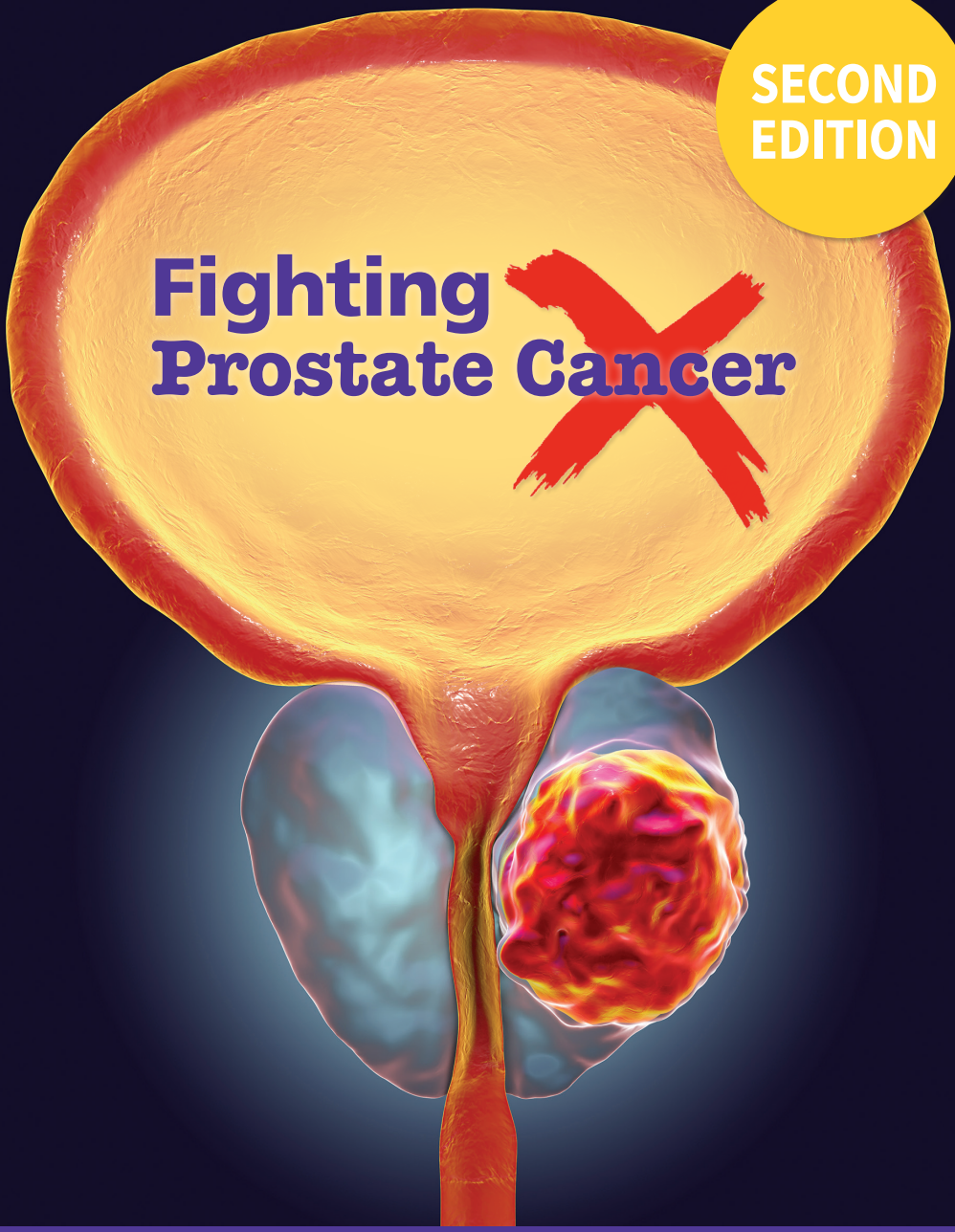
SECOND EDITION

Fighting Prostate Cancer



A SURVIVAL GUIDE

Dr. Jyoti Shah MBE

Fighting Prostate Cancer – A Survival Guide

First published June 2022
Second Edition September 2026
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Medical knowledge is a constantly evolving and changing field. The author has made every effort to ensure the accuracy of the information. This book is published in good faith but the author 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

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PRAISE FOR THE BOOK

WHAT READERS ARE SAYING

"This book is a clear, compassionate, and easy-to-understand guide to prostate cancer. It explains a highly complex subject in a simple way, making it especially valuable for patients and families who may be feeling frightened or emotionally overwhelmed during the difficult times of a cancer diagnosis. A must-read."
Anonymous

"A most excellent book"
Peter

"The book, I must say is the most informative book and keeps one in the loop as what to expect. I feel the NHS should give this book to any man diagnosed with prostate cancer"
Praful

"It is quite excellent. You have given a very clear and reassuring explanation of the issues surrounding prostate cancer. It is a wonderfully comprehensive guide for the laymen"
Graham

"Informative, useful and very helpful"
Pauline

"So much helpful information. I take it to every appointment"
Di

"I found your book extremely informative, written in layman's terms, such that most men should understand its significant message that will hopefully guide men into looking after their health"
Trevor

"A very comprehensive book full of information to help at EVERY stage of this horrible journey"
Nalin

"This book has everything we need on radiotherapy, diet, everything. It is amazing!"
Davida

"This book is a bible for any man with prostate cancer"
Darren

"Great to have everything you need to know in one place"
Roxy

"Everything prostate cancer in one place. You need no other information if you have this book"
Urban

"Read it, understand it, and then you are prepared"
Mark

"Excellent book. I read it in one day. I couldn't put it down – it's that easy a read. BUT it armed me with so much information in this wilderness; it prepared me for the fight ahead"
Robert

"It's really informative. But what I like about it most is that it is very user friendly. This has lots of colours, and photos, which makes it a much easier read!
Sally

"I can't believe I actually love this book, given it's a cancer book! I take it everywhere. This book addresses the key issues surrounding prostate cancer. Having the information helps makes sense of something that otherwise makes no sense. It has helped me and my family so much. I strongly recommend it for anyone and everyone"
Pat



CONTRIBUTORS

Lauren Henson



Lauren is a Macmillan Lead Uro-Oncology Clinical Nurse Specialist at North West Anglia NHS Foundation Trust. She leads a dedicated team of nurses with passion and is the only nurse at the Trust who independently performs prostate biopsies. Her specialist interest is in prostate cancer.

Dr Mike Smith-Howell



Dr Smith-Howell is an experienced and dedicated Consultant Clinical Oncologist at University Hospitals of Derby & Burton NHS Foundation Trust. He specialises in radiotherapy for prostate cancer and is a core member of the urology MDT.

Professor Prasanna Sooriakumaran



Professor Prasanna Sooriakumaran, widely known as PS, is a world-leading urologist and one of the UK's highest volume robotic prostate cancer surgeons. He currently works at University College London Hospitals NHS Foundation Trust. Professor PS is also the Lead Investigator on a £3million UK-wide clinical study examining the role of robotic surgery for men with advanced prostate cancer. www.prostatecliniclondon.co.uk

Chris Wood



Chris Wood has over 30 years' experience in global corporates, followed by many more years running his own business. He has held many senior leadership positions including Chairman of Burton Hospitals NHS Foundation Trust. Chris is a humanist and was diagnosed with prostate cancer in 2022. He is now in remission and living life to the full.

PREFACE



Just recently, a man in his early 60s saw his GP with a cough and had a battery of tests, including his PSA. Imagine his shock when the result was extremely high at over 750. Yet he had no trouble with his waterworks, so how could he have advanced prostate cancer?

There are so many such scenarios. And that is why this book exists.

When I wrote the first edition of *Fighting Prostate Cancer – A Survival Guide* in 2022, my aim was simple: to give men and their families an easy-to-follow, honest guide to understanding prostate cancer. The overwhelming response from patients, partners, clinicians, and community organisations proved the clear need for such information and showed that a book like this cannot stand still.

Prostate cancer is one of medicine's fastest-moving fields. Since the first edition, much has changed for tests and treatments alike. But with more options, comes more complexity. More decisions. More uncertainty. More pressure – for patients and their families.

This updated edition refreshes information to reflect current medical practice. What remains unchanged is this book's purpose: to cut through the jargon and give men and their loved ones the clearest possible foundation for conversations with their clinical teams.

The Fighting Prostate Cancer campaign has been running since 2016. I am deeply grateful to Burton Albion Football Club and Chairman Ben Robinson MBE, Burton Mail, The Freemasons, Rotary Clubs, the many individuals (too many to name) and the community organisations, who have championed this cause.

This second edition would not exist without my co-authors, contributors, my patients (past and present), and Toni and Dean from the Magazine Production Company Ltd, who have again worked their magic. This free resource is made possible by the generous funding by Darren Breen at iMEDicare Ltd Pelvic Health Naturally. Finally, thank you to my very patient husband… for everything.

I hope this second edition reaches further, and reminds every man reading: you are not alone in this.

"This book is dedicated to any man facing the terrifying experience of cancer"

Dr. Jyoti Shah MBE

@missjyotishah

www.fightingprostatecancer.co.uk



When we heard about the work Jyoti Shah was doing, we offered to support the printing of this guide — without hesitation, and without conditions. Fighting Prostate Cancer: A Survival Guide is exactly the kind of resource we wish every man received the day he heard the words "prostate cancer": clear, honest, and written by someone who has spent her career in the room with these patients.

This isn't just business for us. My own grandfather died of metastatic prostate cancer, and that loss is part of why I take this disease so personally – it's why I now have my own PSA checked regularly, now that I'm nearly 55. I know first-hand what it means for a family to lose someone to this disease, and what it means to wish they'd had a guide like this one.

iMEDicare has worked in andrology and male continence management since 2004. We were founded on a simple belief: that men shouldn't have to choose between treating their cancer and living a full life afterwards. Erectile dysfunction and incontinence are common, often expected, consequences of prostate cancer treatment — yet they're still spoken about too quietly, too late, or not at all. Our mission has always been to make sure no man who could benefit from the right device is left unaware of it, and that when he finds it, it's fitted, sized, and explained properly rather than handed over in a box.

Today, that means a dedicated field team of device specialists working across every region of the UK and Ireland, supporting men and their clinical teams directly — and it means most of what we provide can be accessed simply, through an NHS FP10 prescription from your GP.

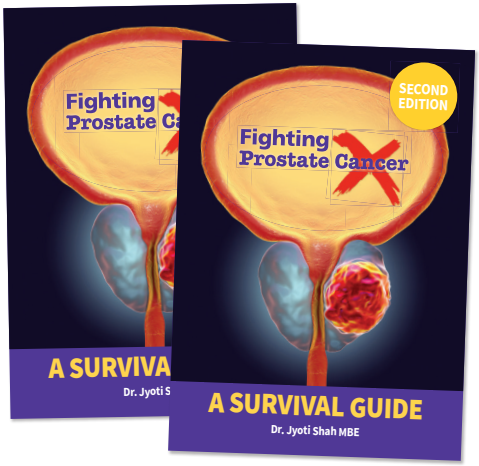
We're proud to fund the printing of this guide as a gesture of support for the urology community and the patients it serves, with no influence over its content and no expectation of anything in return. Jyoti's expertise is her own, and this book stands on it alone.

We hope this guide gives you, and the people who love you, the clarity and confidence to face what's ahead.

Darren Breen – Director

iMEDicare Ltd – ***Pelvic Health Naturally***

www.MyPelvicHealth.co.uk



THE PROSTATE 1

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

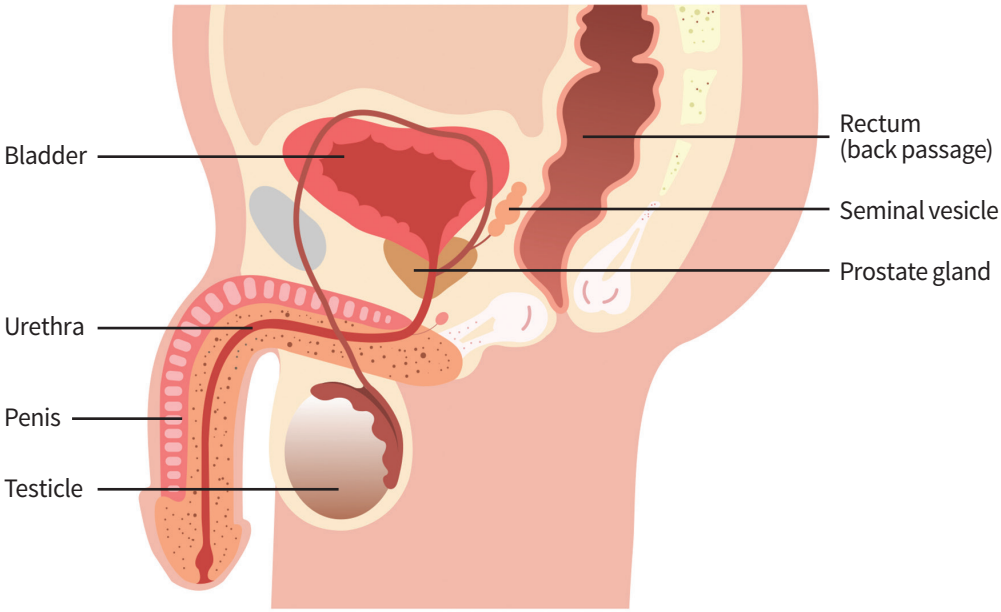
What does the prostate do?

