into the seminal vesicles, or possibly into local lymph nodes can generally be well treated with surgery. Men whose disease has spread to the bones or distant areas generally won't get any benefit from removing the prostate as the disease has already moved elsewhere
- Men also have to be fit enough for the surgery, which is a 3-4-hour operation, so those with medical conditions, especially of the heart and/or lungs, may not be appropriate for it
- Finally, most men with prostate cancer confined to the prostate do not have a risk of death for 10 years or so, and thus the operation is trying to stop men dying in decades to come, not years to come. Hence, those with other medical problems that limit their life expectancy to less than 10 years may not need curative treatment of their prostate cancer, which can often then be simply watched or treated with hormones to keep it at bay

What is nerve-sparing radical prostatectomy?

The nerves that supply the penis and thus give a man his erections run along the sides of the prostate. Most of these nerves are at the 5 and 7 o'clock positions if you imagine the prostate sitting straight and a clock face around it. Hence, depending on where the cancer is in your prostate, will depend on whether the nerves can be spared on one side or both sides. The more nerves that are spared, the better the chance of regaining erections spontaneously. Even if the nerves cannot be spared and the erections do not recover spontaneously, there are many ways of giving men artificial erections - with tablets like Viagra™, vacuum pumps, or small injections. Most men can have erections strong enough for sex after this operation.

What are the advantages of surgery?

- Surgery is generally a one-off procedure and the vast majority of men (more than 19 in 20) go home 1 or 2 days after the operation. It removes the cancerous prostate and thus there is a feeling of closure for most patients
- It also means the PSA blood test should drop to very low levels (less than 0.2) and if it does not, then this suggests the cancer is still there. If it drops to this very low level and then climbs in the future, this suggests the cancer is back. Hence, PSA monitoring after surgery is very accurate in checking for recurrence. With radiotherapy and other treatments where the prostate is still left in place, the PSA measurements afterwards are less reliable at spotting recurrence



- Radiotherapy is given over weeks and thus is not a one-off procedure
- Surgery has an equal chance of cure to radiotherapy for most men with prostate cancer confined to the prostate, and a better chance of cure than novel focal treatments like HIFU and cryotherapy. Hence, for most, fit men it represents the number one treatment choice

What are the side effects of surgery?

It is a big operation and, like with all big operations, there are serious risks like injuring other organs which can be life-threatening. However, in an experienced and skilled surgeon's hands these risks are very low, far less than 1%.

- What is far more likely is the side-effect of impotence. If nerve-sparing is possible, this risk is lessened but by no means zero. Whether a man will be able to have spontaneous erections after surgery and whether these will be strong enough for sex is largely an unknown, and all men should be prepared for a worsening in their erections after surgery. Having a skilled surgeon again lessens the risk but any surgeon that tells a patient he will have strong erections without needing tablets is over-selling the surgery. It is important for men to be prepared for the impact on their erections, but to know that we can help with tablets, vacuum pumps, or injections such that most men can have sex afterwards. It is also important to remember that erections can also recover with time, so even if there are no spontaneous erections six months after surgery, they may be back later. On average, it can take up to 2 years after surgery for the erections to recover on their own, and again this can be sped up with tablets, vacuum pumps, or other treatments for erectile dysfunction
- The other main side-effect from surgery is incontinence or urinary leakage. This tends to occur on coughing, sneezing, and exerting oneself, and can take months to improve. Doing pelvic floor exercises like many women do after childbirth helps this to recover, and most men will get dry and stop wearing pads within 3-6 months after surgery

There are a number of factors that can predict this recovery (more accurately than we can predict erectile function recovery): younger men, thinner men, and those with smaller prostates tend to regain their continence quicker. Also, depending on the location of the cancer, there may be certain technical manoeuvres that the surgeon can perform to improve your continence recovery. These are called bladder neck sparing and Retzius sparing, and you should ask your surgeon if these are possible in your specific case. For the few men who have long-term problems with leaking urine (around 1 in 50 men at 1 year after surgery), there are tablets, injections, or even further surgeries that can help with the problem.

How do I know if surgery is the right choice of treatment for me?

Treating prostate cancer is like skinning a cat; there are many ways to do it and one way is not necessarily better than the others. Your surgeon and oncologist will go through the pros and cons of each treatment choice for you, and your decision will be tailored to what's best for your specific cancer and your quality of life wishes.

How do I prepare for surgery?

- You will be invited for a check at the hospital in a special clinic called the pre-assessment clinic
- Tests done in this clinic include
 - blood tests
 - urine tests to ensure there is no infection
 - an electrocardiogram (ECG) to check the heart
 - possibly a chest X-ray
- It is also likely you will have a covid test
- You should take your regular medicines to this clinic, so the nurse knows what medical conditions you currently have
- The purpose of the pre-assessment clinic is to check your fitness for the surgery
- You may have a tube in your mouth during the anaesthetic, so you will be asked about loose teeth, dentures, caps and crowns

Are there any drugs that need to be stopped before surgery?

- You should take your regular medications on the morning of your operation, unless otherwise instructed by the medical staff or the nursing staff at the pre-assessment clinic
- You may be asked to stop drugs that thin the blood, such as:
 - Warfarin
 - Apixaban
 - Rivaroxaban
 - Edoxaban
 - Clopidogrel
 - Dabigatran

What can I eat before the operation?

- You can have a normal diet leading up to your surgery
- You will need to stop eating and drinking for 6 hours before the operation
- You may be allowed to have plain water up to 2 hours before the operation, but please check with the nursing or medical staff first

What should I take to the hospital?

- Wear loose, comfortable clothing to the hospital
- Take spare underwear
- If you wear contact lenses, please remove them, and wear your glasses
- Do not take any valuables such as jewellery or credit cards with you
- Take some loose change to buy small items such as a newspaper to occupy you while you wait for your operation
- Remember to take your phone and a suitable charger

Do I need any bowel preparation?

Usually not, but that depends on the preferences of your surgeon as well as the complexity of your specific surgery. For example, sometimes after you've had previous treatment like radiotherapy or focal therapy, the body's tissues can all get a little stuck together so to help get the rectum (back passage) away from the prostate, we empty it with bowel preparation. It is not painful to have bowel preparation, and it just helps ensure your bowels are emptied before the operation.

How long will the operation take?

- How long is a piece of string? The answer is, that it varies. But for most surgeons, operating on most patients takes 3-4 hours. The important thing is it takes as long as it needs to take, and even if it takes a little longer that doesn't mean anything has gone wrong
- Most surgeons will call your next of kin after the operation to tell them how it's gone as you will still be in the recovery room and feeling a little groggy from the anaesthetic



How long will I stay in hospital?

Most patients stay one or two nights in hospital after the surgery. Whether it's one or two depends on how you are feeling afterwards, how far away home is, and what your surgeon prefers. If something was to go wrong during the surgery, then you will stay in until it's sorted, and that can be much longer. Fortunately, this is uncommon, happening in less than 5% of people.

Will I have a catheter after the operation?

Yes, you will. Most surgeons place a catheter through the penis (urethral catheter) whereas very occasionally some prefer a catheter through the belly (suprapubic catheter). Which one depends on the preferences of your surgeon, so it is worth asking him/her about this.

How long will the catheter stay?

This can vary, but typically it is 1-2 weeks. If the operation is complex (for example after radiotherapy or focal therapy), a cystogram may be performed first. This investigation involves injecting dye through the catheter to check the anastomosis (join) has healed without leaking.

What happens if I have trouble controlling my urine after the catheter is removed?

- The pelvic floor muscles that control your urine will be weakened after the operation
- It is important to do pelvic floor exercises (Kegels) to strengthen them
- The sooner you start pelvic floor exercises (even before surgery), the better
- Do not do pelvic floor exercises while the catheter is in place
- Generally, leakage of urine will be worse in certain situations, such as:
 - when your bladder is full
 - you are tired towards the end of the day
 - you have drunk a lot of caffeine
 - you have drunk alcohol
 - and will occur with straining, coughing, sneezing, or physical activity
- If you can limit these activities and situations, then you will regain your continence quicker

- There are also certain techniques your surgeon might do during the operation to help limit your incontinence, so please ask him/her about the plans for your specific surgery

How do I manage my pain at home?

- You will normally take regular paracetamol for a few weeks after you go home. Usually this is all you need
- You should try and avoid opiate painkillers as these can slow your bowel function down
- Drinking plenty of water
- Walking at least a mile a day after the operation also helps to settle down the bowels and helps to relieve the pain of a bloated abdomen

Are there any specific signs after surgery that mean I should go back to A&E?

- If you get a temperature
- If you start passing lots of blood especially clots
- If you cannot pass urine
- If your wounds get hot, red, or start producing pus
- If you have a severe increase in pain in your abdomen or down below
- If you feel very unwell in any other way, you need to either contact your hospital or go to Accident & Emergency

How long does the bruising take to settle?

- It is common to have some bruising to the abdomen, penis, and scrotum after this operation
- It will usually settle down in 1-2 weeks but can take longer
- Think of it like a black eye - it might change colours before it settles but if you leave it alone it will settle
- It may be more comfortable to wear tight underwear such as briefs to help with this instead of loose boxer shorts

How do I avoid constipation after the operation?

- Walking plenty
- Drinking lots of water
- Eating fibre will help you avoid constipation after the operation
- Some surgeons will also give you some laxatives to go home with for a few days

Can I have a shower or bath after the operation?

- You can shower a day after your surgery
- Remember to pat the wounds dry so the stitches don't dissolve too quickly
- It is difficult to keep the wounds dry with a bath. Try not to bathe until the wounds have healed, which is usually 4-6 weeks after the operation

When can I drive after the operation?

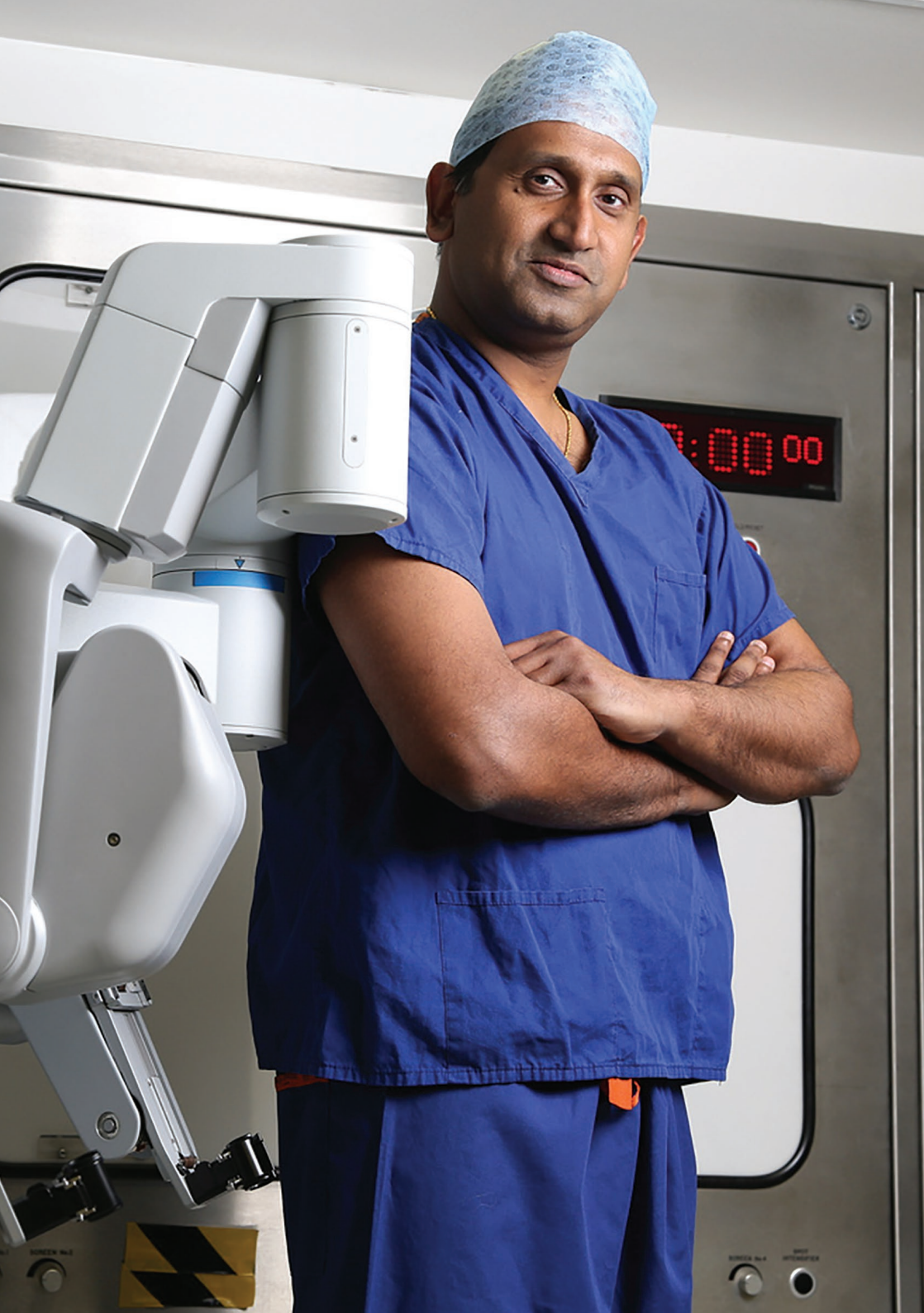
- You can drive 2 weeks after the operation so long as you practice doing an emergency stop on a quiet road and can do this without any pain or an increase in your braking distance
- Start by driving short distances only. Check you don't have any pain, that your urine doesn't become bloody, and that your leakage hasn't increased before increasing your time spent driving

When can I ride a bicycle or a motorbike after surgery?

- 6 weeks after surgery in bikes with a prostate friendly soft saddle
- 3 months after surgery with any saddle

When can I exercise after the operation?