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 liquefies 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

The current Guinness World Record for the largest prostate removed is 2.41 kg with a diameter of 24 cm in a 57-year old man



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

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). Rarely the prostate can grow over 500 grams, and this is called Giant Prostatic Hyperplasia (GPH). 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



Walnut	Ping Pong Ball	Golf Ball	Clementine	Tennis Ball
3.4 cm diameter Approx 20cc	4 cm diameter Approx 33cc	4.3 cm diameter Approx 40cc	5 cm diameter Approx 65cc	6.7cm diameter Approx 150cc

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 / GPH
- 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 size prostate has a volume of 30-40ml
- A medium size prostate has a volume of 40-80ml
- A large size prostate has a volume greater than 80ml

PROSTATE CANCER 2

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 –*** 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 –*** 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 –*** cancer of the blood
- ***Lymphoma –*** 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

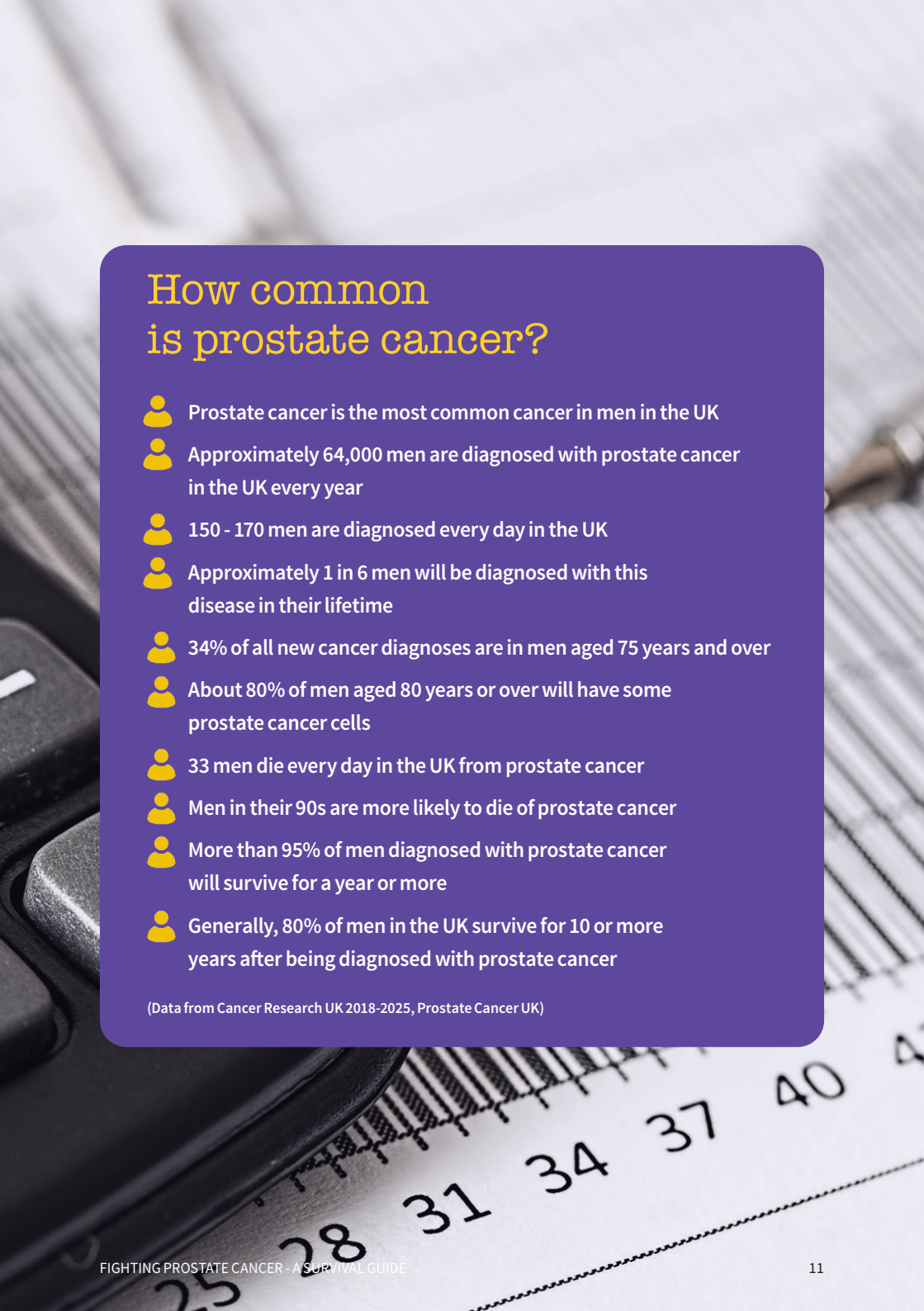
How does cancer spread?

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 64,000 men are diagnosed with prostate cancer in the UK every year
- 150 - 170 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
- 33 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
- Generally, 80% of men in the UK survive for 10 or more years after being diagnosed with prostate cancer

(Data from Cancer Research UK 2018-2025, Prostate Cancer UK)

What are the risk factors for prostate cancer?

- ***Being male***

- ***Age***

  One of the biggest and established risk factors for prostate cancer is age. The risk of getting prostate cancer under the age of 50 years is low but increases if there are other risk factors. Most cases are diagnosed in men over 65 with the highest incidence in men aged 75-79 in the UK

- ***Race***

  Prostate cancer is least common in Asian men 1:13. Men of African-Caribbean descent are at much higher risk 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

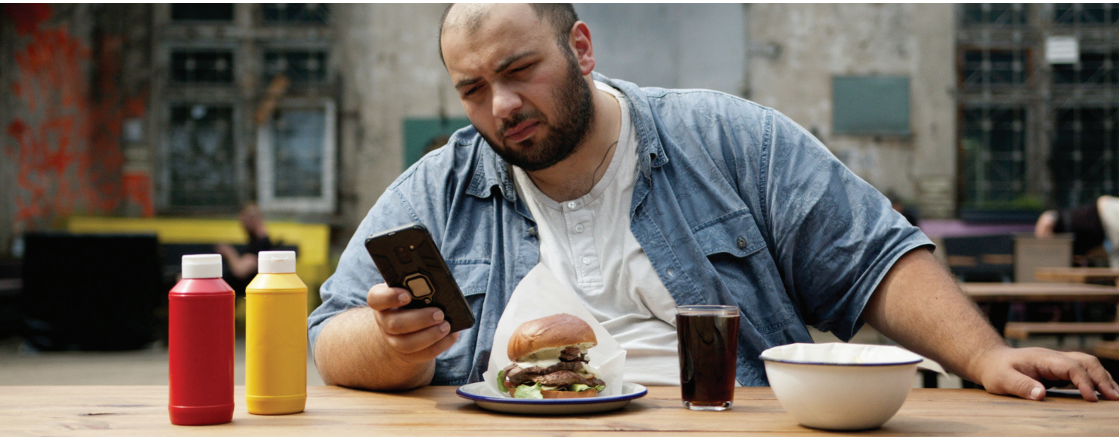
- ***Family History***

  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. True hereditary prostate cancer is defined as ≥ 3 cases in the same family, prostate cancer in 3 consecutive generations, or ≥ 2 cases in the same family diagnosed < 55 years

  - 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, nephew or half-sibling) with the disease
  - Your risk is higher if you have more than one 1st degree relative with prostate cancer
  - 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

(Data from Cancer Research UK 2016-2018)

- ***Genetic Factors***
  - Men with the BRCA2 gene mutation have a higher lifetime risk of prostate cancer and tend to develop the disease under the age of 65. The risk may be higher if you have a BRCA1 variant
  - Prostate cancer risk is 2.1 – 4.9 times higher in men with Lynch Syndrome (Hereditary Non-Polyposis Colorectal Cancer, HNPCC) compared to the general population
- ***Obesity (BMI of 30 or more)***
  Men who are obese are more likely to develop advanced or more aggressive prostate cancer
- ***Diet***
  A diet that is high in red meat (such as beef, pork, lamb, goat, veal, venison, mutton), processed meat (such as bacon, sausage, ham, salami, canned meat) and dairy products may be linked to an increased risk of prostate cancer. Tomato intake (mostly cooked) and lycopenes may reduce the risk of prostate cancer
- ***Testosterone***
  Testosterone supplements in hypogonadal men do not increase the risk of prostate cancer. However, current recommendations are to exclude prostate cancer before starting supplementation in men over 40 and careful monitoring in men who are at higher risk
- ***Chemical Exposure***
  Higher rates of prostate cancer have been identified in firefighters and men exposed to pesticides



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. Frequent ejaculations ≥ 21 times /month compared to 4-7 times/ month is associated with a lower risk of 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 deaths and worse prognosis, even after quitting

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

Gonorrhoea has been associated with a higher risk of 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"

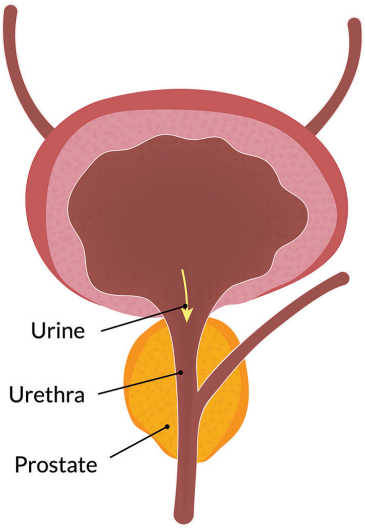
THE SIGNS & SYMPTOMS 3

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?

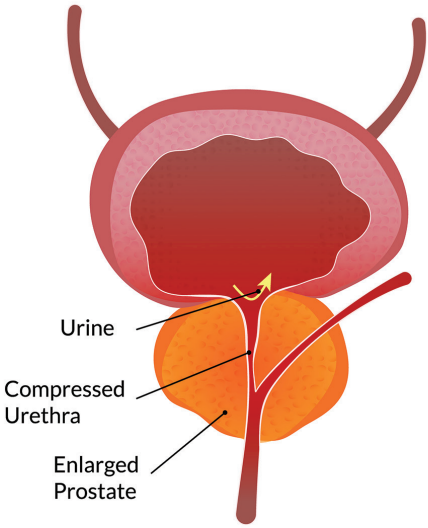
Unfortunately, early prostate cancer does not often cause any problems, which is why it is called a **'Silent Killer'**. Most prostate cancers start on the outer part of the prostate, which means it must grow quite large before it causes any problems

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 causes the common symptoms as men age. This growth is usually benign but can rarely be due to cancer. BPH does not turn into cancer

Normal prostate



Enlarged Prostate



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 (haematuria) or semen (haematospermia)
- 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 – can be due to 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 noted in 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

I have problems with my erections. Could this be a sign of prostate cancer?

Yes, sudden, new onset erectile dysfunction may be due to prostate 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'

PSA – PROSTATE SPECIFIC ANTIGEN 4

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 PSA 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. Intra-individual variations can vary by +/- 15%. Variations can also exist by up to 5% between different laboratories and assays

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. Thus, PSA is prostate-specific but not cancer-specific

- ***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 afterwards. 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 result in an increase in PSA levels for up to 6 weeks
- ***Digital rectal examination***
  An examination of the prostate does not cause a clinically significant rise in PSA levels
- ***Ejaculation***
  Ejaculation can increase PSA by 0.2-1 at 1 hour after ejaculation, and can take up to 48 hours to return to baseline
- ***Vigorous exercise***
  Exercise, especially cycling, can lead to rubbing of the prostate and leakage of PSA causing a temporary increase in PSA levels for up to 48 hours

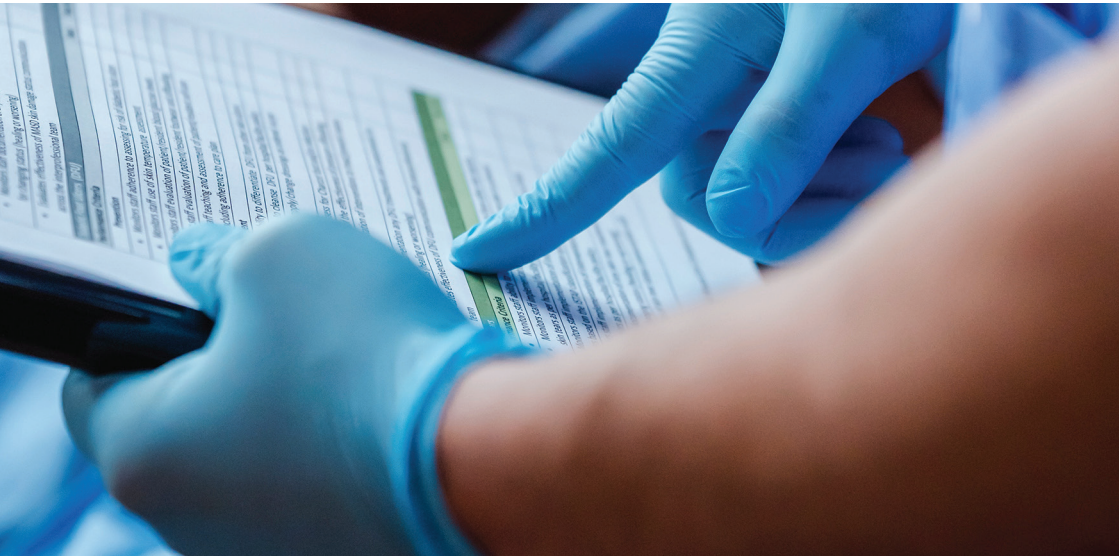
- ***Catheter***
  Having a catheter in the urethra can result in high PSA levels. Wait at least 2 weeks before having a PSA blood test after a catheter has been inserted or removed
- ***Anal sex***
  Any prostatic stimulation, including a massage or anal sex can cause PSA levels to rise for up to one week

Can anything decrease PSA levels?

- 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 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 you do not need 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:

- Ejaculation within 48 hours
- Vigorous exercise, lifting heavy weights or cycling for 48 hours
- Avoid receptive anal intercourse or prostate massage for 1 week before
- Prostate or bladder surgery for 3 months
- At the time of a 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 more 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
- ***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?

If you are over the age of 50 and have a prostate (men or trans women), speak to your GP about the advantages and disadvantages of having your PSA checked

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 referred to as 'PSA anxiety or PSAitis'
- 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 other possibly invasive tests such as biopsies
- A borderline high PSA may need serial tests over months - years causing anxiety and uncertainty
- It 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-treatment'

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 no longer entitled to a PSA blood test. 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), family history (one or more close relatives have prostate cancer), or you have a BRCA1 or BRCA2 gene mutation, 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

Does the 'flu jab affect PSA levels?

There is no evidence that the 'flu jab affects PSA levels. However, COVID-19 jabs can cause a temporary PSA rise

THE DIAGNOSIS 5

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). Since 2023, NHS England has introduced the Faster Diagnosis Standard, which aims to make a definitive diagnosis or rule out cancer within 28 days of receiving a UCR. Just because you have been referred to a urologist on this urgent pathway, does not necessarily mean that you have cancer

Please ensure your GP has your correct phone number, e-mail, and address to put on the referral form. The urology team may call you for a first consultation

How can you prepare for your appointment?

- If you have not heard from the hospital within 7 days of the UCR being sent, please contact your surgery
- Make sure you do any tests that your GP has asked you to do before the hospital visit
- Check where your appointment is, how long you are likely to be there, and what you are required to bring with you
- Plan your travel leaving sufficient time to find parking and the correct department
- Contact the relevant team to rearrange appointments that you cannot attend
- Always bring an updated list of your current medications
- Consider downloading the NHS App on your smartphone or tablet so that you can track your referral and appointments
- Consider taking someone you trust along to your appointments to support you

You may be given a lot of information and so it is useful to have someone who will help you remember things

- Make a list of questions you would like to ask the clinical team

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)

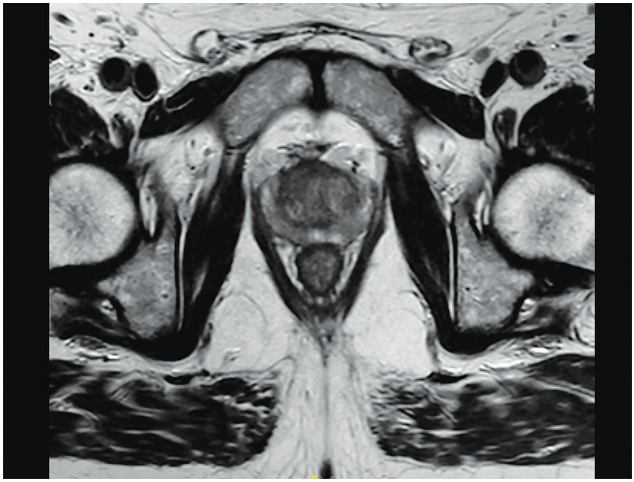
- In approximately 18% of cases, prostate cancer can be detected by a suspicious examination alone, regardless of the PSA level
- You will need to drop your trousers and underwear but not remove them altogether
- You will need to lie on your left side on an examination table
- Your knees need to be brought 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 lubricated gloved finger into the back passage
- The procedure does not take long, usually only 15 - 20 seconds
- It may be uncomfortable but not usually painful
- It is normal to feel anxious and/or embarrassed
- A DRE does not damage the prostate or cause infections
- After the examination, you can get dressed
- You can continue with normal activities after this examination, including driving
- 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
    - Abnormal – may feel hard, firm and / or knobbly, suggestive of cancer

The most money raised at a company quiz for the Prostate Charity is £21,095 achieved by donors from Royal Mail Group at the Royal Mail Group Forum in Birmingham, UK, on 26 June 2012 (source: Guinness World Records)

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 give detailed and accurate images of the prostate and can avoid the need for invasive biopsies in a significant proportion of men

There are 2 types of MRI scans – biparametric (bpMRI) and multiparametric (mpMRI)



MRI scan

Biparametric MRI

A faster (15-20 minutes), more cost-effective MRI scan that does not involve the use of contrast dye. Recent evidence shows that both types of MRI scans are comparable

Multiparametric MRI

This is different from bpMRI scans and uses 3 key sequences:

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

Diffusion-weighted images – 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)

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

Preparing for an MRI scan

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
- Avoid sexual activity resulting in ejaculation for 3-4 days before your MRI scan. This allows the seminal vesicles to naturally widen so that they can be clearly seen on the scan to check for cancer within them

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 required

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 if you are having an mpMRI scan. 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 blurred 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 for an mpMRI scan
- You may feel warm in the machine
- An mpMRI 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 analysing and interpreting X-ray images. Most scans are reported using the PI-RADS (Prostate Imaging – Reporting and Data System) or Likert scoring systems. The latter is more subjective based on the reporting radiologist's experience and the PSA, whereas the PIRADS system is highly structured and rule-based

MRI scans tend to report lesions. A lesion is an area on the scan that looks different from the surrounding prostate area. It doesn't always mean cancer, and could be an area of scarring or irritation

- **PI-RADS 1/ Likert score 1**
  Very low risk – highly unlikely that you have significant prostate cancer
- **PI-RADS 2/ Likert score 2**
  Low risk – unlikely that you have prostate cancer that needs treatment
- **PI-RADS 3/ Likert score 3**
  Intermediate risk – this is a borderline result and means that the risk of clinically significant cancer is equivocal, or we can't tell for sure
- **PI-RADS 4/ Likert score 4**
  High risk – high chance that there is cancer that needs treatment
- **PI-RADS 5/ Likert score 5**
  Very high risk or very suspicious and it is highly likely that there is clinically significant 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 of 1 or 2, then you are unlikely to need a biopsy. Your personalised care will depend on the size of your prostate, your PSA and whether you have other risk factors



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, or if the DRE / PSA suggest the possibility of cancer. 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 with similar, significant cancer detection rates that you may be offered:

- Transrectal ultrasound (TRUS) guided – better for cancers at the back of the prostate (posterior)
- Transperineal biopsy – better for cancers at the front of the prostate (anterior)

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 a slow-growing / non-aggressive cancer (called clinically insignificant), leading to potential over-treatment

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
- A prostate biopsy is not recommended 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 may 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 whilst the infection is treated
- 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 current medications or a copy of your latest prescription

What happens before a TRUS biopsy?

- You can eat and drink normally before a 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 need to provide a urine sample to ensure there is no evidence of infection

What happens during a TRUS biopsy?

- If you have not changed into a hospital gown, you will need to drop your trousers and underwear
- 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 inserted 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 1-2 days 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
- It is normal to feel bruised

What are the possible side effects of a TRUS biopsy?

- Infection
  - o 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

There is a lower risk of infection with this type of biopsy compared to TRUS biopsies. Many Trusts offer this type of biopsy as a default

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 current medications or a copy of your 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 may 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 do not routinely need antibiotics before this type of biopsy, unless you are at a higher risk of infection, such as if you have a catheter in place
- 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 lubricated with 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
- The clinician will decide how many biopsies are required but can be up to 24 cores
- This process takes 20-30 minutes but may be less if you are only having a few samples from a target abnormal area seen on the MRI scan

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 intercourse for at least 1 week after the biopsy

What are the side effects of a transperineal biopsy?

- A transperineal biopsy has a lower risk of infection than a TRUS biopsy
- You may notice blood in the urine – this is usually mild but can last up to 10 days
- 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
- Contact your GP or go to any Emergency Department if you have signs of an infection, such as high temperature, difficulty passing urine, shivering or shaking or if you pass large blood clots

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
- **SelectMDX –** non-invasive urine test that looks at the expression levels of HOXC5 and DLX1 genes. It gives a score indicating the likelihood of high-grade aggressive prostate cancer
- At the present time, none of the above are routinely used in the NHS

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. Most cancers are adenocarcinomas and are described using the Gleason Grade. Other cancer types include squamous cell, sarcoma, lymphoma, or neuroendocrine, of which small cell is the most common
- **Negative** – there is no cancer
- **Suspicious** – the cells contain some abnormal areas but there is no cancer. These can be called HGPIN or ASAP
    - HGPIN – High Grade Prostatic Intraepithelial Neoplasia – abnormal changes in the prostate cells but no cancer
    - 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
    - The chance of finding clinically significant cancer at repeat biopsy after either HGPIN or ASAP is not significantly different to finding cancer after a negative initial biopsy, at 6-8%. Thus, you do not need routine repeat biopsies after finding HGPIN or ASAP (EAU Guidelines, 2026)

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 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 number is the next most common shape or grade

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 and called low-grade or well-differentiated*
- **Gleason score 7 (3+4) or Grade Group 2** - *Gleason score 7 cancers are called moderately differentiated*
- **Gleason score 7 (4+3) or Grade Group 3** - *intermediate grade*
- **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 and Grade Group 4/5 cancers are called high-grade or poorly differentiated*



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. You may require a repeat biopsy

What happens 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)

COPING WITH CANCER 6

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, as 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, 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 or 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 help 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

- 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
- There is still a stigma surrounding cancer, for many reasons and this may make you feel uncomfortable. For example, some people still think cancer is contagious. Remind people of the facts

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
- Make a list of questions that you want to ask and take it 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 or using the NHS App

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
- **Help with finances**
- 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
- To be eligible for some of these benefits, you need to show

- how your condition affects you
- how often you are affected (frequency, such as daily)
- that you are having problems looking after yourself

- **Help with Travel/ Parking**
- Travelling to regular hospital appointments can be expensive. You may be able to get help with travel costs, and this depends on where you live. Talk to your specialist or CNS about this or the Citizens Advice Bureau
- Many hospitals in England offer free or discounted parking for people affected by cancer
- From April 2020, parking in hospitals in England is closer and free if you have a Blue Badge
- The Healthcare Travel Costs Scheme (HTCS) offers refunds for travel costs if you meet 3 criteria:
  - receive a qualifying benefit or meet the NHS Low Income Scheme criteria
  - be referred by a healthcare professional for specialist care
  - attend a separate visit from when the referral was made regardless of where that appointment is
- Keep all receipts / proof of payment
- You must submit any claim within 3 months
- You may be able to get free transport in your area with Patient Transport Services (PTS) – ask your specialist or CNS
- Several charities offer free, volunteer-run transport services to get you to and from your chemotherapy or radiotherapy treatments. Ask your team or the Macmillan Cancer Centre for further details
- People being treated for cancer can get an exemption certificate that allows them to get free prescriptions for all medicines
  - You can get an application form from your GP, pharmacy or hospital doctor and it requires a doctor's signature
  - You will usually get the certificate within 10 days of receipt of the form
  - If you pay for any medication before the certificate arrives, ask for an FP57 refund receipt and form at the time of payment – you then have 3 months to claim your refund
  - It is valid for 5 years or until your 60th birthday and then needs to be renewed
  - You do not need an exemption certificate if you are already eligible for free prescriptions, such as if you are over the age of 60 years

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



STAGING 7

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 in the body and is used to guide the treatment plan. This is determined using various scans depending on:

- Your PSA levels at the time of referral
- 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 – whether the cancer has spread to the lymph nodes

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

TNM Staging

Sometimes the extent of the cancer is determined by the urologists' physical examination of the prostate - this is called clinical staging

- 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 grown outside the prostate capsule (covering of the prostate gland) on one or both sides (T3a) or has spread to one or both seminal vesicles (T3b)
- T4 – the cancer has spread to tissues near the prostate, such as rectum or bladder
- Nx - lymph nodes cannot be assessed
- N0 - no cancer in nearby lymph nodes
- N1 - cancer has spread to lymph nodes in the pelvis
- M0 - no spread further afield
- M1a - cancer has spread to lymph nodes outside the pelvis (including common iliac lymph nodes)

- M1b - cancer in the bone(s)
- M1c - cancer in other sites such as lungs, liver, brain

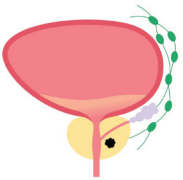
The Number Staging System

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

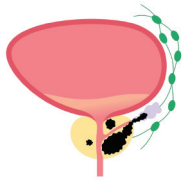
Stage IV – the cancer has spread to other places such as bones – this is called metastatic cancer



Stage I



Stage II



Stage III



Stage IV

The Cambridge Prognostic Group Classification (CPG)

- **CPG 1** (Low Risk)
  - Gleason score 6 and PSA < 10 and Stage T1 – T2
- **CPG 2** (Intermediate Low Risk)
  - Gleason score 3+4=7 (Grade Group 2) or PSA 10-20 and Stage T1 -T2
- **CPG 3** (Intermediate High Risk)
  - Gleason score 3+4=7 (Grade Group 2) and PSA 10-20 and Stage T1-T2 or
  - Gleason score 4+3=7 (Grade Group 3) and Stage T1 – T2
- **CPG 4** (High Risk) – any ONE of the following:
  - Gleason score 8 (Grade Group 4)
  - PSA > 20
  - Stage T3
- **CPG 5** (Very High Risk) – you are categorised as CPG 5 if:
  - Stage T4
  - Gleason score 9 or 10 (Grade Group 5)
  - Multiple High-Risk Factors with at least 2 of the following: PSA > 20, Gleason score 8 (Grade Group 4), or Stage T3

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 within 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 – 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

- If your kidney function test, called estimated glomerular filtration rate (eGFR) is below 30 ml/min/1.73 m^2, the scan may proceed without contrast to avoid further damaging your kidneys
- 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, then this will be injected into the cannula. This allows certain areas to be seen clearer. During the injection, you may feel a warm sensation, like a hot flush. You may also feel the need to pass urine, but this does not happen

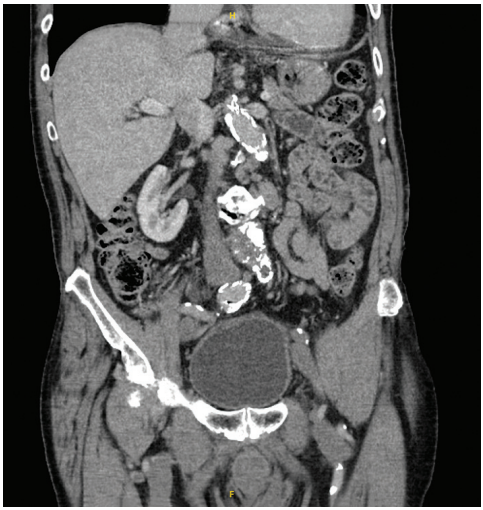


What happens during a CT scan?

- 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 blurred
- 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 (both with and without contrast)

Is the contrast medium safe?

Contrast 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 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
- Notify the X-ray staff if you are allergic to or sensitive to medications, contrast dyes or iodine

What happens before a Bone Scan?

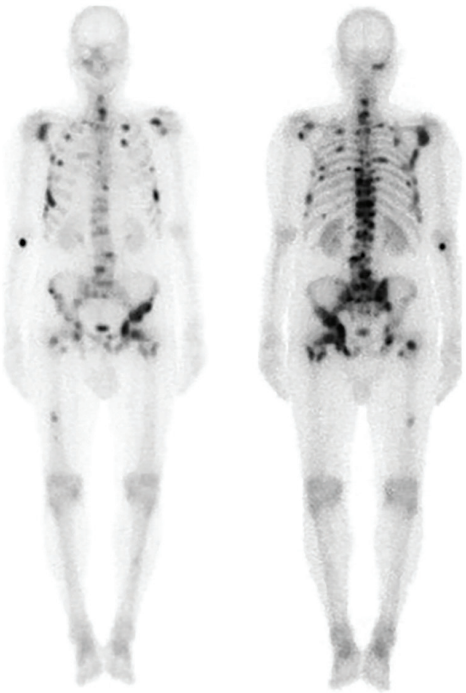
- You will be asked to arrive up to 4 hours before the actual scan
- You will have a small cannula inserted into a vein in your arm or the back of your hand
- A radioactive liquid called a tracer will be injected through the cannula
- Whilst the drug travels through the body, you will need to wait 2-3 hours, so think about bringing a book to read or some work to do to pass the time
- 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 eyeglasses

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 but 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
- 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
- For the rest of the day, wash your hands thoroughly after using the toilet, sit down when you use the toilet and flush the toilet twice – all this helps clear the radiation from your body



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

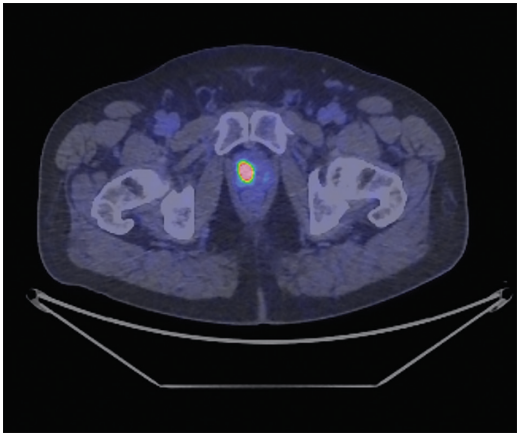
How long does the radiation dose last in my body?

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. It 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 and provides greater accuracy than traditional imaging. Not all hospitals have a PET scanner so you may need to travel long distances for your 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. The radioactive tracer binds to PSMA protein, which is found in large quantities on the outside of prostate cancer cells. The most common radiotracers are Gallium-68 or 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 or suffer with any allergies

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 travels through the body
- Wash your hands thoroughly after using the toilet. Flush the toilet twice for the rest of the day

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 obtain 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
- You can drive after the scan as the tracer does not make you feel drowsy
- You may feel tired due to fasting, lying still during the scan, and the stress of travel/ testing

Common Questions

What level of PSA can a PSMA PET scan detect?

Cancer can be detected when the PSA is as low as 0.2. As it rises, the sensitivity of the scan increases; when the PSA is over 2, the sensitivity of PSMA PET scans is 95-97%

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. Apply a cold compress or gentle pressure. Consider over-the-counter painkillers. 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. On average we get about 3 mSv of background radiation every year.
The radiation from a PSMA PET scan is 4-7 mSv

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 useful to take 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

THE MDT 8

What is an MDT meeting?

An MDT (Multidisciplinary Team) meeting is an essential, regular, structured, minuted meeting where healthcare professionals from various medical specialties meet to plan cancer treatments. By bringing together diverse clinical expertise, the team ensures that each patient's individual needs and well-being remain the central focus of their care. The team pools their collective knowledge to agree on the safest, most effective, and personalised care plan. The MDT also ensures that consistent, evidence-based treatments are explored and agreed upon

Under NICE guideline NG131, MDTs ensure that no single clinician makes treatment decisions in isolation, and that all reasonable options are considered for your cancer. Several things are evaluated to arrive at the best treatment plan:

- ***Cancer Characteristics*** – your PSA trend, Gleason Grade (type of cancer), size of cancer, stage (has it spread)
- ***Tests*** – prostate examination, PSA, MRI, biopsy result, staging scans
- ***Patient characteristics*** – general medical health, life expectancy, symptoms, family history and crucially what is important for you (sexual function, continence, quality of life)
- ***Evidence*** – Guidelines for managing your cancer

Why are MDT meetings in place?