- You should walk at least a mile a day after the operation, but this should be a slow walk (a mile taking 30-45 minutes), to get the bowels working properly and to prevent clots in the legs
- Proper exercise should start 6 weeks after surgery, but that should be fast walking, slow running, or weights that put no pressure on your abdomen
- You should not do any exercise that causes your belly to contract for 3 months after surgery. This is because of the risk of hernia at the wound sites



- If you are a gym goer, you can do the treadmill or do leg/ arm exercises after 6 weeks, but no core exercises like planks or sit-ups for 3 months
- If you are a golfer, you can putt or chip after 6 weeks but no driving for 3 months

When can I have sex after my operation?

You can try to have sex with your partner on top 2 weeks after the operation. Just be careful it is not too vigorous for the first 3 months after surgery.

When can I expect to regain potency?

This varies from person to person and is based on whether the nerves were spared, how sexually potent you were before surgery, your weight, your age, and the skill of your surgeon. On average, it can take anywhere from 3 months to 2 years to regain your potency after this surgery, and as mentioned before, it may never fully recover. But help with tablets, vacuum pumps, or injections can be given to help you get good erections that are strong enough for sex, if you need it.

What follow-up can I expect after my operation?

- You will come to the hospital for your catheter removal (called a TWOC; trial without catheter)
- Then again for a meeting with your surgeon for your histology result
- Then at 3 months after your operation for a PSA check
- Assuming all is in order, you will then have PSA checks every 3 months for the first year, and then at less frequent intervals for the next few years, becoming once a year after 5 years



I started doing Kegel exercises to strengthen my pelvic floor muscles before my surgery. I used a Kegel training app on my phone to remind me to do it regularly. I'm sure it helped me. I only needed pads for a few months after the op.

Common Questions

Will I be asleep for the operation?

Yes, you will be asleep for an average of 3-4 hours for the operation

Can I eat normally after surgery?

For the first few days, your diet should be light and focused on high fibre intake and plenty of fluids. After your bowels feel more normal, then your diet can also go back to what it used to be before the operation

Will I be able to have children after my operation?

Should I bank my sperm?

You will not be able to conceive children after the surgery as the seminal vesicles are removed and the vasa deferens are cut during the surgery. If you wish to have children you need to bank your sperm before the surgery. Your surgeon or nurse will arrange that for you if you ask them

Can I masturbate after the catheter has been removed?

Yes, you can. You may not be able to get an erection but may still be able to masturbate. You may also notice that you don't produce much semen, and this is because the seminal vesicles have been removed with the prostate. You may also notice a change in sensation and your orgasm, which generally improves with time. You may also notice you leak urine when you orgasm and, again, this tends to improve with time as you regain your continence

When can I go back to work?

Depending on the job you do, this will be 2-6 weeks after surgery. If you do a physical job, you might have to start with light duties. It is worth discussing this with your surgeon, so you know what to expect in your particular circumstance



Making a decision about whether to have an operation or radiotherapy is tricky. Both offer similar long-term survival. Therefore, in that regard no one treatment is better than the other. So how do you decide? Do not feel pressured to make a swift decision. You have time on your side. Think about which side effect will affect you more - urinary incontinence, sexual dysfunction or bowel problems? How much time do you want to spend going through the treatment? How long do you have to recover? How quickly do you want to know if your treatment has been successful?

Overview

Testosterone is the main male sex hormone and is mostly made in the testicles. In the context of prostate cancer, it is testosterone that serves as the main food supply or nourishment for the prostate cancer cells. Hormone therapy is also called Androgen Deprivation Therapy (ADT) and is the mainstay of treatment for many types of prostate cancers.

If we remove the body's testosterone, then the prostate cancer cells are deprived of their nourishment and usually shrink or die. ADT works by either blocking the effect of testosterone directly on the prostate cancer cells or stops testosterone from being produced.

When is ADT used?

Hormone therapy can be used to treat the following prostate cancers:

- Before radiotherapy to shrink the cancer when the cancer is confined (localised) to the prostate. This is usually given for 3-6 months before radiotherapy starts and may be continued for up to 3 years after it has been completed. It is not given prior to surgery to treat localised prostate cancer
- Before brachytherapy in localised prostate cancer
- If the cancer is in the area just outside the prostate, it is called locally advanced prostate cancer. ADT is usually given before radiotherapy and continued during and after it has been completed. Sometimes, ADT is used on its own for locally advanced prostate cancer if radiotherapy is not appropriate
- Advanced or metastatic prostate cancer when the cancer has spread to other parts of the body. ADT shrinks the cancer and slows its growth, often helping to reduce any symptoms. This is not a cure but can control the cancer for many years
- If prostate cancer comes back after treatment with surgery or radiotherapy and the PSA level is rising

Types of ADT

There are many different types of treatments to lower the levels of testosterone.

Orchidectomy or Surgical castration

This is surgical removal of both the testicles. Historically, this was the earliest way to remove testosterone, and is permanent. Hence, it is often used for men who will need to be on long-term hormone therapy. It is cheaper than long-term drugs and injections, and is very effective at reducing testosterone levels (by 90-95% in the blood) and very quickly - often within 12 hours. Additionally, it means that you do not need regular injections, especially if you are afraid of needles.

It can involve removing one or both testicles altogether and removing only the tissue in the testicles that makes the testosterone, rather than the whole testicle. This is called subcapsular orchidectomy.

The main side effects of this procedure are:

- An operation and an anaesthetic
- Swelling and bruising after the surgery
- Cosmetic effect of no longer having testicles although you can discuss having testicular prosthesis (artificial testicles like breast implants) to help with this
- Psychological impact of not having testicles

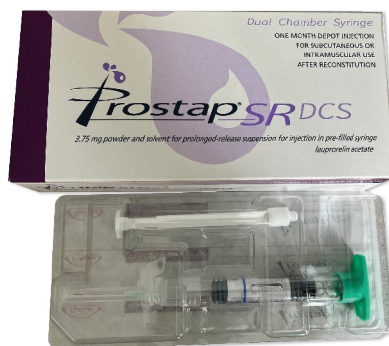
LHRH Agonists

Luteinizing hormone-releasing hormone (LHRH) agonists are also called GnRH agonists and are drugs that lower the amount of testosterone made by the testicles. This is called medical or chemical castration and has the same benefits as surgical castration without the need for an operation. The main difference is that when these drugs are stopped, the effect is reversible.

LHRH agonists are injections that are usually given at the GP's surgery and are injected at a frequency of once a month, once every 3 months or once every 6 months into your arm, abdominal skin, buttock or thigh. Examples of LHRH agonists include:

- Goserelin (Zoladex®)
- Leuporelin acetate (Prostap® or Lutrate®)
- Triptorelin (Decapeptyl®)

LHRH agonists



The Flare

When LHRH agonists are first given, they can cause a rise in testosterone levels before the levels fall. This effect is called the ‘tumour flare’ and can cause bone pain if there is spread to the bones. If there is spread to the spine, then a rise in testosterone can make the cancer grow, resulting in it pressing on the spinal cord. Men can get pain or end up paralysed as a result.

To prevent this flare, you will be given anti-androgen tablets (see below) for 3-4 weeks, which start 1-2 weeks before the first LHRH injection.

Side Effects of LHRH Agonists

Not all men experience any or all the listed side effects. If you do, the severity can vary from mild to very severe.

- **Pain or bruising at the site of the injection**

This will get better without the need for any specific treatment

- **Less or loss of libido**

The drop in testosterone is what leads to lowered or loss of libido as testosterone is what gives you your sex drive. Do not be shy about discussing this with your doctor or even asking for help. There are some herbal remedies such as maca (Peruvian root), which can be added to drinks in a powdered form, ginseng, and ginkgo biloba. Some foods are also thought to increase libido but many of these do not have the science to back the claim. These include celery, nuts, seeds and ginger. One of the most important things is to be open and honest and discuss this with your partner and find non-sexual and non-pressured ways to enjoy time together

- **Erectile dysfunction**

Hormone treatment can result in difficulty getting or maintaining an erection. This can be both upsetting and stressful. It is imperative that you openly discuss sex with your partner, your thoughts, and feelings, and make time for intimate touching rather than waiting for spontaneous desire.

Once hormone treatment has been stopped, erections may return to normal, but this can take up to 3 months to a year. Unfortunately, in some men the effect on the erections can be permanent.

It is important to undertake regular exercise, eat a healthy diet and drink alcohol responsibly. If you are a smoker, please think about stopping as smoking is heavily associated with erectile problems. Long term heavy drinking can lower a man’s ability to have an erection. Try to lower levels of stress, which can be exacerbated by the diagnosis of cancer.

You and your partner should speak with your doctor or healthcare team about your concerns so that appropriate options can be discussed with you. Treatment is free on the NHS (with some restrictions on quantity) for men diagnosed with prostate cancer. Types of treatment options available are:

- **Oral Medications** – these are tablets such as Sildenafil (Viagra), Tadalafil (Cialis) or Vardenafil (Levitra). These work by increasing blood flow to the penis, which can improve erectile function. They take 30-60 minutes to work, and men will need to be sexually stimulated or excited for them to work effectively. It may be better to take them on an empty stomach, so avoid eating a large meal within 2 hours before they are taken. Occasionally men will need to take several doses over different days before they work, and it is key not to be discouraged. Men who are taking nitrate medication; have a blood pressure less than 90/50mmHg; have unstable angina or angina that occurs during intercourse should not receive these drugs. There are other restrictions, and your doctor will discuss these with you to establish if these are suitable
- **Penile Injections** – injecting a drug into the base of your penis is another way of increasing blood flow to the penis. This works within 10 minutes of the injection and lasts for 30-60 minutes. Like the oral medications, you will need sexual stimulation in order to get an erection. One of the side effects of this method is getting an erection that lasts too long and thereby causes pain. If this happens and you have an erection that lasts beyond 4 hours, you should seek immediate medical attention
- **Vacuum Pumps** – this is a plastic cylinder that is placed over the penis. As air is pumped out of the cylinder, blood is drawn into the penis causing the penis to enlarge. This pumping may be required for several minutes. A rubber ring is then placed around the base of the penis to make it hard enough for sex by making sure that the blood stays in the penis. These rings can only be worn for up to 30 minutes at a time. It can take men several weeks to get used to this device and some men experience coldness and numbness after the ring has been removed. Your healthcare team will teach you how to use this device and adjust the size of the ring accordingly
- **Penile Implants** – this is a solid (semi-rigid) or fluid filled tube that is placed inside the penis by way of an operation. These are usually recommended after other options have failed but are not for everyone
- **Shrinkage of testicles**
This can happen with the testicles or penis after hormone treatment and is due to the reduced testosterone levels. It is easier to deal with this once you know that it is a recognised side effect



- **Extreme fatigue or tiredness**

This can be a result of low testosterone levels, frequent travelling to the hospital for tests or appointments, the cancer itself or due to anaemia (low red blood cells) and can vary from extreme tiredness to the ability to carry on with normal daily activities. It can last for a short period of time such as a few months or much longer such that it affects your normal everyday functioning. Although there is no medication to directly help with this, here are some ways to help cope:

- Regular exercise, especially something that you enjoy doing
- Prioritise your activities so that the important tasks are done in the mornings or after some rest when you may have the highest levels of energy. It may help to keep a diary or list to help with this
- Have regular periods of rest whether that is sleeping, sitting or lying down in a quiet place where you feel comfortable. Try to do this before you become tired. Frequent, short rests are better than a longer nap
- You may need to take some shortcuts to help with tiredness such as buying pre-prepared vegetables rather than chopping them yourself
- Try to find ways to get a good night's sleep such as avoiding drinks with caffeine before bedtime or having a warm relaxing bath before bedtime

- **Weight gain**

Weight gain can occur whilst on hormone therapy and tends to be around the waist in the form of fat and loss of muscle mass. Some studies show that this can level off after the first year of treatment. The mainstay of treatment is a good healthy diet and exercise for 30 minutes 5 days a week

- **Changes to memory or concentration**

There are many possible causes for difficulty in concentration or ability to focus on certain everyday tasks. Whilst hormone therapy can be one such cause, other causes include stress, tiredness and anxiety of having cancer. This may be something to discuss with your medical team.

- It may help to keep a notebook or diary of all your appointments and results
- Use lists and notes to remind you of things to do
- Check your understanding of things by repeating information back
- Keep your mind active with crosswords or puzzles
- Do one thing at a time and screen out distractions

- **Mood changes**

Some men feel more emotional or tearful than usual whilst taking hormones for prostate cancer. Additionally, loved ones may notice a change in mood, anxiety or symptoms of depression. This is thought to be a result of changes in testosterone levels, and if you are not aware of this, it can be traumatic. It is useful to recognise these as a normal side-effect of hormone treatments, and of being given a diagnosis of cancer. Some people feel better talking through these emotions with family, friends or a counsellor. There may be a prostate cancer support group near where you live, where you can share these emotions with men in a similar situation as you.

Occasionally, men feel better after some exercise, whilst others have feelings that are so overwhelming that they need to start anti-depressant medication. It is important to be aware that such drugs can take time to start working

- **Growth of breast tissue**

This is called gynaecomastia and is a result of the imbalance of testosterone and oestrogen in the body. The amount of enlargement can vary from a small amount to significantly noticeable breast tissue. This can also be associated with tenderness on one or both sides. This side effect is more common with anti-androgen drugs such as bicalutamide rather than LHRH analogue injections. Treatment options include:

- A single dose of radiotherapy to the breast area
- Tablets such as tamoxifen, which block the activity of oestrogen
- Occasionally an operation to remove some of the breast is required

- **Bone thinning or osteoporosis**

Osteoporosis is thinning of the bones because of low testosterone levels. Testosterone helps to keep bones in a strong condition. Being on hormone treatment for more than 6- 12 months, older age or smoking can increase the risk of bone thinning, which increases the risk of fractures with very slight trauma.