In the UK, MDT meetings are widely recognised as the "gold standard" for cancer care. Introduced in the 1990s, these panels were established to boost survival rates, improve treatment quality, and ensure that every patient receives care aligned with the latest evidence-based guidelines. The key aims are:

- To ensure accurate diagnosis and staging
- Timely treatment of patients with cancer
- Patient care is evidence-based
- Provide co-ordinated, seamless continuity of care
- 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. Think of the MDT as a puzzle and each member brings with them a different piece of the puzzle to arrive at the full picture. Other specialists may join the team from time to time, but the typical team includes:

- **A Lead Clinician** – usually a Urology Consultant, who takes responsibility for the urology cancer services at the hospital
- **Urology Consultants** – surgeons 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** – a doctor who specialises in treating cancer with chemotherapy and other cancer drugs. Oncologists also advise on further testing, monitoring, or drug treatment options
- **Clinical Oncologist** – a doctor who specialises in treating cancer with radiotherapy, chemotherapy and other cancer drugs
- **Histopathologists** – a team of doctors who examine tissue samples (biopsies) under the microscope and help reach a diagnosis
- **Radiologists** – a team of doctors who review and report images such as X-rays, Ultrasound, MRI, CT and PET scans. They also advise on further scans that may be required for monitoring cancers
- **MDT Co-ordinators** – 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 Co-ordinators** – 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 co-ordinating your care with different members of the MDT, and ensuring you have the advice and support you require. You will usually meet your CNS at the time of your cancer diagnosis
- **Extended Team** – this includes Palliative care specialists, Hospital Chaplains, Clinical Psychologists, medical secretaries and other specialists if you have certain medical conditions or cancers

Are all patients discussed in an MDT meeting?

Every cancer patient is officially listed and recorded on the MDT agenda, but not everyone requires a full discussion during the meeting. Instead, patients are guided down one of two pathways based on their specific medical needs:

- **Standard of Care (No Live Discussion):** Patients with straightforward results do not require an open debate. Their treatment plan is matched with pre-approved non-controversial, local and national clinical guidelines, allowing care to start without delay
- **Complex Cases (Live Discussion):** High-risk, rare, or unusual diagnoses are always discussed by the MDT panel to create a bespoke treatment plan

Can patients attend an MDT meeting?

No. This is because multiple cases are reviewed, which risks breaching other patients' confidentiality. However, your CNS or medical team will present your individual views, questions, or preferences to the panel on your behalf. If you have anything specific you wish for them to share, make sure you let your team know

How do patients get added to the MDT meeting list?

Any member of the MDT team can ask for a patient to be discussed. Usually, the urologists or oncologists submit an electronic request to the MDT co-ordinator. The co-ordinator then creates the meeting list, which has a strict cut-off deadline. Doctors from other departments can also ask the urology team for advice, but they must fill out a referral form explaining their exact question and listing the scans they want reviewed

How often does the meeting take place?

Urology MDT meetings typically occur once a week. Because timetables vary, you will need to contact your local hospital to find out what day the urology MDT takes place

How soon will my results be discussed?

Once your results are ready, they will be reviewed at the next MDT meeting. Because these meetings take place weekly, you may wait up to 7 days for your discussion, depending on the exact date your results come back

Can I have my results before the MDT meeting?

It is recommended that diagnostic results undergo review and verification at MDT. Occasionally results change after the MDT review. For example, mis-matched MRI scans and biopsy results are cross-checked during this review process

What happens after the MDT meeting?

You will be informed of the MDT recommendations after the MDT meeting in one of the following ways:

- Face-to-face in clinic
- By telephone
- In writing

Your General Practitioner (GP) will receive a formal copy of the meeting outcome to update your records. You will also automatically receive copies of any correspondence sent to other medical professionals

Will my case be reviewed at an MDT meeting more than once?

While many patients are only discussed at the start of their care to agree on an initial treatment plan, a patient's case can be brought back to the MDT meeting multiple times whenever their circumstances, test results, or health needs change. Sometimes a case may be discussed at a specialist meeting (SMDT). SMDT is a regional panel of medical experts who manage rare, complex, or advanced cases that require specialised equipment or treatments that are not available at local hospitals



Common Questions

Are MDT decisions documented?

After the MDT, the co-ordinator logs the decision electronically and distributes the summary to the team. Each consultant records the detailed discussion in the patient's medical notes for future reviews

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

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

Is the MDT decision legally-binding?

No. The MDT decision is advisory and is a recommendation. The final choice is yours providing all reasonable options and risks have been discussed with you

Does the MDT make the final decision on my treatment?

No. The MDT's role is purely advisory; they pool their expertise to create a formal clinical recommendation. Ultimately, the final choice is always yours. You will make the decision together with your consultant, and no treatment, operation, or procedure will ever start without your clear, informed permission

Are there any challenges within the MDT?

Due to the growing number of cancer cases, and the complex nature of treatments after diagnosis, the key challenge is always having enough time to discuss everyone. Additionally, as you are not present at the MDT, it is important that your voice is adequately represented at the meeting so that assumptions are not made about you, your age or other factors that can potentially narrow available treatment options



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.

ACTIVE SURVEILLANCE 9

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 get 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; focal therapies or brachytherapy) include:

- Your cancer is confined to the prostate – this is called localised prostate cancer
- You have a Cambridge Prognostic Group (CPG) of 1 or 2 (see staging chapter)
- The Gleason score is 6 or 7, suggesting that it is slow-growing
- You may be suitable if you have CPG 3 localised prostate cancer and want to avoid or delay treatment. But, the following criteria apply: Gleason Grade 3+4 (Grade Group 2); absence of intraductal or cribriform pattern (considered poor prognostic features noted on biopsy samples); minimal Gleason pattern 4 disease; PSA <20; stage T1 or T2
- If the cancer starts to grow, then you can still have treatment with the aim of cure
- There are no or minimal symptoms
- You have a life expectancy of 10-15 years and will therefore benefit from treatment, if required, in future
- 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**

Some men are reassured in knowing their cancer is being closely watched and treated only if necessary. Other men find living with cancer that is not being treated stressful and prefer "to get it out" immediately

- **Ethnicity**

Are there any risks of active surveillance?

- Under-sampling – the initial biopsies may have missed a pocket of more aggressive cancer
- Frequent medical appointments
- Needing repeat prostate biopsies
- The main risk of active surveillance is that the cancer can grow faster than expected, but this is rare if you are monitored closely by a specialist
- Rarely the cancer can spread whilst on an active surveillance programme making curative treatment impossible. Studies indicate the risk of this is less than 1 in 100
- Your general health may change making you less suitable for curative treatments
- Some men find being monitored and not having active treatment stressful

What are the risk factors for the cancer getting worse?

There are some factors that are considered high risk for the cancer progressing. You may wish to discuss these with your specialist before starting on an active surveillance pathway

- You have a family history for prostate cancer
- You are of African-Caribbean heritage

- Your PSA density is > 0.15 (chapter 4)
- Your original MRI shows a PI-RADS 5 abnormality
- Any biopsy core (single sample) has > 50% cancer involvement

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 - this sort of follow-up may be carried out remotely without the need for face-to-face consultations with the specialist
- 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

STRATified CANcer Surveillance (STRATCANS) strategy

Men being considered for active surveillance can be risk stratified and followed up using the modified 3-tier STRATified CANcer Surveillance (STRATCANS) strategy. This is an example of an active surveillance pathway using CPG, PSA density, and the presence of an MRI abnormality to divide men into STRATCANS-tiered risk groups:

- STRATCANS group 1 (low intensity) – CPG 1 AND PSA density < 0.15 – least likelihood of progression
- STRATCANS group 2 (moderate intensity) – CPG 2 OR PSA density ≥ 0.15
- STRATCANS group 3 (high intensity) – CPG 2 AND PSA density ≥ 0.15 – highest risk of progression
- The recommendation is that PSA is checked every 3-4 months but should not trigger a change in treatment. Rather, a continuous rise should prompt a repeat MRI scan
- All men on this pathway will need a repeat MRI scan:
    - If the PSA is rising and other causes of a rise have been ruled out
    - Every 5 years if there is no abnormality on the MRI scan (PI-RADS 1 -2)
    - Every 2 years if PI-RADS 3-5, except

- Annual MRI for men in the highest risk STRATCANS group, regardless of MRI PI-RADS score
- A change in the repeat MRI scan could trigger another biopsy

PRECISE Score

Prostate Cancer Radiologic Estimation of Change in Sequential Evaluation (PRECISE) is a standardised scoring system used to monitor cancer on MRI scans in men on active surveillance. It uses a 1-to-5 scale to track changes in size and appearance of lesions compared to the original baseline MRI scan

- PRECISE 1-2: indicates regression such that the lesion has shrunk or is less visible
- PRECISE 3: stable disease - no new lesions, and existing lesions remain stable/ unchanged
- PRECISE 4-5: progression – the lesion has grown or new lesions have appeared
- The score is used to decide whether another biopsy is required
- The scoring system strongly predicts the risk of progression to a higher grade on repeat biopsies or potentially reduces the need for unnecessary biopsies if the score is 1-3



When does active surveillance stop?

- At any time, 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?

The key focus with active surveillance is deferring treatment until it is necessary but with the intent still on cure for men who are expected to live > 10 years. It is recommended for localised disease but requires more frequent tests than with watchful waiting. Watchful waiting tends to be observation for older men, who have limited life expectancy (< 10 years), have many other health problems or cannot have curative treatments. The focus is on quality of life and control with less frequent tests than with active surveillance

Is active surveillance the same as no treatment?

No, it is an observation strategy. You can still have curative treatment 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

When should I choose active surveillance?

If you have a small, slow-growing cancer that is low risk for growth/spread and your cancer does not threaten your life

What is the difference between PI-RADS score and PRECISE score?

Both scoring systems are used to evaluate prostate MRI scans for cancer. However, PI-RADS scores the initial likelihood of cancer at the time of making a diagnosis, whereas PRECISE tracks changes over time on repeat MRI scans

What is the difference between active surveillance and watchful waiting?

	Active Surveillance	Watchful Waiting
Treatment Intention	Cure	Palliation & control
Life Expectancy	> 10 years	< 10 years
Assessment	DRE, PSA, MRI scans, repeat biopsies	Observe for symptoms, PSA 1-2 times per year, scans only to look for spread
Follow-up frequency	As per protocols – usually 3 monthly PSA	Patient-specific
Aim	Minimise side effects of treatment and maintain quality of life	Track symptoms not test results
Eligibility	Low risk, slow growing cancers	Men in any category including advanced disease

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



WATCHFUL WAITING 10

What is watchful waiting?

Watchful waiting (WW) 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 shorten their life

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 appointments and tests
- To control the cancer but not necessarily cure it
- Provides flexibility to start treatment if the cancer starts to grow rapidly or cause symptoms

Who can be on watchful waiting?

- Men who do not want treatment or have no symptoms from their cancer
- Men who cannot have treatment or are too frail
- Men with other life-threatening medical illnesses
- Men with slow-growing cancers such that "you die with it, not of it"
- Men diagnosed at an advanced age and their natural life expectancy means it's unlikely that they will ever need or benefit from treatment
- In men with cancer that has spread after discussion – usually to avoid further detrimental side effects of treatments
- Men who transition from active surveillance (AS) due to increasing age or because they develop other medical problems that mean curative treatments will not benefit them. Studies have shown that up to 50% of men with very low-risk prostate cancer on AS transitioned to WW over their lifetime

What does watchful waiting involve?

- Regular monitoring either with a urologist or your GP every 6 -12 months. This is likely to be your PSA and an enquiry about any symptoms
- Fewer tests than active surveillance – you will not need invasive prostate biopsies
- You may need scans to assess if the cancer has spread – such as a CT or bone scan
- You will put off treatment that may cause side effects, until it is necessary. Alternatively, you may avoid treatment altogether
- If you do get symptoms, your doctor can help you to control and manage them. Many men never get any symptoms
- For older, frail men who may be housebound, regular monitoring of the PSA is not recommended. These men can start hormone treatment, if appropriate, based on symptoms

> 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 symptoms should I look out for?

- Difficulty passing urine
- Deteriorating kidney function
- Blood in your urine
- Extreme fatigue, tiredness or weakness
- Unexplained weight loss
- 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

When do I exit watchful waiting?

You may transition away from WW to start palliative treatment, such as hormones in the following circumstances:

- Symptoms suggesting disease progression
- Rapidly rising PSA or PSA doubling time < 3 months
- Your overall health declines or you develop new medical problems that limit your life, in which case WW will stop



SURGERY FOR PROSTATE CANCER 11

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 only surgical instruments and a cut in the abdomen below the bellybutton
- Laparoscopic radical prostatectomy - using keyhole instruments (similar to chopsticks with instruments on the ends for cutting, grasping, etc)
- Robot-assisted radical prostatectomy - using a surgical robot

Please note that robot -assisted means the surgeon is still in control and moving the robot to do the operation; 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 (keyhole) techniques and can achieve great outcomes for patients using those approaches. However, most surgeons find that the robot-assisted technique works best for them. The robot gives the surgeon greater precision and better vision. If a surgeon can both feel and see better, then this is generally going to result in better outcomes for patients

Returning 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 Rory McIlroy a wooden club. The optimal situation is to have the best equipment in the hands of the best operator; that is, a highly skilled robotic surgeon

Who can have a radical prostatectomy?

- Men with 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 tend not to get any benefit from removing the prostate as the cancer has already moved elsewhere
- Men must also be fit enough for the surgery, which is a 3-4-hour operation. Those with medical conditions especially of the heart, lungs or eyes may not be suitable candidates
- Finally, most men with prostate cancer confined to the prostate do not have a risk of death from the cancer for 10 years or more. The operation is trying to prevent death in decades to come, not the immediate years ahead. Therefore, men 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 simply be watched or managed with hormones

What is nerve-sparing radical prostatectomy?

The nerves that supply the penis and enable erections run along the sides of the prostate. Most of these nerves are located at the 5 and 7 o'clock positions if you imagine the prostate positioned upright with a clock face around it. Depending on where the cancer is located in your prostate, the surgeon will decide whether the nerves can be spared on one side or both sides. The more nerves that are spared, the better the chance of regaining spontaneous erections. Even if the nerves cannot be spared and the erections do not recover spontaneously, there are many ways to achieve erections - with tablets like Viagra, vacuum pumps (such as the SOMAerect Size to Fit brand from iMEDicare Pelvic Health Naturally), or penile injections. Most men can have erections strong enough for sexual intercourse after this operation, though they may not happen spontaneously and men may need assistance



SOMAerect Brand Vacuum Erection Device

What are the advantages of surgery?

- Surgery is generally a one-time procedure, and most men (more than 19 in 20) go home 1 - 2 days after the operation. It removes the cancerous prostate, providing a sense 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, this suggests the cancer is still present. If it drops to this very low level and then rises in the future, this suggests the cancer has returned. Hence, PSA monitoring after surgery is very accurate in detecting recurrence. With radiotherapy and other treatments where the prostate remains in place, the PSA measurements afterwards are less reliable at spotting recurrence
- Radiotherapy is given over several weeks and thus is not a one-off procedure. It is usually combined with hormone therapy for up to 3 years
- Surgery has an equal chance of cure compared 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 upfront surgery represents the best treatment choice for cure

How can prostate cancer come back after surgery?