You may need an X-ray called a bone density or dxa-scan (dual energy X-ray absorptiometry) before you start hormones if your risk is thought to be high. This can be calculated from a bone health questionnaire. There are many possible treatment options, depending on the severity, including:

- Regular walking or physical activity, including exercise that involves you supporting your own weight
- Gentle weight-bearing or resistance exercises at least 3 times a week
- Stop smoking
- You may need calcium or vitamin D supplements

- You may be started on bisphosphonates for osteoporosis or zoledronic acid, which is given at 3-4 weekly intervals
- Another possible drug is denosumab, which is given by way of injection. If you are started on this or zoledronic acid, you may need regular dental evaluations and monitoring of calcium, and kidney function blood tests

• Higher risk of heart attack or stroke

There is some evidence to suggest that taking hormones may increase the risk of a heart attack or a stroke. This risk is higher in men who have high blood pressure, high cholesterol or diabetes mellitus. Possible options to reduce this risk includes the following:

- Being aware of the risk of heart disease
- Good control of your blood pressure and cholesterol – this may require a discussion with your GP
- Eat a healthy, low-fat diet
- Stop smoking
- Drink alcohol within recommended limits
- Maintain a healthy weight
- Stay physically active

• Hot flushes

This is a sudden feeling of warmth that often starts in the face and chest and can spread to the rest of the body. Hot flushes can be associated with redness of the skin and sweating. In some men, they can also cause a sense of anxiety, irritability, feeling panicky or palpitations. They can be called flushes or flashes. This can happen anytime during the day or night and can vary from mild, causing no bother to very severe. The frequency with which they happen, the intensity and how long they last (even at the same dose) can vary from person to person. In some men they can last a few minutes but in others, they can last up to 30 minutes, and drench clothes or bedsheets. Hot flushes can last for a few months or years and are most common with LHRH agonists and less common with anti-androgens. The most common way to stop them is to stop taking hormones. Recovery can take several months but some men still have symptoms years after stopping hormones. There are some ways to help manage hot flushes:

- Keep a diary to help identify certain triggers for the flushes, such as hot, spicy food or alcohol, so that you can avoid them
- Excessive coffee, tea or alcohol can make the hot flushes worse – sip cold or iced drinks instead

- Avoid eating large meals
- Use a fan or air-conditioning to help control your room temperature
- Wear loose layers of clothes so that you can remove items when you experience the flushes
- Try to rest during the day if you are finding it difficult to sleep due to the hot flushes
- Avoid synthetic fibres and instead wear clothes made of natural fibres such as cotton, linen or bamboo as they allow air to circulate
- When taking a shower or bath, use lukewarm water instead of hot water
- If you sweat a lot at night, you could place a towel on the bed to save changing the bedsheets so often
- Use layers of bedclothes so that they can be removed as needed
- Try using a cooling pad to help you stay cool
- Keep a damp towel in the freezer, which you can remove and wrap around your neck when you experience a hot flush
- Try to remain calm under pressure as you are more likely to experience hot flushes when under pressure

If some of the above tips do not help, speak to your doctor about some of the possible specific treatments that can work:

- Medroxyprogesterone 20mg a day is the first choice as recommended by NICE, initially for 10 weeks
- Consider cyproterone acetate 50mg twice a day for 4 weeks if medroxyprogesterone is not effective
- Some anti-depressant tablets such as venlafaxine, paroxetine or citalopram may be of use in this situation
- Some men get relief from alternative therapies such as acupuncture, but there is no good quality scientific evidence to support this
- Consider intermittent androgen ablation – this requires a discussion with your specialist



Intermittent Androgen Therapy

This is a strategy used to overcome the bothersome side effects that are associated with continuous hormone treatment. It involves temporarily interrupting ADT when the PSA level is very low and the disease is under control. It may also help to delay the time to hormone resistance. There is limited evidence for this strategy and NICE recommend PSA blood tests every 3 months and to restart ADT if there are symptoms of the disease progressing or if the PSA rises consistently.

LHRH Antagonists

Degarelix (Firmagon®) is an LHRH antagonist that stops the testicles making testosterone. This injection is used for advanced prostate cancer. Unlike LHRH agonists, the antagonists do not cause a flare or a temporary surge of testosterone and reduce testosterone levels very quickly, usually within hours. This is particularly useful for men who have severe pain or symptoms.

Degarelix is given as an injection just under the skin in your abdomen. The first dose will consist of 2 separate injections, after which there will be one injection per month. Some men may notice pain, redness, bruising or swelling at the site of the injection. This should settle within a few days.

Anti-Androgens

Taking LHRH agonists or having an orchidectomy only removes the testosterone that is made in the testicles. However, 5-10% of the body's testosterone is made by the adrenal glands, and their effect is blocked by taking anti-androgen tablets.

There are certain situations in which these drugs can be useful:

- At the start of ADT to prevent the tumour flare – this will only be for 3-4 weeks. Bicalutamide 50 mg is normally used in this context and is a tablet that you take once a day starting a week or so before the first LHRH agonist injection
- On their own as monotherapy – Bicalutamide 150 mg a day can be used on its own instead of LHRH agonists for high-risk prostate cancer with no spread. Although this is not the gold standard treatment, it is often used for men for whom castration (medical or surgical) is unacceptable or not indicated
- Another use is in men who have prostate cancer that has spread, but do not want standard hormone treatment. This tends to be because men choose to maintain sexual function. Anti-androgen monotherapy has an adverse impact on overall survival, and it is important to have an open discussion about this with your doctor. If your sexual function is still not maintained whilst taking Bicalutamide monotherapy, then it should be stopped and changed to ADT

- In combination with ADT – this is called maximum androgen blockade or combined androgen blockade. This involves ADT (either surgical or medical) combined with an anti-androgen to block the testosterone made by the testicles and the adrenal glands. Having the two drugs together is not standard first line treatment

The following are types of anti-androgens:

- Bicalutamide (Casodex®)
- Cyproterone acetate (Cyprostat®)
- Flutamide (Drogenil®)

Anti-androgens have similar side effects as LHRH agonists but seem to cause fewer sexual side effects. There is some evidence that breast pain and swelling, called gynaecomastia, can occur with long-term bicalutamide treatment – that is with treatment for 6 months or more. Your doctor may recommend that you have preventative radiotherapy to both breast buds before starting such treatment. If radiotherapy does not prevent gynaecomastia, then your doctor may consider weekly tamoxifen.



Bicalutamide tablets

Common Questions

Can hormones alone cure prostate cancer?

No, hormone therapy cannot cure prostate cancer as the aim is to slow the growth of prostate cancer cells. Hormones can shrink the cancer or limit its spread and control the cancer

Will side-effects of treatments limit what I can do?

What you can do depends on what side-effects you have and how bad they are. Most men can carry on with their daily activities, but you may need a little more rest than normal

Are there any tips for talking to my doctor?

It may be useful to keep a diary for everything related to your cancer so that appointments, results and any comments are all in one place. Make a list of any questions you have and take it with you to your appointment, in case you forget. You may also be allowed to take someone with you to the hospital so that they can help to remember what has been discussed. You can always make notes during your consultation

What if my injection is delayed?

It should not make much of a difference to your treatment if your hormone injection is delayed by a few days. If there is a longer delay, then testosterone levels can start to rise. It may be useful to discuss longer acting LHRH agonists, such as the 6 monthly dose to reduce the potential for delays in receiving your injection

How do I know if the hormones are working?

The most common way of monitoring treatment is to have regular PSA blood tests. An increase in the PSA level may indicate that the cancer has started to grow and be active

How low can my PSA get after starting hormone treatment?

PSA levels can be lower than 1 and be registered as undetectable once the hormones have started to do their job at lowering testosterone levels

How long will hormones work for?

On average, ADT can be effective for 2-3 years, but cancer can recur within 12 months of starting ADT in a small proportion of men. This is called castrate resistant prostate cancer, or hormone refractory prostate cancer. As the cancer starts to grow again, it gets strong enough that the standard hormone treatments have less of an effect on it. There are a number of newer 'secondary' hormone therapies that can now be used to slow the spread of the cancer

HORMONE THERAPY FOR ADVANCED PROSTATE CANCER 13

The growth of prostate cancer cells is driven by androgens in the body. Androgens are male sex hormones such as testosterone. Lowering these hormones can help slow the growth of the cancer. Initial hormone treatment as described in chapter 12 can work for months or years, but over time, the cancer cells may start to change and adapt. This is analogous to bugs, who over time, start to develop resistance to certain antibiotics. Similarly, the prostate cancer cells start to grow despite low levels of testosterone and the initial hormones stop being so effective.

At this stage, other hormone treatments may work. The aim of second-line hormone treatments is to control the cancer, delay the onset of any symptoms, manage any symptoms, and prolong overall survival. It is usual to continue with the first-line hormone treatment that you are on, such as your injections.

Drugs to lower androgen production: ABIRATERONE (Zytiga®)

Most androgens are made by the testicles, but a small proportion is also made by the adrenal glands. Whilst LHRH agonists and antagonists stop the testicular production of androgens, they do not affect the androgens made by the adrenal glands, or by the prostate cancer cells themselves, which can feed the cancer.

Abiraterone is an androgen synthesis inhibitor and works by blocking an enzyme called CYP17. This enzyme is found in testicular, adrenal, and some prostate cancer cells and is needed to convert cholesterol to testosterone. It is a type of hormone therapy.

When is abiraterone used?

- In men with advanced prostate cancer that has stopped responding to first-line hormone treatments
- In men with advanced prostate cancer that is high risk (such as high Gleason score)
- In men with advanced cancer with no symptoms or only mild symptoms after first-line hormone treatments
- Before or after chemotherapy in men with advanced prostate cancer
- Abiraterone is preferable over enzalutamide if there is a history of fits or extreme tiredness

How is abiraterone given?

This drug is taken as a pill every day. It can also lower the level of other steroids made by the body, so you will usually take it with a steroid tablet to lower the risk of side effects.

- You will also be prescribed daily prednisone or prednisolone (a corticosteroid)
- Abiraterone is taken once a day
- Take it on an empty stomach and not with food
- Take it at least 1 hour before or 2 hours after food
- Try to take it at the same time every day
- You should not chew or crush the abiraterone tablets – swallow it whole with water
- You will need to continue receiving your LHRH agonist injections during treatment with abiraterone
- Try to avoid excessive alcohol whilst taking abiraterone

What are the side-effects of abiraterone?

Not all men will experience the side-effects, and if you do, they tend to go away after the drug has stopped.

- Fluid retention is build up of fluid, resulting in weight gain or swelling of the legs/ ankles
 - It may help to put your legs on a footstool/ chair/ cushion
 - Exercise may help with leg swelling
 - Support stockings may help
- Lower levels of potassium in the body resulting in muscle weakness, twitching of muscles, cramps or a sense of your heart beating faster or harder
 - You should speak to your doctor straight away if you experience any of these symptoms
 - Most fruits and vegetables are high in potassium, such as oranges, spinach, kale and potatoes
- Raised cholesterol levels
- Raised liver enzymes
- High blood pressure

- Increased risk of infections, such as urine infection
 - Contact your doctor if you are experiencing cloudy or offensive smelling urine, pain or burning when passing urine, shivery, feverish or if you have a fever – you may need antibiotics
- Hot flushes – these are discussed in detail in chapter 12
- Diarrhoea – this is not an infection
 - Drink plenty of fluids
 - Avoid greasy, fatty, or fried foods as they can make the diarrhoea worse
 - Clean the skin around the back passage gently with warm water and a soft cloth – dry completely
 - A barrier cream may help irritated skin
 - Your doctor may advise an anti-diarrhoea tablet
- Skin rashes
- Blood in the urine

How is abiraterone monitored?

- You will be checked regularly whilst on abiraterone to monitor for side-effects and check how your cancer has responded to the treatment
- You will have regular blood tests to check for anaemia and kidney and liver function tests
- Your blood pressure will be monitored regularly

Drugs to stop androgens working: ENZALUTAMIDE (Xtandi®)

Most prostate cancer cells need androgens to grow. For this, androgens need to attach to the prostate cancer cells via a receptor. Anti-androgens also attach to these receptors and stop androgens from attaching, thereby stopping the growth of the cancer. These drugs are also called androgen receptor antagonists.

Enzalutamide is a newer anti-androgen and is another form of hormone therapy.

When is enzalutamide given?

- In men with advanced prostate cancer that is resistant to other treatments that lower testosterone (castrate resistant prostate cancer - CRPC)
- In men with advanced prostate cancer with no symptoms or mild symptoms before chemotherapy

- In men who have had chemotherapy, but the cancer continues to grow
- Usually not in men who have had abiraterone

How is enzalutamide given?

- Enzalutamide is available as capsules
- It is taken once a day with or without food
- Take it at the same time every day
- Swallow the tablet whole – it is not advisable to chew, crush, break, or dissolve enzalutamide
- If you forget to take the dose at the same time on a given day, then take it as close as possible to the usual time
- If you miss a dose completely on a given day, then do not double your dose the next day – just skip the missed dose
- Because this drug does not stop androgens being made, it tends to be used in combination with LHRH agonists or antagonists
- You do not need prednisone or prednisolone with enzalutamide

What are the side-effects of enzalutamide?

Not everyone will experience any or all the listed side-effects. However, the side-effects tend to improve after the treatment has stopped and there is no relationship between getting side-effects and how effective the drug is in controlling the cancer.

- Extreme tiredness and weakness can happen during and for a period after the treatment
 - It is useful to think of your energy stores as a ‘bank’ and over a given day, you need to make withdrawals as well as deposits
 - Balance periods of rest with activities
 - Ask for help with everyday chores
 - Consider frequent, short periods of rest over the day
 - Prioritise your activities that are necessary or important over others that could wait
 - Long, hot showers or baths may make you more tired
- Headaches
- Hot flushes
- High blood pressure



- Diarrhoea
- Gynaecomastia
- Anxiety or nervousness
- A drop in white blood cell count may increase your risk of getting infections
 - Think about avoiding people with colds or flu like symptoms
 - Wash your hands frequently
- There is a slight risk of having a fit (seizure) in < 1% of patients

How is enzalutamide monitored?

You are likely to have regular blood tests checking your full blood count (including white cells), kidney and liver functions, as well as your blood pressure.



Incorporate taking hormone tablets into your daily routine such as after brushing your teeth. You're less likely to forget it that way.

Oestrogens

Oestrogens are hormones that promote female sexual characteristics, and historically, were used to treat prostate cancer that was resistant to hormone treatment. They work in prostate cancer by stopping the testicles from making androgens and are available in tablet form as diethylstilboestrol or a patch to stick on the skin.

However, there is a higher incidence of problems with the circulation with oestrogens resulting in blood clots and treatment can cause swelling and tenderness of the breast tissue.

They are seldom used today due to the emergence of newer hormone treatments as discussed above.

Steroids

Steroid tablets are often used to treat advanced prostate cancer that has stopped responding to other drugs (CRPC). They work by stopping the adrenal glands from making testosterone, which can control cancer growth.

They may be given alone or in combination with chemotherapy agents or abiraterone. Options include prednisolone or dexamethasone.

Advantages of steroids include:

- Treat pain from any areas of spread of the cancer
- Reduce inflammation and swelling caused by spread
- Improve tiredness caused by cancer or its treatments

Side-effects of steroids:

- Increased appetite - try to eat healthy, balanced meals and exercise regularly to avoid putting on too much weight
- Damage to stomach lining leading to increased risk of an ulcer - try to take your steroid tablets with food or just after a meal. Your doctor may also prescribe you a drug to protect the stomach lining
- Difficulty sleeping – try to take your tablets earlier in the day to help with your sleep
- Swelling in ankles and feet due to fluid retention
- You may notice that you bruise easier whilst taking steroids
- Changes in blood sugar levels – men with diabetes may need closer monitoring of their blood sugars
- Increased risk of infections – wash your hands well and seek immediate help if you notice any signs of an infection including temperatures, shivers, and chills
- Avoid live vaccination whilst taking steroids
- Avoid exposure to chickenpox or measles viruses
- You will usually be given a steroid treatment card whilst taking steroids, which you should carry with you
- Do not stop taking steroids suddenly without discussion with your specialist first



I've never had a day's illness, so the whirlwind of appointments and tsunami of information was overwhelming. I just wanted to bury my head in the sand.

Common Questions

Can I have abiraterone if I have had enzalutamide?

Probably not. Research has shown that if you have already had one of these drugs, then the other drug will not work so well. You may be able to switch from enzalutamide to abiraterone if you suffer with severe side-effects of enzalutamide

What if I forget to take my abiraterone tablet?

Take the next dose as usual but do not double the dose. You should let your specialist know if you miss more than one dose

Can I have sex whilst on abiraterone?

Most men lose their sex drive and have problems with their erections whilst taking hormones. If you have sex whilst on abiraterone, you should use a condom and another method of birth control during treatment, and for a week after the last dose

Is there any specific advice on contraception whilst taking enzalutamide?

Men should not try to conceive whilst taking enzalutamide. You should use condoms whilst taking this drug and continue to do so for at least 3 months after the last dose

When do I stop taking abiraterone or enzalutamide?

You may need to stop these drugs if you experience severe side-effects or if they stop working



My cancer had spread to my bones, so I kept a pain diary using a scale of 0-10, with 10 being the worst pain. This helped me to identify patterns of pain throughout the day or triggers for the pain.



Radiotherapy (radiation treatment) uses high energy X-rays, or radioactive substances, to treat prostate cancer.

How does radiotherapy work?

Radiation is harmful to living tissues and damages the DNA in cells. It can kill cancer cells, but also harms healthy tissues and this is what causes some of the side-effects. Healthy normal tissues are able to repair the damage done by radiation, but there may be some permanent changes.

When is radiotherapy used in prostate cancer?

- As a curative treatment when the cancer has not spread beyond the area around the prostate (as an alternative to surgery) – this is called localised prostate cancer
- As a “salvage” treatment if cancer comes back after surgery – this is called recurrent prostate cancer
- To manage symptoms if the cancer has spread and cannot be cured
- To slow progression of prostate cancer if it has already spread

How is radiotherapy given?

- External beam radiotherapy (EBRT), the most common method, uses beams of high-energy X-rays generated by machines and aimed very precisely at the region to be treated. EBRT is given on an out-patient basis
- Brachytherapy involves the insertion of radioactive pellets or needles directly into the prostate under an anaesthetic. This is available on a regional basis in the NHS and may require travel
- Radium-223 is an injection of radioactive material into the bloodstream and is sometimes used to treat prostate cancer that has spread to bones
- Proton therapy uses a beam of sub-atomic particles (protons) in a similar way to EBRT. It is not used in the UK for prostate cancer

External Beam Radiotherapy (EBRT)

The machine used to give EBRT is called a linear accelerator (linac). Most EBRT is given using a technique known as intensity modulated radiotherapy (IMRT). This means that both the shape and the strength of the beam of radiation can be varied as the machine rotates around the patient. This allows for very precise targeting of the treatment and for the radiation dose to surrounding tissues to be kept low.

Preparing for radiotherapy

- Before having EBRT, a CT scan is done to make a computer image of your body that is used to target which areas receive a dose of radiation
- You will be positioned very carefully on a flat couch for the scan and have tattoo dots made on the skin. When you come for treatment, the dots are lined up with laser beams to make sure you are in exactly the right position
- As well as positioning you accurately using tattoos and lasers, we want you to have a comfortably full bladder and an empty rectum because the position of the prostate can be affected by the contents of these organs
- Before each treatment, and before the planning CT scan, you will be asked to empty your bladder and drink some water to partially fill it
- You will also need to have an enema to ensure the rectum is empty. This can sound daunting, but simply involves having 5mls of liquid, squeezed from a small tube into the back passage. You perform this yourself, and it takes about 20 minutes to work

What happens during radiotherapy?

- When you come for treatment, you will be put in the same position as for the CT scan on a treatment couch, using your tattoo dots and lasers
- Your treatment appointment will be around 20 minutes, but the radiotherapy itself only takes a couple of minutes
- You will be alone in the room while the radiation beam is on but will be closely watched at all times and you can talk to the team through an intercom
- The radiotherapy machine moves around the couch at around one metre away and will make some noise
- You will need to lie still
- The beam of radiation passes through your body as the machine moves and is customised to you, based on the size and shape of the cancer seen on the CT scan and MRI scans

- The treatment is completely painless and does not make you radioactive
- You can be around pregnant women and young children during radiotherapy

Why should I choose curative radiotherapy?

- Radiotherapy and surgery are considered equally effective in terms of cure for localised prostate cancer, so it can be difficult to choose between the two options. Often either option is appropriate, and it will be a question of which treatment you feel more comfortable with
- Your surgeon and your oncologist will discuss which might be more suitable for you
- There is an online tool approved by the NHS to help men who are choosing between surgery, radiotherapy, or a conservative approach:

<https://prostate.predict.nhs.uk>

Will I need hormone injections with radiotherapy?

- Hormone treatment is given before, during, and sometimes after radiotherapy
- The prostate is strongly influenced by the male hormone testosterone (see the Hormones chapter)
- Hormone treatment greatly reduces the amount of testosterone you have, and the prostate cancer will shrink as a result
- Hormone treatment and radiotherapy have a combined effect
- The duration of hormone treatment depends on your biopsy and scan results

How long is the course of radiotherapy?

- A course of radiotherapy is given in individual treatments called “fractions”
- Curative radiotherapy is usually given over 4 weeks, with daily treatments from Monday to Friday - 20 fractions are given in total
- Between each fraction of treatment, the body repairs some of the harm done to normal tissues

Until recently, the usual length of treatment was 37 fractions over 7½ weeks. Depending on the stage and grade of your cancer, this approach might still be used. In the future, it might be that even shorter schedules are used but this is not yet routine and is being studied in clinical trials.

Side-effects of prostate radiotherapy

These vary quite a lot from person to person. There are short-term side-effects that come on 2-3 weeks after starting treatment and last for a few weeks afterwards, and longer-term “late” effects which come on months after finishing and may be permanent.

Common short-term side-effects:

- Tiredness - radiotherapy can leave you feeling tired, especially towards the end of your treatment. This can last for several weeks after the treatment has finished. The cause can be the disease itself, stress, the daily travelling, or the treatment. Ways to help this include:
 - Not trying to do too much
 - Limit your activities and rest
 - Save energy to do what you most enjoy
 - Get more sleep at night
 - Frequent short naps may help
 - Ask family or friends for help and support for daily chores such as shopping, driving or childcare
 - Maintain a level of physical activity and a well-rounded, healthy diet
- Bladder bother – passing urine more often, slower flow, needing to go urgently, or pain/burning when passing urine. The bladder is close to the prostate and will invariably receive some of the radiation dose. Most of the symptoms will settle within a few weeks. Ways to manage some of these include:
 - Drink more fluids
 - Avoid large quantities of drinks containing caffeine (especially coffee and tea)
 - Your doctor may check there is no infection causing the burning
 - If you stop passing urine you will need to have a catheter
- Bowel bother – radiotherapy can irritate the bowel and result in going more often, loose motions, increased wind, passing mucus, or bleeding from the back passage. Ways to manage some of these include:
 - Eat a balanced diet
 - Wash the area around your back passage gently
 - You may benefit from topical creams to soothe the area
 - Avoid fried/ greasy or spicy foods

- Avoid dehydration
- Use moist toilet paper
- Sitz baths may help relieve the irritation
- You may need anti-diarrhoea medication

Late side-effects:

- Change in bowel habit, looser stools, passing more wind
- Impotence
- Rectal bleeding, which may require further investigation
- Fertility issues
 - Radiotherapy is likely to make you infertile
 - It is important to use contraception during and after radiotherapy if you are sexually active
 - If you are the recipient of anal sex, then you should avoid intercourse during and for 2 months after radiotherapy as this can increase the chances of rectal bleeding and pain
 - You may notice reduced volume or lack of ejaculate but may have the sensation of ejaculation or orgasm

What is salvage radiotherapy?

After surgery for prostate cancer, there should be no PSA detectable in blood tests. If PSA is detected, it might mean that the cancer has not been cured by the operation. Because PSA is a very sensitive test, the PSA may start to rise before any remaining cancer is large enough to find on a scan. In this situation, a cure can still be achieved by giving radiotherapy to the area around where the prostate used to be - this is called the “prostate bed”.

What is palliative radiotherapy?

Palliative treatment is for the relief of symptoms when a cancer cannot be cured. Prostate cancer can spread to other parts of the body, most commonly to lymph glands and to bones. When this has happened, the cancer is called “metastatic”. Metastatic prostate cancer often causes no symptoms but sometimes the areas of spread (metastases) can be painful, and radiotherapy can relieve the pain. This is usually with a single treatment.



Radiotherapy may sometimes be given to the prostate even when the cancer has already spread. This can help to slow growth of the cancer.

What is brachytherapy?

Brachytherapy allows for a high dose of radiation to be delivered directly to the prostate (“brachy” means short and refers to the distance the radiation travels). It involves the insertion of either radioactive pellets or needles directly into the prostate under a general anaesthetic. The prostate is reached through the area of skin between the scrotum and anus called the perineum, and a small ultrasound probe is put in the rectum to see the prostate and guide precisely where to treat. There are two ways of doing this:

- **Tiny radioactive pellets called “seeds”.** These are about the size of a grain of rice and as many as 120 seeds may be used. The seeds stay in the prostate permanently and the radiation is given over a period of months until the seeds slowly lose their radioactivity. This is known as low dose rate (LDR) brachytherapy
- **Radioactive needles.** These are made from a more intensely radioactive material and are removed after a few minutes when the correct dose has been given. This is known as high dose rate (HDR) brachytherapy and is given over 2-3 sessions or combined with external beam radiotherapy

Hormone therapy is often given with brachytherapy in combination.

Where is brachytherapy available?

Brachytherapy is only available in some cancer centres and may involve travel. The NHS offers access to the service within regional cancer networks, but not at every cancer centre. You may need to stay overnight following treatment. If you need to travel for treatment, it should be possible to have follow-up at your local hospital. Different schedules of brachytherapy are used in different hospitals. The number of appointments can vary according to the technique used and may require separate planning visits.

- LDR brachytherapy with seeds is given in one session
- HDR brachytherapy is usually given in 2-3 sessions but is sometimes combined with a short course of external beam radiotherapy

Who can have brachytherapy?

Not everybody can have brachytherapy. This depends on

- The biopsy and scan results

- The size of your prostate – brachytherapy is not suitable for prostates larger than 70cc
- It may not be suitable if you have poor urinary flow
- You need to be fit enough to safely have an anaesthetic

Safety Precautions after brachytherapy

After LDR brachytherapy with radioactive seeds, you are carrying a bit of radioactivity in your prostate and there are some safety considerations.

- You will be asked to carry a card stating that you have had radioactive implants
- You will be advised to avoid prolonged close contact with pregnant women or children for a few months, even though the radiation is almost completely absorbed in the prostate
- You should use a condom for sex for the first few months because there is a very small risk a seed could be passed into the semen at ejaculation
- Radiotherapy is likely to make you infertile
- If you are the recipient of anal sex, then you should avoid intercourse during and for 2 months after radiotherapy as this can increase the chances of rectal bleeding and pain
- You may notice reduced volume or lack of ejaculate but may have the sensation of ejaculation or orgasm
- If you were to die within the first 2 years of treatment, you would have to be buried rather than cremated, so that nothing radioactive is released into the atmosphere

After HDR brachytherapy, these conditions do not apply because nothing radioactive is left inside the prostate.