Cancer cells can circulate around the body (called circulating tumour cells), which typically die when the prostate is removed. However, occasionally these cells don't die completely but instead lie dormant and become active later to cause a recurrence, even after the prostate is removed. That recurrence is often in the area where the prostate used to be (called the prostatic bed), or rarely in the nearby pelvic lymph nodes or bones. If cancer comes back in the prostatic bed, then men can have radiotherapy

Can I have surgery AFTER radiotherapy?

If men experience a recurrence after radiotherapy, surgery is usually not appropriate. This is because radiotherapy can cause significant scarring around the prostate, making surgery very difficult. This can result in complications such as long-term urinary leakage, impotence, and damage to important organs near the prostate. There are some highly experienced surgeons who are skilled enough to operate after a radiotherapy recurrence, but even in their hands the outcomes are worse than with upfront surgery

What are the side effects of surgery?

It is a major operation and, like all major operations, there are serious risks such as injury to 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 reduced but by no means eliminated. Whether a man will have spontaneous erections after surgery and whether these will be strong enough for intercourse is unpredictable, and all men should be prepared for a worsening of their erectile function after surgery. Having a skilled surgeon lessens the risk but any surgeon who promises a patient strong erections without needing help afterwards is over-selling the surgery. It is important for men to be prepared for the impact of surgery on their erections, but to know that help is available with tablets, vacuum pumps, or injections such that most men can have sex afterwards. It is also important to remember that erections can recover with time, so even if there are no spontaneous erections six months after surgery, they may return later. It can take up to 2 years after surgery for the erections to recover on their own, and this recovery can be supported with the various available treatments for erectile dysfunction
- The other main side-effect from surgery is incontinence or urinary leakage. This tends to occur with coughing, sneezing, and physical exertion, and can take months to improve. Doing pelvic floor exercises (similar to those many women do after childbirth) helps with recovery, and most men will regain dryness and stop wearing pads or using an incontinence device within 3-6 months after surgery

Several factors can predict recovery:

- skill and experience of the surgeon
- your age - younger men tend to recover continence faster
- your weight – men of normal weight tend to recover faster than those who are overweight
- the size of the prostate – the larger the prostate, the harder it is to get around it during surgery, and the longer it can take for men to recover continence afterwards
- how good continence was before the operation – men who were dry before surgery will recover faster than those who had some leakage beforehand
- although no surgeon can prevent all urinary leakage after surgery, ask your surgeon about their continence rates, both at 3 months and 12 months, and about what they do to minimise risk of urinary leakage. There is a technique called Retzius-sparing, which has been proven to reduce leakage rates after surgery, and is appropriate for some men depending on the location of the cancer in the prostate

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

What should I do before my surgery?

- Ensure you are taking regular exercise to be as fit as you can be before the operation
- If you smoke, stop
- If you are overweight, try to lose some weight before surgery
- If you wish to have biological children in the future, arrange sperm banking
- Start pelvic floor exercises before surgery (see below for instructions)
- Buy some continence pads so you have them at home when you need them
- Ensure you have medications, such as paracetamol or ibuprofen at home as you may need them after surgery
- Ask your surgeon about penile rehabilitation before surgery if preserving your erections is important

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, if necessary
- It is also likely you will have a COVID-19 test
- Take your regular medicines and any natural treatments you are taking 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 operation/anaesthetic
- 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 team 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 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 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

What can I expect during my stay in hospital?

- A surgical drain (a tube to remove any fluid or blood from around the surgical site), which is usually removed before you go home
- You will be encouraged to eat and drink as soon as you feel able
- Encouraged to walk around as soon as possible after surgery
- Given pain relief, usually paracetamol and sometimes stronger painkillers if needed

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 5-7 days. 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

How do I manage my catheter at home?

- Always keep the catheter bag below the level of your bladder to prevent urine flowing backwards
- Empty the catheter bag regularly; do not let it get too full
- Drink plenty of fluids (at least 2 litres per day) to keep your urine flowing and prevent infection
- Some blood in the urine is normal in the first few days; drink more water if this occurs
- Catheter spasms (bladder cramps) are common and can be uncomfortable. They usually settle with time. Walking and staying hydrated can help
- You can shower with the catheter in place; just ensure the bag is secured and below bladder level
- You will return to the hospital to have your catheter removed (this is called a TWOC; trial without catheter)

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

- Almost all men will experience some urinary leakage after catheter removal; this is normal and expected. This is reduced if you have a Retzius-sparing operation
- Use continence pads to manage leakage. Start with larger pads and work down to smaller ones as your control improves
- There are incontinence management devices available to assist in the interim, such as urethral control devices (e.g., the Pacey Cuff), washable incontinence underwear (such as Wearever Washables), urinal devices (such as Afex Core body worn urinal) or petal sheaths (e.g., Men's Liberty) – all available from iMEDicare Pelvic Health Naturally. Remember you can mix and match devices for optimal comfort in different situations



Pacey Cuff



Afex Active Urinal Device

- Pelvic floor exercises (Kegels) are essential to strengthen your muscles and regain continence. The sooner you start pelvic floor exercises (ideally before surgery), the better your recovery will be
- Do not do pelvic floor exercises while the catheter is in place
- Leakage tends to 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 consumed alcohol
  - You are straining, coughing, sneezing, or with physical activity

How do I manage my pain at home?

- You will normally take regular paracetamol for a few weeks after going home. This is usually all you need
- Try to avoid opiate painkillers (such as codeine or tramadol) as these can slow your bowel function
- Drinking plenty of water will help
- Walking at least a mile a day after the operation also helps settle the bowels and relieve the pain of abdominal bloating

Are there any warning signs after surgery that mean I should seek medical attention?

- Fever or high temperature
- Passing lots of blood or large blood clots in your urine
- If you cannot pass urine
- Wounds that become hot, red, or produce pus
- Severe increase in pain in your abdomen or down below (in the pelvis)
- If you feel very unwell in any other way, you need to either contact your hospital or go to any Accident & Emergency department

How long does the bruising take to settle?

- It is common to have some bruising on 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 supportive underwear such as briefs instead of loose boxer shorts

How do I avoid constipation after the operation?

- Walk regularly
- Drink plenty of water
- Eat a high fibre diet to avoid constipation after the operation
- Some surgeons may 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
- Pat the wounds dry gently so the stitches don't dissolve too quickly
- It is difficult to keep the wounds dry when bathing, so avoid baths 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 providing you can perform an emergency stop on a quiet road without pain or an increase in your braking distance – always check with your insurer
- Start by driving short distances and check for pain, blood in your urine, or increased leakage before increasing your driving time

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

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

When can I exercise after the operation?

- Walk at least a mile a day at a gentle pace (30-45 minutes per mile) after the operation to help your bowels work properly and to prevent blood clots in the legs
- Proper exercise should start 6 weeks after surgery, but that should be limited to fast walking, slow running, or weight training that doesn't put pressure on your abdomen
- Avoid any exercise that causes your belly to contract for 3 months after surgery This is due to the risk of hernia at the wound sites
- If you go to the gym, you can use the treadmill or do leg/ arm exercises after 6 weeks, but no core exercises like planks or sit-ups for 3 months


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- If you play golf, you can putt after 2 weeks and chip after 6 weeks, but no driving or the use of woods for 3 months

When can I have sex after my operation?

You can attempt sexual activity 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 erectile function?

This varies from person to person and depends on whether the nerves were spared, how sexually potent you were before surgery, your weight, your age, and your surgeon's skill. On average, it can take anywhere from 3 months to 2 years to regain erectile function after this surgery, and it may never fully recover. However, help is available with tablets, vacuum pumps, or injections to enable erections that are strong enough for sexual intercourse

What is penile rehabilitation?

Using therapies to keep your penis healthy, helps men achieve erections suitable for intercourse, maintain the length and girth of the penis, and improve the chance of erections after treatments such as surgery or radiotherapy for prostate cancer. It is like doing physiotherapy exercises after a knee replacement

- What therapies are available?
  - Counselling/ sex therapy
  - Medications such as Viagra, Cialis, Levitra or Stendra
  - Penile injections
  - Intraurethral suppositories
  - Alprostadil cream (such as Vitaros)
  - Masturbation can be considered a form of penile rehabilitation
  - Using Vacuum Erection Device (VED) known as vacuum pumps to draw blood into the penis, forcing the tissues to stretch and receive more oxygen
  - Combination of treatments
  - Weight control, limiting alcohol intake and not smoking
- When should I start penile rehabilitation?
  - Best to ask your doctor, but usually as soon as possible after the catheter has been removed and within 3 months of surgery. Wait at least 6 weeks after surgery before using VEDs

- Some surgeons recommend starting a few weeks before surgery as a way to 'jump-start' your recovery

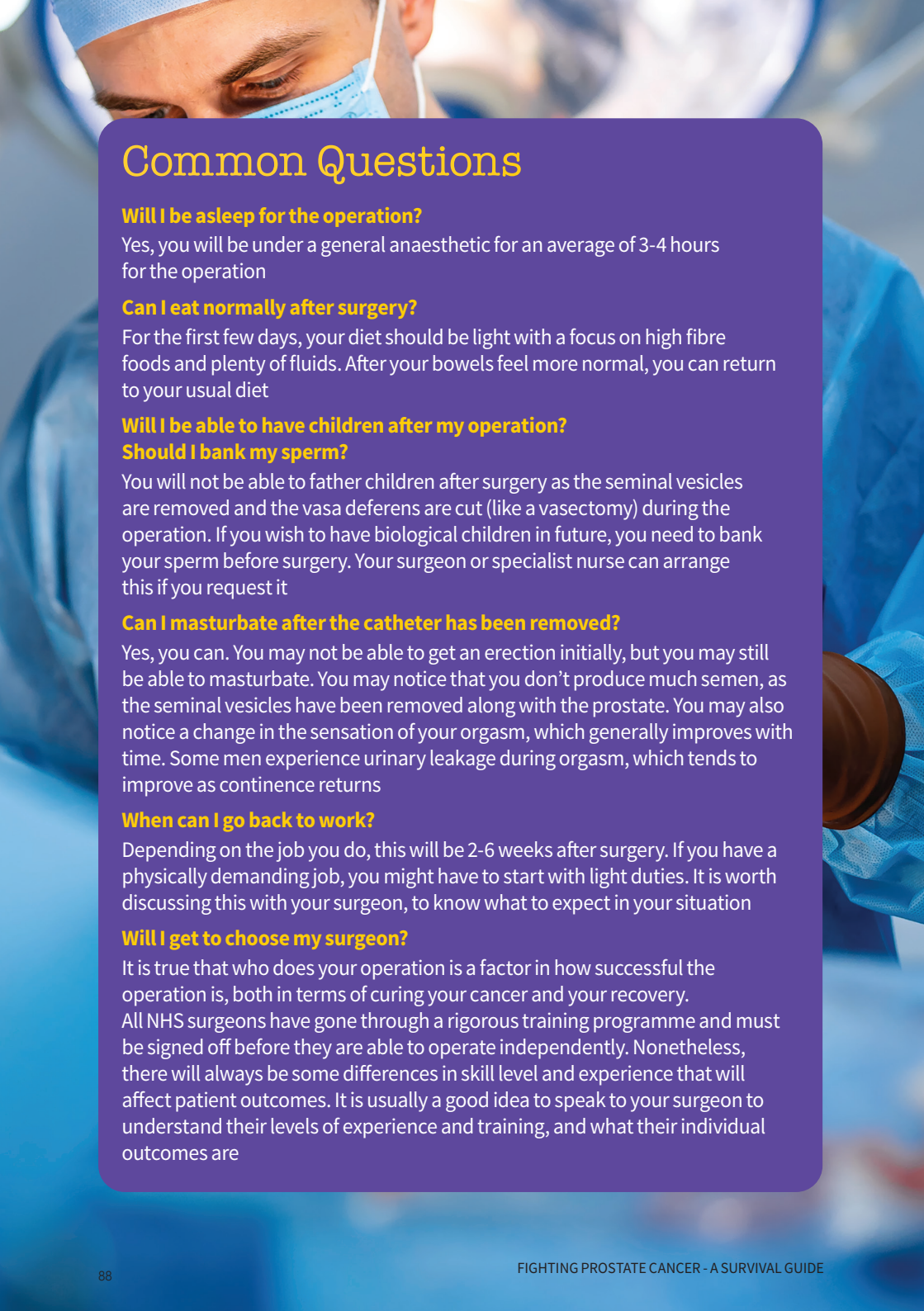
- How long do I have to do penile rehabilitation after surgery?
  - It can take 6-12 months for a minor response, but maximum recovery can take 1-3 years

What follow-up can I expect after my operation?

- You will return to the hospital for your catheter removal (TWOC)
- A consultation with your surgeon to discuss your histology results
- A PSA check 3 months after the operation
- Assuming all is well, you will 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.

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?



Common Questions

Will I be asleep for the operation?

Yes, you will be under a general anaesthetic 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 with a focus on high fibre foods and plenty of fluids. After your bowels feel more normal, you can return to your usual diet

Will I be able to have children after my operation? Should I bank my sperm?

You will not be able to father children after surgery as the seminal vesicles are removed and the vasa deferens are cut (like a vasectomy) during the operation. If you wish to have biological children in future, you need to bank your sperm before surgery. Your surgeon or specialist nurse can arrange this if you request it

Can I masturbate after the catheter has been removed?

Yes, you can. You may not be able to get an erection initially, but you may still be able to masturbate. You may notice that you don't produce much semen, as the seminal vesicles have been removed along with the prostate. You may also notice a change in the sensation of your orgasm, which generally improves with time. Some men experience urinary leakage during orgasm, which tends to improve as continence returns

When can I go back to work?

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

Will I get to choose my surgeon?

It is true that who does your operation is a factor in how successful the operation is, both in terms of curing your cancer and your recovery.
All NHS surgeons have gone through a rigorous training programme and must be signed off before they are able to operate independently. Nonetheless, there will always be some differences in skill level and experience that will affect patient outcomes. It is usually a good idea to speak to your surgeon to understand their levels of experience and training, and what their individual outcomes are

FOCAL THERAPIES 12

What are focal therapies?

Treatments for prostate cancer that use energy generated by machines to precisely target and destroy cancer cells. The aim is to treat the cancer and preserve as much healthy, normal tissue as possible. There are 3 main types of focal therapies:

- HIFU – High-Intensity Focused Ultrasound that uses heat to destroy cancer cells
- Cryotherapy – uses cold gases passed directly into the prostate via small needles to freeze and kill cancer cells. Usually used for anterior cancers
- Irreversible electroporation (IRE) – uses needles in the prostate to deliver electric current to treat the area, usually in the anterior prostate

What is the Index Lesion?

Most significant cancers will have a main, most aggressive area that can be identified in the prostate. This area is the most dominant focus and the highest Gleason Grade and drives the cancer's behaviour. Often there may be smaller, satellite lesions, but whether the cancer will spread is often determined by the main, dominant focus (index lesion). The rationale for focal therapies is that treating the index lesion may provide adequate cancer control

Are there any alternatives to focal therapy?

- Whole gland treatments – surgery, radiotherapy or brachytherapy
- Monitoring – active surveillance for low-risk disease

How do I decide what treatment to have?

Many men are suitable for several different treatments. It is important to see specialists about all the treatments that you are eligible for, so that you can make an informed decision about which treatment to have

Think about what is important to you – whether this be more certainty with regards to the treatment of the cancer or minimising side effects such as urinary incontinence and erectile dysfunction. Talk to a specialist nurse about the pros and cons of various treatments once you have seen all the specialists

HIFU

What is HIFU?