Side-effects from brachytherapy

Short-term, related to the procedure (or anaesthetic)

- Pain - this may be relieved by using an ice pack over the area or taking simple over-the-counter pain killers. A warm bath may also help
- Infection
- Blood in the urine or semen - this is normal for a few days after the procedure. If it gets worse or you pass clots, you should tell your doctor. Drink plenty of water to flush the blood out
- A chance of needing a catheter after the procedure - usually only for a few days

Long-term side-effects

- Infertility - if you want to store your sperm to have children in future, talk to your doctor about sperm banking before you start treatment
- Impotence
- Narrowing of the urethra (the urine pipe) possibly requiring an operation
- Change in bowel habit

Possible early/short-term side-effects

Start during radiotherapy or shortly after completing radiotherapy and usually resolve within two to six months of finishing radiotherapy. Frequencies are approximate.

Expected
50%–100%



- ☐ Tiredness
- ☐ Urinary frequency (passing urine more often than normal), **urgency** (sudden urge to pass urine) and **slower flow** compared to normal

Common
10%–50%



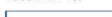
- ☐ Hair loss in the treatment area
- ☐ Bowel frequency (opening your bowels more often than normal) and **urgency** (sudden urge to open your bowels)
- ☐ Looser stools

Less common
Less than 10%



- ☐ Skin reactions
- ☐ Cystitis
- ☐ Rectal pain/discomfort
- ☐ A feeling of fullness
- ☐ Bleeding from your bladder or bowel

Rare
Less than 1%



- ☐ Urinary incontinence
- ☐ Urinary retention

Possible late or long-term side-effects

May happen many months or years after radiotherapy and may be permanent. Frequencies are approximate.

Expected
50%–100%



- ☐ Infertility – Radiotherapy will affect your fertility. Please let us know about your plans for having children and we can advise accordingly.

Common
10%–50%



- ☐ Urinary daytime/night-time frequency (passing urine more often than normal) and **urgency** (a sudden urge to pass urine)
- ☐ Bowel urgency (a sudden urge to open your bowels)
- ☐ Looser stools – with more mucous or wind compared to normal
- ☐ Changes in ejaculate – such as reduced amount, dry, altered consistency or blood stained
- ☐ Loss of orgasm
- ☐ Change to penile length/appearance
- ☐ Inability to achieve an erection

Less common
Less than 10%



- ☐ Cystitis/pain when you urinate – due to bladder inflammation
- ☐ Incomplete emptying of your bladder or reduced bladder capacity
- ☐ Urinary stricture (a narrowing in your water pipe which may require surgery)
- ☐ Bowel frequency (opening your bowels more often than normal)
- ☐ Rectal pain/discomfort – due to rectal inflammation
- ☐ Bleeding from your bladder or bowel
- ☐ Intermittent abdominal discomfort

Rare
Less than 1%



- ☐ Urinary incontinence including urine leaking (1%)
- ☐ Pelvis/hip bone thinning and/or fractures
- ☐ Bowel/bladder damage which may require surgery – due to perforation (hole), fistula (abnormal connection between two parts of your body), bowel obstruction (blockage) or severe bleeding
- ☐ An increased risk of a different cancer in the treatment area
- ☐ Radiotherapy to your pelvic lymph nodes:
 - Lymphoedema** – fluid build up in your legs and potentially your scrotum
 - Malabsorption** – problems with nutrient absorption
 - Neuropathy** – damage to nerves which could cause pain, numbness or weakness in your legs.

Adapted with permission from The Royal College of Radiologists

Common Questions

Can I have radiotherapy at any hospital?

No. Radiotherapy is a very specialised treatment requiring complex equipment and expert staff to run it. If your local hospital doesn't have a radiotherapy department, you will be treated at the nearest hospital that does. This may require travel

Can I choose my treatment times?

If a particular time of day is more convenient, the radiotherapy staff will try their best to arrange your appointments to suit you

Can I drive/work after radiotherapy?

Yes, you can drive/ work, but you may have side effects later during radiotherapy which make you less willing to do so

What about parking?

You are not guaranteed a parking place, but parking is usually free when attending for treatment

What if I don't have transport?

Hospital transport can be provided, but this can sometimes mean long waits

What if I miss a treatment?

Treatments will usually be delivered every day, Monday to Friday. If you miss a treatment, it will be added at the end. Gaps of more than a few days might mean a change in the treatment plan

Are there any conditions that mean I cannot have radiotherapy?

Previous pelvic radiotherapy. Active inflammatory bowel disease (ulcerative colitis or Crohn's disease)

How long will I be on hormones after radiotherapy?

This depends on the grade and stage of your cancer. It may be that you stop hormone treatment when radiotherapy finishes, or continue for up to 18-24 months in total. Your oncologist will advise

What is a spacer?

This is a liquid gel or a balloon that increases the distance between the prostate and the rectum. This protects the rectum from radiation and reduces some side effects of radiation therapy. Ask your oncologist for more information

What is chemotherapy?

Chemotherapy is a cancer treatment that uses drugs to kill cancer cells.

How does chemotherapy work?

Chemotherapy drugs stop cells that grow and divide quickly. Although cancer cells grow and divide quickly, so do many other normal cells in the body, which is why healthy cells are also affected by chemotherapy. The damage to healthy cells can result in side effects, but they tend to improve after chemotherapy has stopped.

When is chemotherapy given?

- As a first-line treatment for men who have been diagnosed with prostate cancer that has spread outside the prostate. This is usually alongside standard first-line hormone treatment
- In men who have advanced prostate cancer that has stopped responding to hormone treatments

When is chemotherapy not given?

- If you are not fit to have chemotherapy
- In men who have localised prostate cancer
- It is rarely given to men who have locally advanced prostate cancer

What drugs are used?

In the UK the most common chemotherapy drugs that are used are docetaxel or carbazitaxel. Docetaxel is usually the first drug that is used in combination with a steroid, such as prednisolone. When this drug stops working, carbazitaxel may be considered.

How is Chemotherapy given?

These drugs are injected into a vein as an infusion over a period of about an hour. You will normally be sitting in a comfortable chair during this time in the out-patient chemotherapy department. This means that you do not need to stay in the hospital. There is no tablet form of docetaxel. The dose is calculated based on individual patient factors.

Chemotherapy is usually given over a cycle. One cycle consists of a period of treatment followed by a rest period to recover from the drugs. This cycle could be 3 or 4 weeks. For prostate cancer, chemotherapy starts at any point within 3 months of starting hormones and up to 6 cycles are given.

Will I be given any other drugs with chemotherapy?

- You will be given steroids throughout the chemotherapy. This may be continuous or just for a few days around the time you are due to receive the actual chemotherapy
- Some men feel sick during chemotherapy, and you may therefore be given anti-sickness tablets or injections to help with this
- There is a higher chance of infections during chemotherapy, and you may need antibiotics
- You should continue your normal prescribed medications during chemotherapy unless your oncologist advises you otherwise. If you are in any doubt, speak to your oncologist

Before Starting Chemotherapy

- Consider getting any dental work done before starting chemotherapy as the drugs can increase the risk of infection
- Make sure you tell your oncologist about any vitamins or herbal medications you are taking - they may interact with the chemotherapy
- Do not take any immunisation or vaccination without discussing it with the oncologist first
- You may need to talk to your employer about some time off work whilst you are having your chemotherapy – one cannot predict the body's reactions to these drugs and therefore how you will feel during the chemotherapy cycles
- If you live alone, you may not feel up to cooking. Consider freezing some meals ahead of starting chemotherapy and having some easy meals at hand
- You may feel too tired to do chores around the house, so ask for help in advance
- It may be useful to have a thermometer at home so that you can check your temperature during your chemotherapy
- Take something with you during your chemotherapy sessions to keep you occupied. Consider a book, a laptop, a newspaper or listening to music
- Check with your hospital as to whether you are allowed to take a friend or relative with you

- If you feel too tired to drive to and from the hospital, ask for help with transportation
- Before each session you will have a blood test to check your white cell count, your haemoglobin and platelet levels

Managing common side-effects of chemotherapy

Side-effects tend to happen because the chemotherapy affects healthy cells as well as cancer cells. Most side-effects improve once the treatment has stopped.

- Extreme fatigue
- Increased risk of infection due to a decrease in white blood cells (these fight infection). If your white cell count drops to very low levels, it is called neutropenia.
 - Your chemotherapy nurse will check your levels before each cycle starts. If it is too low, then the dose may be deferred
 - Wash your hands often with soap and water
 - Always carry hand sanitiser with you
 - Avoid contact with people who are sick with ‘flu-like illnesses, measles, colds, or chickenpox
 - Avoid large crowds to minimise risk – go to cinemas, theatres, shopping when they are less crowded
 - Try not to cut yourself with a razor or when cutting nails
 - Use a soft toothbrush
 - Try not to scratch any skin pimples
 - Use lotions to soften dry, cracked skin to avoid breaking the skin barrier
 - Try not to rub your skin after a shower or a bath
 - Wash fruits well before eating them
 - Avoid undercooked or raw foods that can cause an infection
 - Be careful eating anything that is out of date, which may increase the risk of infection
 - If you have any signs of infection, especially a high temperature, contact your doctor immediately
- Easy bruising or bleeding

This can happen due to a drop in your body’s platelets. You may notice bleeding from gums when brushing your teeth or nosebleeds. You may also notice bruising with little or no injury.

- Blow your nose gently
- Avoid dental floss or toothpicks that may increase bleeding from gums
- Avoid a razor and instead consider an electric shaver
- Avoid contact sports such as boxing or football, which might lead to injury
- In the event of bleeding from your mouth, try rinsing your mouth with ice water
- Feeling out of breath

This may happen because a drop in the haemoglobin levels from the chemotherapy. Discuss this with your doctor in case you need some time for the red blood cells to recover or a blood transfusion, if the levels are very low
- Loss of appetite may happen because you have lost your sense of taste, are feeling sick or your mouth is sore
 - Consider eating frequent small meals
 - Drink milkshakes, smoothies, or soup, which may be easier than solid foods
 - Using plastic cutlery may help with the metallic taste in your mouth
 - Doing more activity may make you feel more hungry
- Hair loss

Chemotherapy can result in hair loss anywhere on your body. This tends to start a few weeks after chemotherapy starts and it may be a little at a time or in clumps.

 - Consider wearing a hat when outside to protect your scalp
 - Avoid very hot or very cold places
 - Sleep on a satin pillowcase as this causes less friction than cotton
- Feeling sick
 - This can be managed with anti-sickness medication
 - Consider bland meals
 - Avoid very spicy foods, fatty or fried foods, or excessively sweet foods
 - Try to eat small meals frequently
 - Drink plenty of water
 - Avoid strong smells such as onions, garlic, coffee, or fish
 - Breathe deeply when you feel like you might be sick – fresh air may also help
- Diarrhoea
 - Drink plenty to avoid dehydration
 - Fatty, fried, and spicy foods may make this worse
 - Low fibre foods such as bananas, white rice, or yoghurts may help

- Try to avoid rubbing your skin and consider using baby wipes
- If you are unable to keep up with drinking fluids, have had more than 4 episodes in a 24-hour period, or have a high temperature, call your doctor immediately
- Mouth ulcers
 - Avoid mouthwashes with alcohol
 - Eat soft foods such as mashed potatoes
 - Drink plenty of fluids
 - Avoid acidic foods and juices such as oranges or lemons
 - Avoid very hot foods, which may hurt the sores
 - Avoid spicy or very salty foods or crunchy foods that may further scrape your mouth
 - Sucking on ice may relieve the pain
 - Consider using a straw to drink fluids
- Sensitive skin
 - Take quick, warm showers rather than long baths
 - Pat your skin rather than rub it
 - Use a mild soap
 - Avoid strong smelling creams or aftershave lotions – especially those with alcohol
 - Avoid direct sunlight
 - Use sunscreen
 - Keep your lips moist and use a lip balm with SPF of at least 15
- Nail changes
 - Nails may become darker, turn yellow or become more brittle. They may fall off, but they will eventually grow back
 - Keep your nails well-trimmed
 - Wear gloves around the house, for example whilst washing dishes or working in the garden
- Numbness or tingling in the fingers or toes
 - You may notice a burning sensation in the hands or feet
 - This is called peripheral neuropathy and there is no treatment to prevent this
 - Inform your doctor if this happens – they may decrease the dose of the drug, delay the next dose, or stop the treatment



- Fluid build-up
 - This can cause your ankles or legs to swell or a sense of bloating
 - Avoid salty foods
 - It may help to elevate your legs on a footstool

Common Questions

Who oversees my chemotherapy?

This treatment falls under the remit of an oncologist and a chemotherapy nurse

Can I work during chemotherapy?

Depending on your job, you may be able to continue work during chemotherapy. However, you may need to change your job, the hours you work, or remain off work depending on what you do, and how you feel during chemotherapy

What if I miss a dose of chemotherapy?

Your doctor may skip a cycle due to side effects. If you cannot make a dose, discuss this with your oncology team

How do I know if the chemotherapy has worked?

You will have regular appointments with the oncology team to monitor your progress, check your PSA levels and discuss the results of any scans that have been requested to monitor your cancer



Everyone I spoke to had some advice or opinion to offer. I learnt that not all cancers are the same and not everyone's experience is the same. It's best to talk to the medical team.

“Palliative care is NOT about dying. It is all about living.”

What is palliative care?

Palliative care is about improving quality of life for patients and their families. It can be used at any stage of the disease alongside other treatments, or on its own towards the end of life. It provides an extra layer of support for men with cancer.

Treatments vary from medication to changes in nutrition (dietary advice), relaxation techniques (such as massages or aromatherapy), alternative therapies such as acupuncture, targeted radiation to help with areas of pain, or radiotherapy to the prostate to help with ongoing bleeding in the urine.

The focus is patient-centred holistic care for patients with serious illnesses and their families.

What is end of life care?