High-frequency ultrasound waves that provide concentrated heat at a specific point, called the focal point. The waves travel through the prostate to the focal point, and heat, up to 65-90 °C, treats a small area, usually the size of a grain of rice. This process is repeated until all the visible cancer is killed

When can I have HIFU?

- Primary HIFU – as a first treatment for localised prostate cancer
- Re-do HIFU – as a second treatment if the cancer comes back or has not completely been treated after the first HIFU session
- Salvage HIFU – if cancer comes back after previous radiotherapy, surgery or cryotherapy

Who is eligible for HIFU?

The following patients are considered ideal candidates for HIFU:

- Those with low – intermediate risk prostate cancer (Gleason Grade 3+3, 3+4 or 4+3) – these are considered relatively slow growing
- PSA < 15-20
- Cancer localised to the prostate and has not spread (stage T1, T2 or T3a)
- Cancer visible on MRI scan
- Cancer confirmed at biopsies
- Small - moderate sized prostates (volume < 40 cc)
- Unifocal or unilateral small area of cancer on MRI
- Good overall health meaning suitable for a general anaesthetic
- Life expectancy > 10 years
- Patients seeking a less invasive treatment choice for their cancer
- Cancer located at the prostate base or posteriorly, especially if only on one side

Are there any men who cannot have HIFU?

- Men with high-risk, aggressive cancers (Gleason Grade 8-10)
- Extensive cancer especially if on both sides of the prostate
- High PSA > 20 – this is because a higher PSA increases the likelihood of spread
- Men with cancer that has already spread outside the prostate (not localised)

- Large prostate glands or cancers at the front of the prostate (anterior lesions) – this is because the energy delivered by the machine may not reach far enough to provide effective treatment
- Cancers near the sphincter or urethra as this increases the risk of strictures and incontinence
- High level of prostatic calcification as seen on MRI – the energy cannot travel through the dense calcification leaving prostate tissue behind untreated. Additionally, calcifications tend to reflect the energy leading to unwanted heat being reflected to the rectum with the risk of rectal damage
- Previous brachytherapy
- Cancer not visible on MRI
- Men who cannot have an MRI scan
- Unable to have a general anaesthetic
- Men who cannot have the probe inserted into the rectum
- Prior rectal surgery, inflammatory bowel disease or colitis may mean you cannot have HIFU

What are the advantages of HIFU?

- Minimally invasive treatment that is organ preserving
- No cuts to the skin like with radical prostatectomy and no blood loss
- Image-guided, precise targeting of cancer with little damage to nearby tissues
- Often done as a day-case procedure
- Quicker recovery than with other radical treatments
- Fewer side effects
- Comparable and effective cancer control when compared to other radical treatments
- Can be repeated if required
- You can still have other treatments if your cancer comes back – although the chance of getting side effects may be higher
- Does not involve radiation or the need to take hormones

Are there are limitations to HIFU?

- Limited long-term data as relatively new technique – especially after 10 years
- There is a risk of not treating all the cancer
- Not suitable for cancers in all parts of the prostate

- May require lengthy travel as not available in all hospitals
- Side effects include:
    - Urinary issues with < 5% incidence. Specifically rushing to pass urine, going frequently, retention, and urinary incontinence – tends to be temporary and resolves within weeks. This is less than for surgery, and about the same as radiotherapy
    - Urinary infection – risk is slightly higher due to catheter
    - Testicular infection resulting in pain and swelling in one or both testicles (epididymo-orchitis)– see your GP to get antibiotics
    - Blood in urine can last for up to 12 weeks after the treatment – drink plenty of water
    - Passing debris in the urine is common and expected – this is like scabs falling off and due to breakdown of the treated tissue, which comes out in the urine – can take up to 8 weeks to settle
    - Erectile dysfunction occurs in 5-20% of patients
    - Bowel problems are rare unlike after radiotherapy, and it is common to experience temporary discomfort in the first few days. A mild laxative may help
    - Mild pain between the testicles and rectum in the perineum and resolves within days with simple painkillers like paracetamol or ibuprofen
    - Reduced or absent ejaculatory fluid leading to dry orgasm – can happen in 50% of men
    - 1:4 risk of cancer coming back within 5 years requiring further HIFU
    - Risk of cancer coming back requiring surgery or radiotherapy – about 1 in 10 within 10 years
    - Rarer side effects include urethral stricture (narrowing in the pipe) or rectal fistula
    - Complications related to the general anaesthetic, DVT (blood clot in legs) or chest infection
- May need further treatment with surgery or radiotherapy if the cancer comes back leading to a higher possibility of side effects than if you did not have HIFU first

What happens before HIFU?

- Your local MDT will decide which treatment option is suitable for you and discuss this with you
- If you are interested in exploring focal therapy as an option, you will be referred to a centre that does it

- The specialist MDT will confirm that the cancer is visible on MRI and fits the eligibility criteria
- The specialist team will counsel you and consent you for the procedure
- You will usually have a pre-assessment appointment – this will check your suitability for a general anaesthetic and may involve blood tests, ECG, and chest X-ray. You will be advised on any medication that needs to be interrupted before the procedure, such as blood-thinners or anti-inflammatory medications. Let the clinical team know if you are taking any herbal products with blood thinning properties
- You will be advised to stop eating from midnight the day before the procedure (at least 6-8 hours before HIFU). Some units suggest clear fluids after a light breakfast to help clear the rectum. Your individual centre will advise accordingly
- You should be able to drink clear fluids until 2 hours before admission to the hospital

What happens during HIFU?

- On the morning of the procedure, you will be given an enema to empty your bowels and clear the rectum. This enables better images in theatre
- 1-2 hours after the enema, you will be taken to theatre and given a general anaesthetic. You will usually have a small cannula inserted into the back of your hand for this. The anaesthetic ensures that you are perfectly still during the procedure as the waves are precisely aligned
- Once you are asleep, the team will position you on your right side (lateral decubitus) or on your back with your legs supported (extended lithotomy)
- A catheter will be inserted into the bladder usually through the penis, but occasionally through the abdomen (suprapubic catheter)



- A lubricated probe is inserted into the rectum to both image the prostate and deliver the treatment, with real-time monitoring of treatment effect using 3-dimensional images
- Each HIFU treatment lasts a matter of seconds destroying tissue the size of a grain of rice. The procedure is repeated delivering multiple treatments to a predefined area of the prostate determined by the MRI and biopsy results
- The ultrasound waves are emitted, controlled and directed using a computer system
- The procedure takes 2- 4 hours and depends on the size and location of the area to be treated

What to expect after HIFU

- You will be taken to a recovery area
- It is normal to feel a little groggy after the anaesthetic
- You can eat and drink as soon as you are awake
- You will be encouraged to walk as soon as you can
- After an anaesthetic, you will need someone to drive you home and stay overnight with you
- You should take mild painkillers at home, as required. Usually, over-the-counter medication is adequate
- You will be discharged with the catheter, which will be removed after 1-2 weeks
- You will be discharged with antibiotics for 3-7 days after HIFU (increased risk of infection with a catheter in place) – please complete the course
- You should pass urine with a good flow after the catheter has been removed; occasionally you may need an alpha-blocker such as tamsulosin to help because of the prostate being swollen. This settles after 6-8 weeks
- If you experience spasms or pelvic cramping, it may help to sit in a warm bath
- You should resume normal activities as soon as you can. If you have a desk job, you should be able to start it again within 2-3 days after the procedure. Avoid saddle-based activities such as cycling, horse-riding, or motorbikes for the first few weeks as the pressure can delay healing and it will be uncomfortable
- Avoid strenuous exercise or exercise increasing abdominal pressure for 4 weeks and especially with the catheter in place
- You can usually drive 48 hours after an anaesthetic, but it is always best to check with your car insurer

When should I seek medical attention?

- If you are finding it difficult to pass urine
- There are large blood clots in your urine
- You feel unwell/ shivery and shaky – this may be a sign of an infection related to the procedure

What follow-up can I expect after my HIFU treatment?

- Your catheter will be removed after 1-2 weeks. If you live a significant distance from the hospital where you have had HIFU, consider arranging this at a local hospital
- If there are any concerns during the procedure, you may have an early MRI scan after 1-2 weeks
- Your PSA will be checked at 3 months, and most men will see a drop in their PSA at this stage. Sometimes due to the ongoing prostate healing, there may only be a slight or no drop. In this case, the PSA will be repeated 2-3 months later
- Note that because healthy prostate has been left in place, your PSA level will not be zero
- You will usually have a PSA check every 3-6 months after HIFU for a few years. If your PSA continuously rises after treatment, it suggests the cancer may have come back
- You will usually have an MRI scan at years 1, 3 and 5 to look for residual cancer
- Any suspicious areas on the MRI scan will warrant repeat biopsies

What are the indicators of treatment failure?

- Usually rising PSA and lesions detected on the MRI scan +/- from biopsies
- Significant cancer in the treated zone is called in-field failure
- New significant cancer in an untreated area of the prostate is called out-of-field failure
- Rising PSA is called biochemical failure
- Metastatic disease is called clinical progression

CRYOTHERAPY (OR CRYOABLATION)

What is cryotherapy?

Uses extreme cold directly on cancer cells causing them to effectively burst and therefore die. This is usually done under an anaesthetic as a day-case procedure, like HIFU. There are only a few centres around the country doing this procedure, so be prepared to travel. It is not often used as a first-line treatment option

Who can have cryotherapy?

- Localised prostate cancer and CPG 1 -3
- Cancer that has come back after previous treatments, such as after radiotherapy (salvage cryotherapy)
- If your cancer has come back after previous cryotherapy, like HIFU, you may be able to have a repeat treatment with cryotherapy

It is generally not recommended if you have advanced prostate cancer, high-risk (CPG 4-5) cancer, if you have had previous rectal or anal cancer, have a large cancer or a large gland that makes it difficult to treat without damaging nearby structures

Common Questions

Are focal therapies NICE approved?

Yes, both HIFU and cryotherapy are approved for treatment in specific centres or as part of a clinical trial

Why is my penis swollen after HIFU?

This can happen and is noticeable 1-2 weeks after the procedure. It tends to resolve spontaneously within a couple of months

Can I still father a child after HIFU?

If you still have some ejaculate, then this is likely to contain sperm. However, if you have a completely dry orgasm, then you cannot. Consider sperm banking before HIFU if you want to conceive. Discuss this with your team

Why is my PSA rising after HIFU?

This may mean that you still have some residual cancer or the cancer has come back. An MRI scan and possible further biopsies may be required

Will HIFU damage the whole prostate?

The waves are precisely targeted to the cancer and the determined focal point. There is no damage to the tissues the waves travel through

How will I know that my rectum won't be damaged in HIFU?

The machine used has a built-in water-cooling system (chiller) that circulates chilled water through the probe to keep the rectum cool. The system also continuously monitors rectal wall temperatures and proximity to the rectal wall with software generated, automated fixed distance safety buffers

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HORMONE THERAPY 13

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. On its own, it is not a cure for prostate cancer

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
- You may receive ADT alone if you have other medical conditions that mean you cannot or do not want treatments such as surgery or radiotherapy
- 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 3 types of treatments to lower testosterone levels: surgery, injections and tablets

What does castrate level of testosterone mean?

Blood testosterone levels of < 50 ng/dL is traditionally defined as castrate level. Achieving and maintaining this is the main goal of ADT

Orchidectomy or Surgical Castration

This is surgical removal of both the testicles. Historically, orchidectomy was the earliest way to remove testosterone and is permanent. It can be used for men who need to be on life-long 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 or 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:

- It is irreversible
- Involves an operation and an anaesthetic
- Swelling and bruising after the surgery
- Cosmetic effect of no longer having testicles although you can discuss having testicular prostheses (artificial testicles like breast implants) to help with this
- Psychological impact of not having testicles
- You may still get side effects such as hot flushes and problems with your erections
- It will affect your ability to have children

LHRH Agonists

Luteinising 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 but 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 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®)
- Leuprorelin acetate (Prostap® or Lutrate® or Staladex®)

LHRH agonists





- Triptorelin (Decapeptyl® or Gonapeptyl®)
- Buserelin (Suprefact®) – given as an injection three times a day for 7 days; then as a nasal spray from day 8 at a frequency of 6 times a day

Tumour Flare

A transient rise in testosterone levels starting approximately 2-3 days after the 1st dose of an ADT is called the '**tumour flare**'. It can last about a week and result in significant clinical symptoms because the rise in testosterone can cause the cancer to grow quickly for a short while. For example, it can lead to increased bone pain from areas of spread in the bones, obstructive kidney failure, or if there is spread to the spine, then the cancer growth can put pressure 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 you must start 1-2 weeks **before** the first LHRH injection

Side Effects of LHRH Agonists

Not all men experience any or all of the listed side effects. If you do, the effects can vary from mild to very severe. Many of the listed effects are reversible upon stopping the medications

- **Pain or bruising at the site of the injection**
  - This usually gets better without the need for any specific treatment
  - If there is a fresh bruise, apply a cold compress for 10-15 minutes
  - Do not rub the area for a few days
  - Rotate the site of injections

- **Less or loss of libido**

  Testosterone gives you your sex drive. Hence, the drop in testosterone is what leads to lowered or loss of libido. 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, Ashwagandha and gingko biloba
  - Some foods, such as celery, nuts, seeds, fenugreek and ginger are thought to increase libido but many of these do not have the science to back the claim
  - Try natural aphrodisiacs such as chocolate, oysters, and garlic
  - 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 from 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. Treatment options available are:

  - **Tablets –** known as PDE-5 inhibitors, these drugs work by increasing blood flow to the penis, which can improve erectile function. Examples include Sildenafil (Viagra), Tadalafil (Cialis), Avanafil (Stendra) or Vardenafil (Levitra). They take 30-60 minutes to work, and men will need to be sexually stimulated or aroused 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; taking Riociguat for pulmonary hypertension; have a blood pressure less than 90/50 mmHg or have unstable angina or angina that occurs during intercourse should not take these drugs. There are other restrictions, and your doctor will discuss these with you to establish if these treatments 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 PDE-5 inhibitors, you will need sexual stimulation to achieve an erection. Some people struggle to inject themselves, which often leads to people discontinuing this type of treatment. One of the side effects of a penile injection is getting an erection that lasts too long and causes pain. If this happens and your erection lasts beyond 4 hours, you should seek immediate medical attention
- **Vacuum Pumps –** such as SOMAerect Size to Fit available from iMEDicare Pelvic Health Naturally – 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 ensure that the blood stays in the penis. These rings can only be worn for a maximum of 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, as the correct size and type of ring will reduce the chance of this
- **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 reduction in testosterone levels. It is easier to cope 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 visits to the hospital for tests or appointments, the cancer itself or due to anaemia (low red blood cells). It can be severe enough to affect your everyday activities. Tiredness can come on suddenly and last a few minutes or continuously whilst you are on treatment. Although there is no medication to directly help with this, there are some ways to help cope with this:

- 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, which may mean sleeping, sitting or lying down in a quiet place where you feel comfortable. Try to do this before you become tired
- Adjust your position so that you do things sitting rather than standing
- You may need to take some shortcuts to help with tiredness such as buying prepared vegetables instead of 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. Think about reducing your normal portion size

- **Nausea/ Tummy pain**

  This tends to be mild. Eat small, frequent meals and avoid strong smelling / greasy foods that may trigger the nausea. Ginger or peppermint tea may help

- **Changes to memory or concentration**

  There are many possible causes for difficulty in concentration or inability 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
  - Use post-it notes to remind you of things around the house
  - Avoid doing too many things at the same time
  - Take regular rest
  - Check your understanding of things by repeating information back
  - Keep your mind active with crosswords or puzzles

- **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 made aware of this, 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 who are 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 and smoking are recognised risk factors for bone thinning, which increases the risk of fractures with only light trauma

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

  - 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

- **Body Hair**

  Testosterone is the main driver for healthy hair growth. Reduced testosterone levels therefore result in thinning or complete loss of hair. It is important to recognise that this, as with many of the side effects of ADT is unavoidable, but reversible once the treatment stops. It can happen anywhere in the body

- **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 include:

  - 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 cause a sense of anxiety, irritability, feeling panicky or palpitations. They can also be called hot flashes (American English). This can happen at any time 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. Tips to help manage hot flushes include:

  - Keep a diary to help identify certain triggers for the hot 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 and keep hydrated
- Avoid eating large meals
- Stop smoking
- Use fans or air-conditioning to keep your rooms cool
- Wear loose layers of clothes so that you can remove items as required
- Avoid synthetic fibres and instead wear clothes made of natural fibres such as cotton, linen or bamboo as they allow air to circulate
- Try using a cooling pad to help you stay cool
- Keep a handheld fan with you
- Keep a damp towel in the freezer, which you can remove and wrap around your neck when you experience a hot flush
- Spray your face with cool water using a spray bottle
- Use lukewarm water instead of hot water when taking a shower or a bath
- Use layers of bedclothes so that they can be removed as needed
- Use light cotton bedsheets instead of a duvet
- If you sweat a lot at night, you could place a towel on the bed to save changing the bedsheets frequently
- Try to rest during the day if you are finding it difficult to sleep due to the hot flushes
- Try to remain calm under pressure as you are more likely to experience hot flushes when under pressure
- Try herbal remedies such as sage or Evening Primrose Oil
- If some of the above tips do not help, speak to your doctor about possible medical treatments that may 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 some relief from alternative therapies such as acupuncture, but there is no good quality scientific evidence to support this

- Consider intermittent androgen therapy – 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 steady, 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. Intermittent ADT allows men to regain their quality of life as it causes fewer side effects but works as well as continuous treatment

LHRH Antagonists

Degarelix (Firmagon®) is an LHRH antagonist that stops the testicles making testosterone and is used for advanced prostate cancer. Unlike LHRH agonists, the antagonists result in a rapid decrease in testosterone levels within hours, without any tumour flare. Therefore, anti-androgen tablets are not required at the start of treatment. Castrate levels can be achieved by day 3, which 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

You might continue Degarelix injections 4-weekly or switch to LHRH agonists. Most of the side effects are similar to those of LHRH analogues, but specific to Degarelix include changes in blood pressure, increase in blood sugars and anaemia.

Relugolix (Orgovyx ®) is a new LHRH antagonist that is available in tablet form. It works in the same way as the other types of hormone treatments to lower testosterone levels and achieves castrate levels by day 4. It is an alternative to injections and can be used in advanced hormone-sensitive prostate cancer, in combination with radiotherapy or prior to radiotherapy

On the first day, you will need to take 3 tablets as a loading dose; thereafter it is 1 tablet a day to be taken at the same time. This drug does not cause a tumour flare, and anti-androgens are not required at the start of treatment

The side effects of Relugolix are like other hormone treatments due to the change in testosterone levels, but specifically include diarrhoea, constipation, muscle or joint pain. One of the concerns about this treatment strategy is remembering to take the tablet every day, but studies have shown that adherence is similar to that with injections

Relugolix is vulnerable to fluctuations in heat and moisture and unlike other medications, should not be stored in a pill box. Doing so can lead to the drug degrading and not working so well

Practical considerations for Relugolix include:

- do not remove it from its container. Leave it in its original bottle
- do not remove the desiccant in the original bottle
- do not store it in the bathroom, kitchen counter near appliances or car glove compartment
- tighten the lid after opening
- keep it in a cool, dry place such as a bedroom drawer, away from heat and moisture or windows

Anti-Androgens

Taking LHRH agonists or antagonists or having an orchidectomy only stops testosterone made in the testicles. However, 5-10% of the body's testosterone is made by the adrenal glands

Prostate cancer cells have receptors on them that are like locks. When testosterone (the key) attaches to these receptors (the lock), it can stimulate growth of the cancer cells. Anti-androgens compete with testosterone by attaching to the lock themselves and therefore stopping testosterone from doing so. This leads to normal or slightly higher blood testosterone levels



Bicalutamide 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. It is not needed with the LHRH antagonists
- 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 ADT. Libido and bone density tend to remain preserved with this drug and is an option for men who 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 cause fewer sexual side effects. There is some evidence that breast pain and swelling, called gynaecomastia, can occur with long-term bicalutamide treatment (> 6 months). Your doctor may recommend that you have preventative radiotherapy to both breast buds before starting this drug long-term. If radiotherapy does not prevent gynaecomastia, then your doctor may consider weekly tamoxifen 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 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. Consider taking 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 and ask for a copy of your clinic letter

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 of weeks 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. A persistent increase in the PSA level may indicate that the cancer has started to grow and be more 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 newer 'secondary' hormone therapies that can now be used to slow the spread of the cancer

What is hormone-resistance?

At the time of diagnosis, prostate cancer cells depend on testosterone for their survival. Treatment with ADT aims to decrease testosterone levels and 'starve' the cancer cells in what is called hormone sensitive prostate cancer. Over time, the cancer cells adapt and start to grow despite castrate levels of testosterone. These cells no longer respond to ADT, and this is called hormone-refractory or castrate-resistant prostate cancer. There are several options at this stage, but you would usually continue ADT to keep your testosterone levels low

HORMONE THERAPY FOR ADVANCED PROSTATE CANCER 14

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 13 can work for months or years, but over time, the cancer cells can 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 ADT stops working effectively (called castrate-resistant prostate cancer)

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 ADT injections to keep testosterone levels low. If they go up, the cancer may grow further

Where can my cancer come back after treatment (recurrent or relapsed prostate cancer)?

- within the prostate if you have not had it removed
- where the prostate was if you have had surgery – called prostate bed
- just outside the prostate within the pelvis
- anywhere in the body – called advanced or metastatic prostate cancer

What is second line hormone therapy?

- drugs that block the production of androgens throughout the body including by prostate cancer cells – androgen synthesis inhibitors such as Abiraterone
- newer anti-androgens that block the action of testosterone (the key) throughout the body by competitively and more strongly attaching to the androgen receptors (the lock) than testosterone (Enzalutamide, Apalutamide, Darolutamide)

Drugs to lower androgen production: ABIRATERONE (Zytiga®)

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 produce testosterone. It is a type of hormone therapy and lowers testosterone levels

When is abiraterone used?

- Localised or locally advanced prostate cancer that is at high risk of spreading – Abiraterone MUST be started within 12 weeks of starting first-line ADT
- Patients who have cancer that has come back after initial radical treatment (recurrent cancer), such as with surgery or radiotherapy with high-risk features
- Newly diagnosed advanced (metastatic) prostate cancer in combination with first-line ADT
- In men with advanced prostate cancer that has stopped responding to first-line ADT
- 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
- If you miss a dose, skip it and take the next dose at your normal time. Do not take extra or double doses
- 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 – both can damage the liver
- Store the tablets at room temperature

What are the side-effects of abiraterone?

Not all men will experience the side-effects, but 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 elevate your legs on a foot stool, chair, or cushion above the level of your heart
  - Regular movement and gentle exercise such as walking may improve circulation
  - Soaking your feet in a cool Epsom salt bath or gently massaging upwards from the ankles can help move the extra fluid
  - Use compression socks to help push fluid upwards towards your heart
- Can 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 such as potatoes, spinach, kale and avocadoes are high in potassium. Think about steaming or microwaving these vegetables to preserve as much potassium as possible rather than boiling them
- Raised cholesterol levels
- Raised liver enzymes – usually mild and returns to normal levels when the drug is stopped
- 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 13
- Diarrhoea – this is usually not due to an infection
  - Drink plenty of fluids to stay hydrated
  - Avoid greasy, fatty, fried foods or dairy-rich foods as they can make the diarrhoea worse
  - Eat small, frequent meals and snacks rather than large ones
  - 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 – usually every 2 weeks in the first 3 months after starting abiraterone, and then every 4 weeks - 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, kidney and liver function tests
- Your blood pressure will be monitored regularly

Drugs to stop androgens working: Androgen Receptor Pathway Inhibitors (Enzalutamide, Apalutamide, Darolutamide)

These anti-androgens attach to androgen receptors and stop androgens from attaching, thereby stopping the growth of the cancer. Enzalutamide is a newer anti-androgen and is another form of hormone therapy

ENZALUTAMIDE (Xtandi®)

When is enzalutamide given?

- Men with advanced hormone-sensitive prostate cancer with no symptoms or mild symptoms before chemotherapy
- Men with advanced prostate cancer that is resistant to other treatments that lower testosterone (castrate-resistant prostate cancer)
- 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 in capsule or tablet form
- It is taken once a day with or without food
- Take it at the same time every day
- Swallow the tablet whole – do not 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



- Store the medication at room temperature
- 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 of time 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
- Posterior Reversible Encephalopathy Syndrome (PRES) - a rare disorder of the nerves causing headache, tiredness, fits, confusion and changes in vision with/without high blood pressure - contact your healthcare team straight away if you have these symptoms. You may need an urgent brain scan such as an MRI
- Increased risk of falls and fractures
    - Ensure rooms are well lit and use night lights if you wake up at night
    - Keep rooms free of clutter and trip hazards, such as rugs
- A drop in white blood cell count may increase your risk of getting infections
    - Avoid people with colds or flu-like symptoms
    - Wash your hands frequently
- There is slight risk of having a fit (seizure) in < 1% of patients

	APALUTAMIDE (Erleada®)	DAROLUTAMIDE (Nubeqa®)
What is it?	New class of oral anti-androgen - Androgen Receptor Pathway Inhibitors (ARPIs)	
When is it used?	1. Metastatic hormone-sensitive prostate cancer – when the cancer has spread but is still responding to ADT 2. High-risk prostate cancer that has not spread but has stopped responding to ADT (non-metastatic castrate-resistant prostate cancer) 3. Darolutamide can be used when cancer has spread with ADT + Docetaxel chemotherapy– called Triplet Therapy	
How is it administered?	Tablet form with ADT	Tablet form with ADT
Do I also need to take steroid tablets?	No	No
Normal dose	4 tablets a day (60mg each) or single tablet of 240 mg with or without food	2 x 300mg tablets twice a day WITH food
Dosing advice	1. Swallow the tablets whole at the SAME time every day 2. Do not split, break, chew, or crush the tablets 3. If you miss a dose, take the normal dose as soon as you remember on the same day. Do not take extra tablets to make up for the missed dose 4. If you are sick and vomit your tablets, do not take extra tablets 5. Store the tablets at room temperature	
Common side effects	Extreme tiredness, Skin rashes, Increased risk of falls and fractures, High Blood Pressure, Hot flushes, Joint Pain, Reduced appetite, Diarrhoea	Does not cross the blood-brain barrier so less risk of dizziness, skin rashes and falls. Still possible to experience severe tiredness. Increased risk of infections due to a decrease in white cells, Liver changes, Skin rashes, Joint Pain, Reduced appetite, Increased weight, Diarrhoea
Rare side effects	Seizures (fits), Stroke, Hypothyroidism	Seizures (very rare), Heart issues
Contraception	Use condoms in combination with another highly effective birth control method during treatment and for 3 months after stopping treatment	Use condoms during and for 1 week after stopping treatment if your partner is pregnant, and highly effective contraception if your partner is of childbearing age
Sperm Donation	Do not donate sperm during treatment and for 3 months after stopping	

How is enzalutamide monitored?

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

Oestrogens

Oestrogen tablets such as Stilboestrol® are hormones that promote female sexual characteristics, and historically, were used to treat prostate cancer resistant to hormone treatment. They work by reducing the amount of testosterone made by the testes

Although the risk of bone thinning is low compared to other hormone treatments, there is a higher incidence of problems with the circulation resulting in blood clots. They can also cause swelling and tenderness of the breast tissue. Oestrogens are seldom used today due to the emergence of newer hormone treatments as discussed above

Steroids

Low-dose 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 help to 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 of the cancer such as in the bones
- 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 more easily 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 vaccinations 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

PARP Inhibitors: Olaparib (Lynparza®) and Talazoparib (Talzenna®)

PARP is a protein that helps repair damaged cells such as those with cancer. Olaparib and Talazoparib block PARP. Without PARP, the damaged cancer cells cannot repair and are more likely to die

OLAPARIB (Lynparza®)

Who can have Olaparib?

- castrate-resistant advanced prostate cancer with abiraterone and prednisolone providing certain conditions are met (such as you cannot have chemotherapy)
- if you have advanced castrate-resistant prostate cancer with either BRCA1 or BRCA2 gene mutation

How is it taken?

- Available as tablets that must be swallowed whole with or without food
- You will need to take 2 tablets twice a day, about 12 hours apart
- Do not crush, dissolve, chew or split the tablets
- You will usually continue ADT even if the cancer has stopped responding to ADT
- If you miss a dose, take the next dose at the usual time but do NOT take extra to make up for the missed dose
- Avoid grapefruits, grapefruit juices, Seville oranges and Seville orange juice whilst taking Olaparib

Can I have sex whilst taking Olaparib?

- Yes, but you should use a condom and other highly effective birth control whilst on this treatment and for 3 months after the last dose
- Do not donate sperm whilst taking Olaparib or for 3 months after the last dose

What are the possible side effects?

- Increased risk of infection due to reduced white cells
- Anaemia due to decreased red blood cells, which may make you feel low in energy, breathless or dizzy and light-headed
- Tiredness and weakness
- Feeling sick, reduced appetite or heartburn
- Changes in your taste – this usually returns to normal within a few weeks of stopping treatment
- Diarrhoea

TALAZOPARIB (Talzenna®)

When is this drug used?

- Talazoparib with enzalutamide can be used as an option for untreated castrate-resistant metastatic prostate cancer in adults, only when:
  - chemotherapy is not clinically indicated and
  - abiraterone plus prednisolone is not tolerated, or
  - there are clinical conditions that mean abiraterone plus prednisolone cannot be used

How is it taken?

- The recommended dose is 0.5 mg talazoparib in combination with 160 mg enzalutamide once daily
- ADT is usually continued during treatment if you have not been surgically castrated
- Swallow the tablet whole with or without food – do not crush, chew, dissolve or break the tablet
- Take the tablet at the same time every day
- If you vomit after taking talazoparib, do not take an extra dose; instead take your next dose at the usual time
- Do not use curcumin (found in turmeric root) or large quantities of turmeric root in food while you are taking this treatment as it may increase potential side effects. Using spices in food is not likely to cause a problem

Are there any side effects?

- The possible side effects are like those with Olaparib
- There is a small increased risk of blood clots and a < 1% chance of developing a second cancer called leukaemia
- You should use effective contraception, even after a vasectomy, during treatment and for at least 4 months after the last dose

Common Questions

Am I eligible for 'early' abiraterone?

As of early 2026, abiraterone is available for men with high risk non-metastatic prostate cancer. This means relatively fit men with no distant spread of the cancer or those with only pelvic localised lymph nodes; or those who have at least 2 of: Stage T3 or T4, or Gleason score 8-10, or PSA > 40

What if I forget to take my ARPI 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

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

Is there any benefit to maximum androgen blockade in the age of these newer anti-androgens?