End of life is a type of palliative care and is used as patients get close to the end of life.

What is the aim of palliative care?

Palliative care is about care and comfort rather than cure. It is often referred to as symptomatic care. The aims of such care include:

- Treat and prevent symptoms of the disease or side effects of treatments, such as pain, nausea, and tiredness
- Addressing a patient's emotional needs
- Treating a patient's physical and social needs
- Helping a patient with practical needs such as getting to appointments or help with finances
- Helping patients with spiritual needs
- Providing the above for caregivers, families and loved ones

Who is palliative care best for?

- Men who have side-effects of the cancer or its treatments
- Men who choose not to have any curative treatments
- Men who have had treatment, which has failed and do not want any more treatments
- Men who have decided that further treatments will cause more harm than good
- Older men who have other conditions that are more likely to cause death than the cancer itself
- Men with advanced cancer who want a better quality of life

How can palliative care be used alongside other treatments?

Whilst specialists focus on treating the cancer, palliative care teams work with you to focus on managing side-effects and symptoms, such as:

- Help with waterwork symptoms such as weak flow, difficulty starting or stopping urination, or an interrupted stream
- Passing urine frequently
- Pain on passing urine
- Pain in the back or hips
- Ongoing blood in the urine
- Difficulty with erections
- Incontinence due to prostate cancer or after surgery
- Tiredness caused by hormone treatment
- Difficulty sleeping or anxiety

Who is in the palliative care team?

Much of this type of care is coordinated in the community by your GP but can be initiated by your hospital team. The palliative care team consists of professionals from many different specialties who work together, such as:

- GP
- District nurse
- Palliative care doctors and nurses
- Urologists
- Oncologists

- Clinical nurse specialists
- Community nurses – this includes Macmillan, Marie Curie, community, palliative care, or hospice nurses
- Healthcare assistants – trained professionals who may help with washing, dressing, or taking your medication on time
- Physiotherapists provide help with movement or mobility problems
- Dieticians
- Pharmacists
- Counsellors who help patients understand and process their emotions after a cancer diagnosis
- Social workers – part of local social services who help with non-medical support such as having meals delivered to your home or help with the cost of getting taxis to hospital if you do not drive
- Occupational therapists – professionals who focus on your ability to do everyday activities and help with adapting your home or providing equipment such as a wheelchair
- Chaplain or spiritual advisors who help with feelings towards death and dying

When does palliative care start?

At any stage that you ask for it, starting at the time of your diagnosis. Palliative care does not always result in death as it can be provided to someone during treatments such as chemotherapy, from which recovery is possible.

Palliative care can transition to end of life care if the patient is expected to die soon from the cancer.

When does end of life care begin?

When it is required and can last days, months or years. It is a process, often if your cancer treatments have not worked. This approach to care can be delivered at home or in a facility such as hospice.

Where is palliative care given?

- Hospital
- Nursing or residential homes
- Outpatient clinics

- Home
- Hospice

When do I start thinking about end of life care?

- Your cancer is life-threatening
- You are having frequent visits to emergency departments with symptoms
- Day-to-day living is starting to get uncomfortable
- Your cancer treatment has stopped working
- Your quality of life has reduced

What do I need to do as I get towards the end of life?

- Start to think about advanced decisions about your future, such as:
 - What type of care you want in future
 - What treatments you do not want – for example some people do not want to be on a mechanical ventilator even if you may die by refusing this type of care
 - Think about whether you would like resuscitation should your heart stop
 - Who you want to make decisions about your care if you are unable to do so, such as if you are drowsy or unconscious towards the end
 - Where you would like to be cared for
 - Where you would like to die
 - Your funeral wishes – a burial or a cremation? What music?
 - What religious beliefs need to be considered
 - Communicate your thoughts and decisions to loved ones and your specialists
- You cannot ask for help to end your life in the UK as your disease progresses
- Think about your finances and communicate this to a loved one
- Make sure your family knows where to find house deeds, your passport, and insurance details
- Does your family know where to find details of gas, electricity, water, phone suppliers and contracts?
- Where are your passwords kept and who do you want to know this information?
- Make a will
- Think about writing everything down



- Communicate your decision about organ donation to your loved ones – even if your organs cannot be used, tissues and corneal donation can be possible in most cases
- Think about donating your body to medical teaching or research



Common Questions

Is palliative care only available at the end of life?

No. It can be available at any age and at any stage of the disease, even when the cancer is curable. However, most men tend to focus on palliative care and quality of life as their cancer advances

Does palliative care mean I am dying?

No. It can mean that the disease has a limited prognosis, but you can have palliative care for many months or years. This is not the same as end of life care

Does palliative care mean other treatments for my cancer will stop?

No, Palliative care can work alongside other treatments such as radiotherapy or chemotherapy

Can I receive treatments to cure my cancer with palliative care?

Yes, if you wish with palliative care. However, with end of life care, only symptom relief will be provided



Dame Cicely Saunders founded the first modern hospice in London in 1967, starting a move to focus on a dignified end of life for all.



One of the most common questions I get asked by men is, “What can I do to reduce my chance of getting prostate cancer?” Whilst a lot is known about the impact of nutrition on heart disease, diabetes, and obesity, less is known for a fact about nutrition and prostate cancer. There is no evidence about certain foods preventing prostate cancer, and the relationship between diet and prostate cancer is poorly understood. Research is ongoing in this field, but we know that eating a healthy, balanced diet and being active is key.

When being treated for cancer, your body is working hard to recover. For example, radiotherapy and chemotherapy can lead to damage to healthy cells as well as cancer cells. The body, therefore, needs to work extra hard to repair the damage caused. Staying healthy and being strong is important.

Do any foods lower the risk of prostate cancer?

- Soy

Soybean has been used in the Far East for centuries as a staple food source. We know that the Japanese diet, which is high in green tea and soy is associated with a low risk of prostate cancer. Foods containing soy include:

- Soy milk
- Tofu
- Soy meat alternatives
- Soy sauce
- Edamame are soybeans and can be used as a snack or vegetable
- Miso is a salty soy paste that is used in Japanese cooking
- Tempeh is made from fermented soybeans and is a plant-based source of protein, originally from Indonesia. It is less processed than tofu but may contain more calories

- Green Tea

Green tea is full of antioxidants and considered to have many beneficial effects on the body

- Drink 3-6 cups a day
- Steep the teabag for 3-5 minutes for optimum flavour

- Generally, using 1 teaspoon of leaves per cup of tea works but this will vary depending on taste preferences
- Be mindful that green tea contains caffeine, which may aggravate your waterworks, but the quantity of caffeine is far less than in coffee

- Pulses

Pulses are a good source of protein and are helpful to build and repair body tissues. Three heaped tablespoons of pulses provide up to 9g of protein and count as one of your 5-a-day. Pulses include all dried beans, peas, and lentils, such as:

- Chickpeas or hummus
- Black-eyed peas
- Red, green, brown, and yellow lentils – think about substituting meat in a Bolognese with brown lentils
- Kidney beans – consider adding these to a chilli
- Cannellini or butter beans – these can be added to salads for lunch
- Be wary of lentil crisps – whilst they are higher in fibre and protein than other crisps, they can still be high in fat or salt

- Tomatoes

Tomatoes and tomato products contain high quantities of lycopene. There is a suggestion that consuming lycopene-rich foods may lower a man's risk of getting prostate cancer, but the evidence is limited. Lycopene is found in cooked and processed tomatoes, such as:

- Ketchup
- Pizza sauce
- Canned tomato sauce
- Tomato soups and purees

- Cruciferous vegetables

There is some evidence that cruciferous vegetables may lower the risk of prostate cancer. They are also a good source of fibre and count as one of your 5-a-day. Such vegetables include:

- Bok choy
- Broccoli
- Brussels sprouts
- Cabbage

- Cauliflower
- Horseradish
- Kale
- Turnips
- Pomegranate

Some studies have shown benefits in men with prostate cancer, but again, the results are conflicting. Pomegranate juice is generally safe and useful to incorporate into a healthy diet

- Selenium

Selenium is a powerful antioxidant but there is no evidence that it reduces the risk of getting prostate cancer. It is naturally found in:

- Meat
- Vegetables
- Brazil nuts
- Brewer's yeast
- Shellfish
- Mushrooms

Can anything make prostate cancer worse?

- Dairy foods and Calcium

Dairy foods are high in calcium, which is required for bone health. As the link between calcium and prostate cancer remains controversial, it is important to ensure that the body gets enough but not too much calcium. Avoid a high-calcium diet.

- Avoid consuming more than 1,500mg of calcium a day. According to the British Dietetic Association, adults need 700mg of calcium a day
- Non dairy sources of calcium include soy milk, soy yoghurt, and green leafy vegetables
- Processed meat and red meat
 - It is important to reduce animal fat in your diet
 - Avoid processed meat as found in sausages, burgers, bacon, ham, or salami
 - There is a link between prostate cancer and red meat consumption so limit the intake of beef, lamb, and pork
 - Consider alternatives such as chicken or fish



- Avoid charred meat

Charred meat that results from cooking at high temperatures may release a chemical that is linked to an increased risk of cancer

- Think about partially cooking foods in a microwave, oven or stove first to reduce grilling times
- Trimming the fat off meat can reduce charring
- Plant-based meat alternatives or grilled vegetables are healthier

- High-fat diet

There is some evidence that a high-fat diet can stimulate higher testosterone levels, which may promote cancer growth. A low-fat diet will also reduce the risk of obesity

- Reduce the intake of saturated and trans fats found in red meat, milk, butter, cheese, mayonnaise, cakes, biscuits, fried and processed foods
- Consider rice vinegar, balsamic vinegar, lemon juice as salad dressings
- Increase fresh fish intake such as salmon, sardines, mackerel, and trout – these contain omega-3-fatty acids, which are beneficial. Fish should ideally not be fried
- Use olive oil or avocado oil, in moderation
- Avoid frying foods – consider baking, poaching, or steaming
- Avoid fatty snacks such as crisps and biscuits – consider fruit instead

Other Tips to Stay Healthy

- Consider a high natural fibre diet found in fruits, vegetables, wholegrains, nuts, wholegrain cereals, and lentils
- Cut down on foods and drinks that contain a lot of sugar, such as chocolate, cakes, sweets, biscuits, and fizzy drinks
- Limit your calorie intake to avoid gaining excess weight. If you are overweight, think about losing weight
- Stop smoking
- Lower alcohol intake and stick to the government guidelines on recommended daily limits. High alcohol intake can also increase your weight
- Drink plenty of water during the day but limit the intake of fruit juices and smoothies as they contain a lot of sugar
- Try to get exposure to sunshine to increase levels of vitamin D in the body. You may wish to speak to your doctor about vitamin D supplements

- Regular exercise

Regular exercise can improve heart health, bone health, decrease risk of diabetes, reduce anxiety and fatigue, and reduce obesity. Aim to be active at least 5 times a week

- Aerobic exercise burns calories and can be moderate (2.5 hours/ week) or vigorous (75 minutes/ week), depending on your fitness levels
 - Walking at a pace of at least 3.5 miles/ hour, cycling at 10 miles/ hour or less, gardening, dancing, playing golf and doubles tennis are examples of moderate exercise. You should feel slightly out of breath but still able to talk and finish a sentence
 - Running at 5 miles/ hour, fast walking at 4.5 miles/ hour, fast cycling, swimming, or singles tennis are examples of vigorous exercise. You may only be able to say a few words before you need to stop to take a breath
- Consider the following:
 - Find a sport or activity that you enjoy to increase the chance of you persevering with it
 - Try group exercises if you like doing things with other people - join a walking group
 - If you are new to exercise, then aim for 10-15 minutes a time and build up slowly
 - Try to incorporate exercise into your lifestyle, such as getting off the bus one stop earlier, take the stairs rather than the lift, park further away from the entrance to a supermarket
 - Stand up regularly and walk around the house or garden
 - It is recommended to do gentle resistance exercises such as lifting weights if you are on hormone therapy
 - Ask for help if you need it



Government guidance states that men should not regularly have more than 14 units of alcohol a week. This roughly equals 6 pints of beer/ cider; 6 medium glasses of wine; 12 glasses of spirits such as gin/ vodka.

Common Questions

Should I take multivitamin tablets to help my prostate cancer?

There is no evidence to suggest that multivitamin tablets are a beneficial treatment for prostate cancer. Such tablets should not replace a balanced healthy diet. An exception to this may be vitamin D supplements, especially in dark-skinned people

Can diet cure prostate cancer?

No, but a healthy diet will benefit your overall health

Are there any herbal supplements that may help prostate cancer?

There is no evidence that taking herbal or complementary medicines will help

Is it safe to exercise if I have metastatic prostate cancer?

Be careful when exercising with cancer that has spread to the bones. This is because they are more likely to fracture if you fall or injure yourself whilst exercising

What is the Rainbow diet?

Colourful fruit and vegetables are considered to contain specific nutrients that support health. The idea of this healthy diet is to include all the colours during a week

- Red foods are rich in antioxidants and found in raspberries, strawberries, watermelon, apples, tomatoes, red peppers, red cabbage, radish, and kidney beans
- Orange foods contain nutrients like beta-carotene and are found in carrots, turmeric, sweet potatoes, pumpkin, orange peppers, butternut squash, mangoes, oranges, and nectarines
- Yellow foods are good for digestion. Examples include sweetcorn, pineapples, chicory, bananas, yellow peppers, plantain, and golden delicious apples
- Green foods are good for oxidative stress and are found in spinach, broccoli, cabbage, avocados, peas, pears, green peppers, okra, lettuce, olives, kiwi, and green beans
- Purple-blue foods contain powerful antioxidants that help to protect cells from damage. Examples include beetroot, purple lettuce, aubergines, plums, aduki beans, turnip, figs, and purple grapes

There are many reasons men choose to travel before, during and after cancer, whether it is for a holiday or a family emergency. Whilst travel is possible most of the time, there are some extra things to think about if you have cancer.

Initial Considerations

- Are you fit to travel?
 - You should ask your doctor if you are at a good point in your treatment journey to travel
 - Do you feel up to travelling?
- Will you need any special medicines or equipment?
- Think about travel insurance
 - This may be difficult, so start to look for appropriate insurance providers early
 - This may be more costly
 - You may need to provide the company with a letter from your doctor
 - You **MUST** tell the insurance company even if your cancer treatment is active surveillance
 - Shop around to get a reasonable quote but check what they cover

Travelling in the UK

- Take a doctor's letter with you, which summarises your condition and treatments
- Note your NHS number
- Take contact details of your key worker
- Carry a copy of your latest prescription with your current medication listed
- A list of any allergies you may have
- If you have mobility problems, take your Blue Badge with you

Travelling abroad with medication

- Carry a copy of your latest prescription with you - include generic names
- Know your allergies if you have any
- Take enough medicines to last you the entire holiday
- Check the expiry date of the medication for the whole trip
- If you are on hormones, ask your GP to change your preparation to either a 3 monthly or a 6 monthly preparation to give you time between injections to travel
- Carry all your medication in labelled containers to minimise the risk of problems with customs
- It is useful to carry 2 sets of medications with you. Keep one in your hand luggage and the other in the suitcase in case one gets lost
- Keep a copy of a doctor's letter on you in case you need to explain your medication at customs
- Think about when to take your medicines whilst abroad – think about sticking to a routine or perhaps the same time as you took them at home
- Some countries have restrictions on taking drugs like morphine, so you may need to check with the airline and the relevant embassy about the rules in advance of travelling

Travelling abroad with equipment

- If you have problems with your waterworks, such as incontinence following surgery, then you may be using pads regularly. Remember to pack enough for the entire trip. Carry some in your hand luggage and extra in your suitcase
- If you have a catheter, take enough to last you the whole trip. You may need to carry a doctor's letter explaining what the equipment is for. Make sure you have some in your hand luggage. Don't forget to pack drainage bags
- If you are performing self-catheterisation, it is useful to carry a doctor's letter explaining this
- Pack spares of all your equipment

Safety when travelling

- If you are travelling very soon after a scan involving a radioactive tracer (for example a Bone or PET scan), then you may still have minute doses of radiation in your body after the scan. This can be picked up by sensitive airport radiation monitors.

Take your scan appointment letter with you to show the staff that any activation is due to the drug that has been injected

- If you have had brachytherapy, then the seeds may set off the sensitive radiation sensors. You should have been given a card, which you should carry with you
- Taking a flight shortly after surgery can increase your risk of getting a blood clot in your legs, called a deep vein thrombosis (DVT). Having a pelvic cancer, like prostate cancer, can also increase the risk of getting a DVT, especially on a long-distance flight, car, train or bus journey. Consider the following:
 - Ask your specialist if it is safe to travel
 - Consider compression stockings – you may need to check if you can wear these with your specialist
 - Take regular exercise such as walking up and down aisles. If you are on a long car journey, plan frequent trips to stretch your legs and walk around
 - Drink plenty of water regularly
 - Minimise your intake of alcohol
- Drugs like chemotherapy increase your risk of getting an infection
 - Check with your specialist about the best time to travel
 - Wash your hands regularly
 - Carry a hand sanitiser and use it regularly when you touch surfaces such as door handles and cash machines
- You may be more sensitive in the sun whilst on holiday due to treatments
 - Think about protecting your skin with high sun protection factor (SPF) creams of at least SPF 30 and apply them generously 15-30 minutes before going out in the sun
 - ◆ SPF 15 offers approximately 93% protection against UV rays
 - ◆ SPF 30 offers approximately 96% protection against UV rays
 - ◆ SPF 60 offers approximately 98% protection against UV rays
 - Protect your lips with a lip balm with SPF of at least 30
 - Wear a wide brimmed hat in the sun
 - Cover as much of your skin as possible, especially areas like your shoulders that can burn easily
 - Wear loose clothing
 - Wear sunglasses to protect your eyes from UV radiation – wraparound sunglasses are safer

- Try to avoid the sun by sitting in the shade, especially when the sun is at its strongest between 11am and 3pm
- If you have waterwork problems such as urgency, it may be useful to sit in an aisle seat and in a row nearer the toilets on flights and trains. You can also get a Toilet Card, which is a card that should give you access to toilets in shops and service organisations that are not normally available to the public
 - Prostate Cancer UK has an Urgent Toilet Card
 - Macmillan offers a Toilet Card
 - The Urology Foundation has a pee card
 - Bladder and Bowel UK has a Just Can't Wait Card



Eating & Drinking Safely on Holiday

- Drink clean water
- Where possible, drink only bottled water and check that the seal has not been tampered with
- Avoid ice cubes in drinks
- Avoid unpasteurised milk
- Avoid ice creams as they may have been made with unpasteurised milk
- Only eat cooked food
- Avoid eating street foods unless you know that they have been cooked fresh in front of you
- Try not to eat leftovers or reheated food
- Avoid eating foods that have been exposed to flies
- Dry packaged and factory sealed foods such as crisps are usually safe to eat
- Ensure fruits are washed in clean and safe water before you eat them
- Avoid salads

Other Practical Points

- Speak to your doctor about whether you need vaccinations and if they are safe to have, depending on where you are travelling to
- Take a first aid kit
- If you are going to a tropical country that places you at a high risk of insect bites, then consider the following:

- Take insect repellent sprays and creams with you
- Use a plug-in repellent in your room, especially at night
- Cover your legs and arms at night
- Sleep under a mosquito net
- Keep a copy of your prescription, your doctor's letter summarising your condition and treatments and travel insurance documents on you in your hand luggage and separately in your suitcase
- Alternatively store your medical information in your smartphone but also keep hard copies
- Keep a list of close family or friends and your key worker with your passport in case you fall ill, and they need to be contacted





Having cancer and associated treatments can affect your sex life in many ways, such as:

- Make you feel less interested in having sex
- You may feel too tired for sex
- Feeling anxious or afraid
- Having a cancer diagnosis can be associated with sadness and a sense of loss
- Changes in your orgasm and ejaculation
- Not being able to get or keep an erection
- Not being able to father children

Why is my libido lower?

- Hormone treatments that decrease blood testosterone levels can dampen sexual desire and male sex drive
- Having a cancer diagnosis can make you feel anxious, worried, or more preoccupied
- You may still be able to have an erection even with low libido

What causes the problems with erections?

- Prostate biopsies can affect erectile function, but this tends to improve after 3-6 months
- Surgery for cancer can affect the nerves that are needed for a normal erection. Nerve-sparing surgery can lower the risk but not everyone can have this type of surgery. For example, it is more challenging to perform nerve-sparing surgery in men with high-risk prostate cancer. Additionally, the skill of your surgeon can affect this outcome. If your nerves are intact, then many men will see an improvement over time – this could be months and years later
- Radiotherapy can damage the nerves, but it can take longer to recover from the effect on erections
- Hormone treatments can lower blood testosterone levels, which can affect the ability to have an erection

Why has the amount of ejaculate changed?

It is common to make less semen after radiotherapy. If you can have an erection, then you can still have an orgasm, although the volume at ejaculation may be much less. This is not harmful, and you may be able to father a child with a smaller amount of sperm.

What is a dry orgasm?

- After surgery for prostate cancer, you will no longer make any semen and therefore your orgasms will be dry
- Orgasms will feel different, but you can still reach sexual climax
- Remember orgasm is not the same as ejaculation – you will be able to have an orgasm, just not normal ejaculation
- Dry orgasms are not harmful, but you will not be able to father children through intercourse
- Over time, many men grow to enjoy dry orgasms. One prostate cancer survivor said it was “good, but not as good”
- If you want to father children in future after prostate cancer treatment, then speak to your doctor about storing sperm in a sperm bank before you start treatment

Will having prostate cancer affect the size of my penis?

Some men report a decrease in the length of the penis, which can be when it is flaccid or erect, after surgery for prostate cancer or with hormones combined with radiotherapy. This is less seen after radiotherapy alone.

This can cause low satisfaction with sex lives, problems with emotional relationships and some men regret the choice they made for treatment of their cancer. If this is important to you, please discuss it with your medical team before confirming your prostate cancer treatment plan.

There is some evidence that taking drugs to increase the flow of blood to the penis may help and for most men, the problem returns to normal over time.

Tips to help with sexual difficulties

- If you are on continuous hormone injections, then discuss the possibility of intermittent hormone ablation with your doctor. Intermittent periods of time without hormones may allow your libido and erections to recover. It can take several months for recovery and the risk is that your cancer may not be so well controlled whilst you are off the hormone injections

- Talk to your partner and be open about your thoughts, feelings, and concerns. Communication is vital. Listen to your partner's feelings. You may not actually feel like sex given the diagnosis, the effect on your body of the treatments and the exhaustion of lots of appointments. Give yourself time and space to adjust
- Take your partner to hospital appointments so that you can both understand what is going on. It is also useful to have an extra pair of ears when you are being told sensitive information!
- Manage your expectations about what you want. Ask your partner what they want. Are other forms of intimacy any good if you can't have intercourse? This may take the pressure off actual intercourse. Consider the following:
 - Hugging/ cuddling may be comforting
 - Kissing
 - New ways of touching or caressing
 - A massage
 - Time for physical stimulation and for each other
 - Do things that you enjoy doing together if intercourse is not feasible or achievable
- Consider oral tablets such as sildenafil, tadalafil or vardenafil. They are not suitable for everyone and work by increasing the flow of blood to the penis. It may take a while for the tablets to give a true response, but it is important not to give up. It may take months or years to get an erection that will allow penetrative sex. However, taking a pill may boost confidence that you are doing something to help with the situation. You will need to be aroused for these tablets to work so foreplay is needed, and may explain why they are less effective in men who are on hormones
- Try an injection of a drug such as alprostadil into your penis. It is a small needle and helps with the blood flow in the penis. You or your partner will need to do the injection, but you will be taught how to do it properly. They are not suitable for everyone and can take 10-15 minutes to work after stimulation, lasting up to an hour
- Vacuum pumps work by drawing blood into the penis to get an erection. A soft ring is then placed around the base of the penis to keep the erection firm. This stops the blood from flowing back out of the penis, but you can only leave it on for a maximum of 30 minutes before it causes damage to the tissues. One of the biggest complaints of this treatment is that men find their penis becomes cold and semi-rigid, but they can also help with maintaining penile length and thickness

- An inflatable implant may be an option if the above treatments are not effective. However, this requires an operation
- If you are the recipient of anal sex, you may find penetration less pleasurable after the prostate gland has been removed. You should avoid receiving anal sex for:
 - 6 weeks after a radical prostatectomy
 - 2 months after radiotherapy
 - 6 months following brachytherapy with insertion of radioactive seeds
 - 2 months after HDR brachytherapy
- Staying healthy is important for a satisfactory sex life, and this includes regular exercise, getting enough rest and sleep, reducing stress, drinking alcohol responsibly, and not smoking
- Seek help with a therapist to deal with sexual issues



Common Questions

Can I pass prostate cancer through sex?

No, having sex will not pass the cancer to your partner

Are there other reasons that may increase the chance of erectile dysfunction?

- Being older, particularly over 40 years
- Previous sexual problems
- Other medical conditions such as diabetes or heart disease
- Taking certain medications can result in sexual problems

What is penile rehabilitation?

This helps to get your penis back to 'normal' after treatment for prostate cancer. The aims are to maintain blood flow to the penis through frequent erections, reduce damage to the penile tissues and regular penile stimulation. A program of penile rehabilitation after surgery can help erections to recover more quickly and can include any of the erectile dysfunction treatment options alone or in combination. The program will involve a certain number of 'artificial erections' per week after surgery, which is not for intercourse but for better penile health

What can I do if I leak urine during orgasm?

Consider emptying your bladder before intercourse. Pelvic floor exercises can also help reduce the risk of this happening. Consider using a condom if you leak

Where can I get help?

Speak to your GP who may refer you to a hospital andrology clinic, a psychologist or sexual health counsellor depending on your specific needs



Cancer is a part of my life - our lives. But, I live with it; with the thought it might come back. But, I will not let it rule my life.



ABBREVIATIONS

ADT	Androgen Deprivation Therapy
ASAP	Atypical Small Acinar Proliferation
BPH	Benign Prostatic Hyperplasia
CNS	Clinical Nurse Specialist
CT	Computerised Tomography
DHT	Dihydrotestosterone
DNA	Deoxyribonucleic Acid
DRE	Digital Rectal Examination
DVLA	Driving and Vehicle Licensing Agency
DVT	Deep Vein Thrombosis
ECG	Electrocardiogram
ERBT	External Beam Radiation Therapy
Gy	Gray
HIFU	High Intensity Focused Ultrasound
HNA	Holistic Needs Assessment
HNPCC	Hereditary Non-Polypsis Colorectal Cancer
IMRT	Intensity-Modulated Radiation Therapy
LHRH	Luteinising hormone releasing hormone
MDT	Multidisciplinary Team
MRI	Magnetic Resonance Imaging
NICE	National Institute of Clinical Excellence
PET	Positron Emission Tomography
PHI	Prostate Health Index
PIN	Prostatic Intraepithelial Neoplasia
PI-RADS	Prostate Imaging – Reporting and Data System
PSA	Prostate Specific Antigen
PSMA	Prostate Specific Membrane Antigen
SPF	Sun Protection Factor
TRUS	Transrectal Ultrasound Guided
TURP	Transurethral Resection of the Prostate
UCR	Urgent Cancer Referral
UV	Ultraviolet Rays
2WW	Urgent Cancer Referral

GLOSSARY OF TERMS

Active Surveillance	Monitoring strategy used for men with cancer that is localised to the prostate. The aim is to cure the cancer and defer any treatment options until necessary
Adenocarcinoma	A type of cancer that starts in the glands – this is the most common type of prostate cancer
Adjuvant treatment	When a different treatment modality is added to a primary treatment with the aim to increase effectiveness, it is called adjuvant treatment. For example, hormones given to patients after initial radiotherapy
Adrenal Glands	Two small glands situated above the kidneys and produce various hormones. They also make a small amount (approximately 5%) of the body's testosterone
Advanced Prostate Cancer	Prostate cancer that has spread to other parts of the body and is no longer localised to just the prostate
Androgen Deprivation Therapy	Hormones given to men to reduce the levels of male sex hormones (for example, testosterone) in the body. The effect of this is to slow down the growth of prostate cancer cells
Anti-androgen	Oral tablets that block the action of testosterone and dihydrotestosterone by attaching to the cell receptors. An example is bicalutamide
Asymptomatic	No obvious signs or symptoms of a disease
Atypical Small Acinar Proliferation	Changes in the cells of the prostate that may be cancer or not. At this stage it is unclear. This requires monitoring as it can increase the chance of being diagnosed with cancer at a later stage
Benign Prostatic Hyperplasia	Benign (non-cancerous) growth of the prostate, which can cause symptoms
Biopsy	Taking a sample of tissue from the body, which is looked at under a microscope to see if there is cancer present
Bone Scan	A scan of the entire skeleton to see if cancer has spread to the bones
Brachytherapy	Treatment of prostate cancer by inserting radioactive seeds into the prostate. Also called internal radiotherapy

Castrate Resistant Prostate Cancer	This happens when the testosterone levels in the body remain low, but the prostate cancer cells continue to grow. These cells may still respond to other hormone drugs such as abiraterone
Castrate Sensitive Prostate Cancer	The cancer is sensitive to low levels of testosterone that can be achieved either by removing the testicles or by hormone agonists / antagonists
Chemotherapy	Treatment of cancer using chemical drugs that affect cell division of both normal and cancer cells. This tends not to be a curative treatment
CT scan	Cross-sectional pictures of the body (like slices of a loaf of bread). Used to assess the extent of cancer or treatment planning for radiotherapy
Cryosurgery	Localised treatment of prostate cancer by freezing part or all the prostate using argon gas
Cyberknife®	A type of radiotherapy
Digital Rectal Examination	Examination of the prostate by inserting a gloved and lubricated index finger into the back passage to examine the prostate - this only takes a few seconds
Dihydrotestosterone	A metabolite of testosterone that is a lot more active and effective than testosterone. It is blocked by drugs such as finasteride or dutasteride
Erectile dysfunction	Also known as impotence. The inability to achieve a natural erection sufficient for satisfactory penetration or intercourse
External Beam Radiotherapy	Radiotherapy delivered by a machine from outside the body and directly aimed at the prostate
Gleason Grade	A method of classifying prostate cancer cells into how aggressive they are. The system uses 5 patterns scored from 1-5
Gleason Score	The Gleason score is determined by adding the primary and secondary grade for prostate cancer such that the most aggressive cancer would be Gleason Score 5+5 =10

Gray	A unit of absorbed dose of ionizing radiation
Gynaecomastia	Enlargement of breast tissue in men, which can be a side effect of androgen deprivation
Haematuria	Blood in the urine
High Intensity Focused Ultrasound	High intensity ultrasound energy that uses heat to destroy cancer cells
Hormone Resistant Prostate Cancer	Also called hormone refractory prostate cancer. This happens when the cancer is no longer responding to any type of hormones including drugs such as abiraterone or enzalutamide
Immunotherapy	Treatment of prostate cancer by stimulation of the body's immune system
Incontinence	Inability to hold urine in the bladder. This can be a side effect of removing the prostate (radical prostatectomy) or radiotherapy for cancer
Intermittent Hormone Therapy	A way to alleviate some of the side effects associated with hormone treatment. Hormones are stopped when the PSA level is low and steady, but started again when the PSA levels start to rise
LHRH Agonists	Drugs that suppress the body's production of testosterone from the testicles (for example Zoladex)
LHRH Antagonists	Drugs that bind to receptors in the pituitary gland causing less release of LHRH, which leads to a decrease in production of testosterone from the testicles
Life Expectancy	This is a measure of time and estimates how long (usually in years) a person will survive
Localised Prostate Cancer	Cancer that is confined to the prostate
Locally Advanced Prostate Cancer	Cancer that is just outside the prostate and may involve the seminal vesicles, the bladder, the back passage, or nearby lymph nodes. This is staged as T3 or T4
Lymph Nodes	Small bean shaped clusters of cells, also called lymph glands, that are part of a network of organs and vessels situated throughout the body. They are part of the immune system but can become enlarged due to spread of cancer

Maximum Androgen Blockade	This is a form of hormone treatment that combines castration (medical with drugs or surgical by an operation) with an anti-androgen tablet
Metastases	Spread of cancer from one part of the body to another part of the body via blood, lymph or direct extension
Multiparametric MRI	An MRI scan that incorporates information about the prostate using T2-weighted, diffusion-weighted, and dynamic contrast-enhanced imaging
Multidisciplinary Team	A team of health professionals who are involved in your care. This includes urologists, oncologists, radiologists, histopathologists, clinical nurse specialists and a coordinator
Neoadjuvant	A treatment that is given before another planned, definitive treatment. For example, androgen deprivation is started in the neoadjuvant setting before definitive radiotherapy is delivered
Orchidectomy	Removal of both testicles by an operation to reduce the body's testosterone levels – also called surgical castration
Osteoporosis	A decrease in the quantity or amount of bone
Palliative Care	The aim of palliative care is to manage any symptoms from cancer that has advanced. This includes medical, emotional, and practical treatments with a more holistic approach to care. Although this can be at the final stages of life, men can be on palliative care for several months or years depending on their needs
Pelvic Node Dissection	Removal of the lymph nodes near the prostate – this can be done as part of the staging process to see if they are full of cancer or as part of the definitive operation to treat the cancer
Perineum	This is the area of the body between the back passage (rectum) and the bottom of the scrotum. Biopsies can be done through here or brachytherapy seeds are implanted through the perineal skin directly into the prostate
Peripheral Zone	This area of the prostate is the most rear and outer part of the prostate and where up to 75-80% of cancers start

PET Scan	This is a special type of scan that looks at whether the cancer has spread anywhere else. It is not available in all hospitals and tends to be used to see if the cancer has come back after treatment
Prognosis	A term used to predict the course of the cancer to help patients plan for their future
Prostate Biopsy	Removing samples of the prostate to make a diagnosis
PSA	A protein made by the prostate's normal and cancer cells. It is used as a 'marker' for prostate cancer but can be artificially elevated in several situations, such as urine infections
PSA Nadir	The lowest level to which a man's PSA drops following definitive treatment such as radiotherapy
Radical Prostatectomy	Removal of the entire prostate gland and possible nearby lymph nodes, either as an open operation or using a keyhole approach, which can be laparoscopic or robotic assisted
Recurrence	Return of cancer after a period of remission
Remission	Disappearance of any signs of cancer that can be temporary or permanent
Staging	As assessment of how far a cancer has spread. The TNM staging system is an example of a staging system to assess the extent and severity of cancer, which then helps establish the correct treatment options
Systemic Therapy	Any treatment (usually drugs) that can reach the whole body and all cells
Testosterone	Male sex hormone that is made by the testicles and helps prostate growth. A small amount is also made by the adrenal glands
Transrectal Biopsy	Biopsies of the prostate taken via the back passage under local anaesthetic
Transperineal Biopsy	Sampling of the prostate through the perineum, which can be done under local or general anaesthetic
Ureter	The tube that connects the kidney to the bladder

Urethra

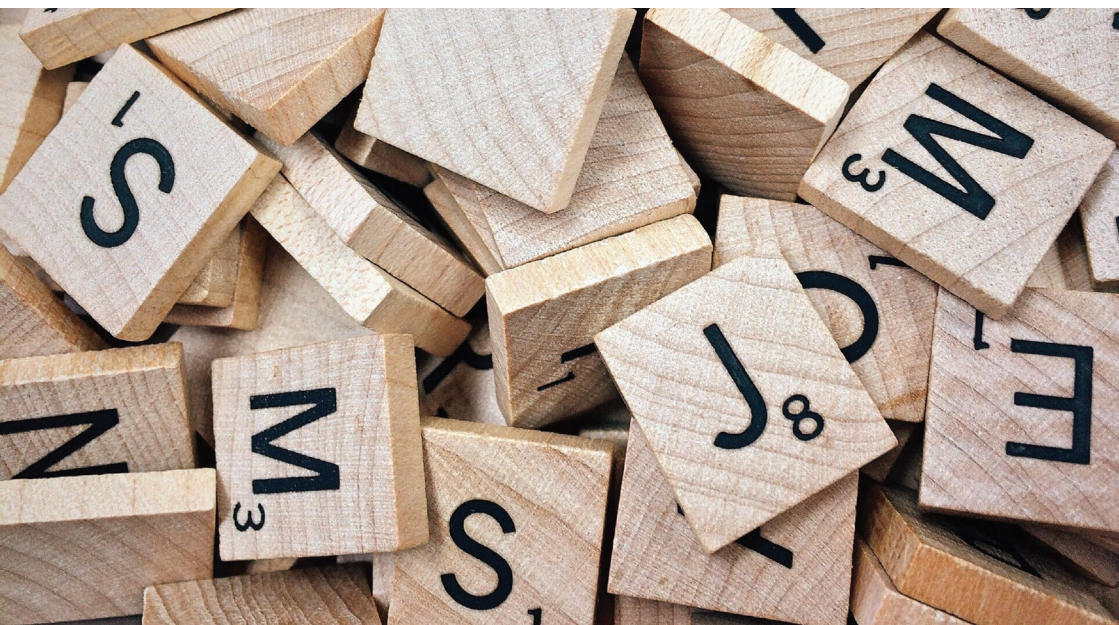
The tube that carries urine from the bladder to outside the body. It starts at the neck of the bladder and runs through the prostate. It also carries semen

Urinary Retention

The inability to completely empty the bladder

Watchful Waiting

Monitoring prostate cancer in men who are older, sick with other medical illnesses or choose not to want treatment. The aim is control rather than cure



USEFUL ORGANISATIONS

Disabled Living

Burrows House, 10 Priestley Road
Wardley Industrial Estate, Worsley
Manchester, M28 2LY
Tel: 0161 214 4591
Email: bbuk@disabledliving.co.uk
www.bbuk.org.uk

The British Association of Urological Surgeons

*Provides information about prostate operations
& surgeons around the country*
The British Association of Urological Surgeons Ltd
Royal College of Surgeons
38 - 43 Lincoln's Inn Fields
London WC2A 3PE
Email: admin@baus.org.uk
www.baus.org.uk

Cancer Research UK

PO BOX 1561
Oxford OX4 9GZ
Tel for cancer nurses: 0808 800 4040
Email for general enquiries: supporter.services@cancer.org.uk
www.cancerresearch.org

Cancer Support UK

Provides practical & emotional support to people with cancer
Aldwych House
71-91 Aldwych
London WC2B 4HN
Tel: 020 3983 7616
Email: hello@cancersupportuk.org
www.cancersupportuk.org

Macmillan Cancer Support

Provides financial, emotional, practical advice & support for people with cancer & their loved ones

PO Box 791

York YO1 0NJ

Macmillan Support Line Tel: 0808 808 00 00

www.macmillan.org.uk

Marie Curie

The UK's leading end of life charity providing nursing & hospice care & information on all aspects of dying

89 Albert Embankment

London SE1 7TP

General enquiries Tel: 0800 716 146

Support line Tel: 0800 090 2309

Email: supporter.relations@mariecurie.org.uk

www.mariecurie.org.uk

Pelvic Radiation Disease Association

Provides support & information to people with long term side effects of radiotherapy

62 Norbiton Avenue

Kingston upon Thames, KT1 3QP

Email: info@prda.org.uk

www.prda.org.uk

Prostate Cancer UK

UK's leading prostate cancer charity providing financial, emotional & practical advice & support for men with prostate cancer & their loved ones

Fourth Floor, The Counting House

53 Tooley Street

London, SE1 2QN

General enquiries Tel: 0203 310 7000

Specialist Nurses Tel: 0800 074 8383

Email: supportercare@prostatecanceruk.org

www.prostatecanceruk.org

MY RESULTS

	Date	Result
My PSA at the start		
Prostate biopsy result (Gleason score)		
MRI scan		
CT scan		
Bone Scan		
Other Scans		

Date	Plan / Comment / Notes

MY APPOINTMENTS

MY NOTES

FIGHTING PROSTATE CANCER - A SURVIVAL GUIDE

According to Prostate Cancer UK, one man dies from prostate cancer every 45 minutes. For a cancer that is relatively slow growing but one that is so common in men, early diagnosis is key to survival.

The lifetime risk of prostate cancer is 1:8 men.

This not-for-profit book provides men and their families with an easy to read and understandable guide to navigate the overwhelming journey that follows such a diagnosis.

Fighting Prostate Cancer – A Survival Guide

takes you step by step through:

UNDERSTANDING PROSTATE CANCER



THE DIAGNOSIS



TREATMENT OPTIONS & POTENTIAL SIDE EFFECTS



LIVING WELL WITH & AFTER PROSTATE CANCER

Dr. Jyoti Shah BSc (Hons) MBBS MRCS MD MS DHMSA FRCS (Urol) PHF is a Macmillan Consultant Urological Surgeon. She is passionate about raising awareness of prostate cancer and spearheads the Fighting Prostate Cancer campaign. Her work has received national coverage including BBC's *The One Show* and *Trust Me, I'm a Doctor*. She was Commissioning Editor of the Royal College of Surgeons of England's journals and Editor-in-Chief of *Medical Woman*. This is her sixth book.

ISBN 978-1-3999-2574-7



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