ADT in combination with an older anti-androgen daily, such as bicalutamide provides a small survival advantage (<5%) compared to ADT alone and this benefit peaks at 4-12 months. This minimal survival advantage must be balanced against the increased side effects, and the availability of newer combination therapies that are more effective

> 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 15

Radiotherapy or 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, which can result in 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 (radical radiotherapy) when the cancer is confined to the prostate (localised prostate cancer), as an alternative to surgery
- With a curative intent if cancer has started to break out of the prostate, or has spread to the area just outside the prostate (locally advanced prostate cancer)
- As "salvage" treatment if the cancer comes back after surgery – this is called recurrent or relapsed 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

What types of radiotherapy are there?

- External Beam Radiotherapy (EBRT) is the most common method and uses beams of high-energy X-rays generated by machines aimed precisely at the region to be treated. EBRT is given on an out-patient basis
    - Intensity-Modulated Radiation Therapy (IMRT) uses the images from your planning CT scan to map the prostate and nearby organs. The radiotherapy beams deliver precise radiation to the prostate
    - Stereotactic Ablative Radiotherapy (SABR) uses higher radiation doses at each treatment. Because the dose is stronger, fewer overall treatment sessions are required (typically 1-5 sessions)
    - 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

- Internal radiation, called Brachytherapy involves the insertion of radioactive pellets or needles directly into the prostate under an anaesthetic. This is often combined with EBRT and is available on a regional basis in the NHS, and may require travel
- Systemic radiation such as Radium 223, is an injection of radioactive material into the bloodstream and is sometimes used to treat prostate cancer that has spread to the bones

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 precise targeting of the treatment and for the radiation dose to surrounding tissues to be kept low

What happens before radiotherapy?

- Radiotherapy is given in a hospital radiotherapy department
- You will be seen by a clinical member of the team first, who will explain the treatment, the schedule and potential side effects. You will then be asked to sign a consent form
- Before having EBRT, you will have a CT scan to generate a computer image of your body that is used to plan which areas receive a dose of radiation
- There may be a short wait after the scan and before the treatment starts during which time the team will be planning your schedule
- You will be positioned very carefully on a flat couch for the scan and have tattoo dots marked 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
- The position of the prostate can be affected by the contents of your bowel and bladder
- 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 to try to keep the bladder the same size each time
- 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 lie on a treatment couch using your tattoo dots and lasers to precisely replicate the position you were in for your CT scan
- Your treatment appointment will be around 20 minutes, but the radiotherapy itself only takes a couple of minutes. Preparing your bladder and bowels beforehand will take more time
- 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 around one metre away and will make some noise
- You will need to lie very 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 your planning scans
- The treatment is completely painless
- You will not be radioactive, and you can be around pregnant women and young children during radiotherapy
- You can go home after each treatment

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 may be required before, during and sometimes after radiotherapy
- The prostate is part of the reproductive system and is strongly influenced by the male hormone testosterone (see chapter 13)
- 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

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
- A shorter schedule of radiotherapy has recently been approved for use in the NHS for early stage, low-grade prostate cancer. This is known as Stereotactic Ablative Body Radiotherapy (SABR) and delivers a higher dose of radiotherapy at each treatment session, allowing a full course of treatment in 5 fractions. This is usually given without the need for hormone treatment
- In the future, it might be that the shorter schedule used in SABR is extended to cancers of a higher stage or grade and used in combination with hormone treatment. This is not yet routine and is being studied in clinical trials

Side-effects of prostate radiotherapy

These vary from person to person. There are short-term side effects that come on 2-3 weeks after starting treatment and for a few weeks afterwards. Longer-term, "late" effects, which come on months after finishing radiotherapy 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 when you can
    - 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 with daily chores such as shopping, driving or childcare
    - Maintain a level of physical activity and a well–rounded, healthy diet

- Think about having your shopping delivered
- Try doing some of your jobs whilst sitting down

- Bladder bother – symptoms such as passing urine more often, slower flow, needing to go urgently, 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 a urinary catheter
- Bowel bother – radiotherapy can irritate the bowel and symptoms include going more often, loose motions, increased wind, passing mucus, 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
- Skin/ Hair changes – you may experience hair loss in the treatment area, including your pubic hair. This is more likely to be patchy and tends to grow back, often thinner, over weeks and months. You may also notice that the skin becomes dry, flaky or changes colour

Late side-effects:

- Change in bowel habit, looser stools, passing more wind
- Erectile dysfunction
- 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 intercourse, 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 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 scrotum and anus called the perineum. A small ultrasound probe is then 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 several 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

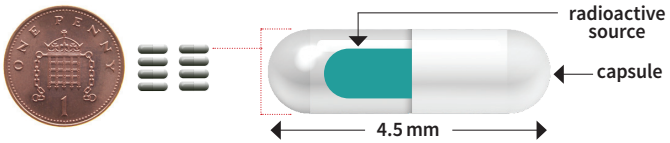
Different schedules of brachytherapy are used in different hospitals. The number of appointments can vary according to the technique used and may require separate planning visits

- LDR brachytherapy with permanent seeds is given in 1 session. The radiation dose is then delivered over weeks and months to the prostate. The acute side effects resolve over months
- HDR brachytherapy is usually given in 2-3 sessions but is sometimes combined with a short course (approximately 3 weeks) of external beam radiotherapy

Can I 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
- You may not be able to have it with some types of inflammatory bowel disease
- You may not be able to have it if your rectum has been removed
- You will need an interval of at least 3 months after a TURP before having brachytherapy, to allow adequate healing



Configuration of a brachytherapy seed

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 intercourse, 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 painkillers. 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 blood clots, you should tell you 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
- Erectile dysfunction
- 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**

Less common
Less than 10%

- ☐ **Skin re**
- ☐ **Cystitis**
- ☐ **Rectal**
- ☐ **A feelin**
- ☐ **Bleedin**

Rare
Less than 1%

- ☐ **Urinary** a urinary
- ☐ **Urinary**

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

It is widely claimed that the advent of radiotherapy started with the serendipitous discovery of X-rays by Wilhelm Conrad Roentgen in 1895. However, French physicians Imbert and Imbert are credited as applying the earliest forms of radiotherapy to the prostate in 1904 to a case of advanced prostate cancer

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, but you may have side effects later during radiotherapy, which may 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 rectal spacer?

A liquid gel that increases the distance between the prostate and the rectum, thereby protecting the rectum from high radiation doses, and potentially decreasing some of the side effects of the treatment. It is usually inserted using a needle through the skin behind your scrotum (perineum), under local anaesthetic and takes 20-30 minutes. After injection, the gel forms a soft, water-based cushion, which stays in place for about 3 months, after which it is safely absorbed by the body. Ask your oncology doctor for more information

Will my weight affect radiotherapy?

It is important to maintain a steady weight during your radiotherapy treatment as weight changes can alter the position of the prostate. If you are overweight or obese, then radiotherapy can take longer due to the time required in positioning you at each treatment session

CHEMOTHERAPY 16

What is chemotherapy?

Chemotherapy is a strong cancer treatment that circulates throughout the body in the bloodstream, to kill cancer cells. These drugs can help men live longer and relieve symptoms but they are unlikely to cure prostate cancer

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. This is why healthy cells are also affected by chemotherapy. The damage to healthy cells can result in side effects, which 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: hormone or castrate-sensitive prostate cancer
- First-line treatment for advanced prostate cancer as part of Triplet therapy
- In men who have advanced prostate cancer that has stopped responding to hormone treatments: metastatic castrate-resistant prostate cancer
- To treat rare types of faster growing prostate cancers, such as small cell prostate cancer

When is chemotherapy not usually given?

- If you are not fit to have it due to other medical conditions or you are too weak
- In men who have localised or locally advanced prostate cancer

What drugs are used?

In the UK docetaxel or cabazitaxel are the most commonly used chemotherapy drugs. Docetaxel tends to be the first drug that is used in combination with a steroid, such as prednisolone, and is not available in tablet form. When this drug stops working, cabazitaxel may be considered

How is Chemotherapy given?

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

Before:

- You will be assessed for your fitness and suitability for chemotherapy
- You may have a long, thin plastic tube called a central line inserted. This will stay in place during your treatment
- The dose you receive depends on your general health, height and weight
- A few days before each session, you will need to have blood tests for your kidney function, white cell count, haemoglobin, platelets and possibly others, which can be done at your local surgery

During:

- The results of your blood tests will be checked
- The team will check how you are feeling
- Your temperature, pulse and blood pressure will be checked
- If you do not have a central line, you will have a cannula inserted
- The drugs will be 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

After:

- Your cannula or central line will be flushed and disconnected
- The team will check how you are feeling
- You may be given medication to take home, if required and instructions on what symptoms to look out for
- You will then be discharged and given the next appointment

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

Practical Issues 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
- Do not take any immunisation or vaccination without first discussing it with your oncologist
- You may need to talk to your employer about taking 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 and light 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 cycles
- Consider a chemotherapy 'grab' bag. This can include books, a laptop, a newspaper or headphones for music during your treatment schedule. Think about hard sweets to help with the altered taste, lip balm, skin lotion, a handheld fan, snacks and a drink. Think about packing warm clothes / layers in case you get cold
- 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
- Tell your team if you have a special occasion; dates for your treatment can be flexible

Managing common side-effects of chemotherapy

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

- Extreme fatigue
  - Plan your daily activities so that you can do things when you have the most energy levels
  - Stay active with mild to moderate exercise such as walking or swimming
  - Take short naps during the day but try not to sleep too much as this will interfere with how you sleep at night
- 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
- Check your house for trip hazards such as rugs. Avoid falls and trips as you can bruise easily
- Avoid bumping into things
- Wear protective gloves when doing any housework or gardening
- Some over the counter painkillers like aspirin or ibuprofen can increase your risk of bleeding or bruising – ask the pharmacist for alternatives

- Feeling out of breath
  This may happen because of 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 soups, 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 begins and it may be a little at a time or in clumps. It can take months to regrow
  - Consider wearing a hat when outside to protect your scalp
  - Wash your hair every 2-4 days with a mild shampoo such as baby shampoo
  - Avoid very hot or very cold places
  - Sleep on a satin pillowcase as this causes less friction than cotton
  - Avoid hair dyes during treatment and for up to 6 months after completing chemotherapy until your hair growth is stronger
  - If your eyelashes have fallen out, consider wearing sunglasses when outside to protect your eyes from dust
- 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 from 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 – aim for 8-10 glasses of water a day
  - Fatty, fried, and spicy foods may make this worse
  - Low fibre foods such as bananas, white rice, dry toast 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 or redness/ tenderness in the mouth, tongue or lips
  - 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
  - Use a straw to drink fluids
  - Avoid smoking or tobacco products
- 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 with SPF of 30 or higher
  - 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
  - Wear sturdy, non-slip shoes to protect your feet
  - Be cautious when using an iron or cooking using a stove or oven as you are less likely to feel the heat
  - Use your elbow to check the temperature of water so you do not burn
  - Inform your doctor if this happens – they may decrease the dose of the drug, delay the next dose, or stop the treatment
- Memory changes, difficulty concentrating, focusing or remembering things
  - Use a calendar, alarm or use features available on your smartphone to keep lists or track appointments, taking medications or social commitments
  - Make lists
  - Think about taking photos on your phone. For example, take a photo of your car to remind you where you have parked it
  - Try not to multi-task and focus instead on one activity at a time
  - Make sure you get enough sleep to allow your brain to rest
  - Think about a new hobby or learning a new skill
- 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



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.

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



PALLIATIVE CARE 17

"Palliative care is NOT about dying. It is all about living."

What is palliative care?

Palliative care is defined by the World Health Organisation as an approach that improves the quality of life of patients and their families who are facing problems associated with a life-limiting illness that is unlikely to get better, such as cancer

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 to prevent and relieve suffering by early identification

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 blood 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 for patients who are close to the end of life; typically, those likely to be in the last 12 months 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, an interrupted stream, or 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

What is the difference between palliative care and end of life care?

	Palliative Care	End of Life Care
When does it start?	At any stage of your illness, even as early as the point of diagnosis. 'Right support at the right time'	Final weeks, months or last year of life
How long does it last?	Months to years	Last few hours; weeks; months or final year
What is the aim?	Improve quality of life and treat the *impact* of the cancer	Provide comfort, dignity and a peaceful death
Can this mean curative treatment?	Can be given alongside curative treatments	Curative treatments are usually stopped
What are the main goals?	1. Manage any symptoms from the disease or side effects of treatments, such as pain, vomiting, tiredness 2. Provide emotional, spiritual and psychological support 3. Offer practical support such as help with getting to appointments or with finances 4. Practical help to get specialised equipment such as pressure relieving mattresses, adjustable beds, grab rails or shower chairs 5. Provide help to families, caregivers and loved ones	1. Control symptoms such as pain, nausea, fatigue 2. Maximise comfort 3. Facilitate honest discussions about death 4. Provide mental and emotional support such as anxiety or fear about dying 5. Ensure your choices are respected so that you are in control 6. Practical support such as help to create a Will or confirm your advanced care preferences 7. Help and support for family and loved ones
Who is it best for?	1. Men who have side effects of the cancer or its treatments 2. Men who choose not to have any curative treatments 3. Men who have had treatment, which has failed and do not want any more treatments 4. Men who have decided that further treatments will cause more harm than good 5. Older men who have other conditions that are more likely to cause death than the cancer itself 6. Men with advanced cancer who want a better quality of life	When you are approaching the final year of life

Who is in the palliative care team?

Much of this type of care is co-ordinated 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

Where can palliative care or end of life care be given?

- Hospital
- Nursing or residential homes
- Outpatient clinics
- Home – with the right support in place, many people can die at home, if they wish
- 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
    - If you would want to be admitted to hospital
    - These can be documented in a Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)
    - Where you would like to be cared for towards the end of your life
    - 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
- Keep all your key documents in a safe place and ensure your carer/ a family member knows where that is. Examples of key documents include: Birth Certificate, Passport, Driving Licence, valid up-to-date Will, recent bank statements (and bank account details), Pension Plans, Insurance Policies, National Insurance Number, pre-paid funeral plan, House Deeds
- Does your family know where to find details of gas, electricity, water, phone suppliers and relevant contracts?
- Where are your passwords kept and who do you want to know this information?
- Make a Will if you have not done so already
- Think about writing everything down

- Is there anyone you want to spend time with?
- 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 be used at any time after a terminal diagnosis. You can have palliative care for many months or years and ensures that you have the support you need with your condition. 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

Do I have to pay for palliative care?

Palliative care is part of NHS healthcare and is usually free for UK residents. It can also be free when provided by charitable organisations. Sometimes, you may have to pay for certain aspects of your social care, depending on where you live and your financial position



DIET, EXERCISE AND PROSTATE CANCER 18

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 about diet and prostate cancer. There is little 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, Soya 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
  - 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 help 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

- Vitamin E

There is no strong evidence that Vitamin E supplementation is protective against prostate cancer. Vitamin E is found in:

  - Nuts - Seeds - Wholegrains - Green leafy vegetables - Avocado

- 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 consuming more than 1,500mg of calcium a day
  - Avoid high-fat dairy foods or a high-calcium diet
  - Non dairy sources of calcium include soy milk, soy yoghurt, and green leafy vegetables
  - 1 glass (200 mls) semi-skimmed milk contains approx. 240mg calcium
  - 1 pot (150 g) flavoured yogurt contains 200 mg calcium
  - 30 gm cheddar cheese contains 240 mg calcium

- 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

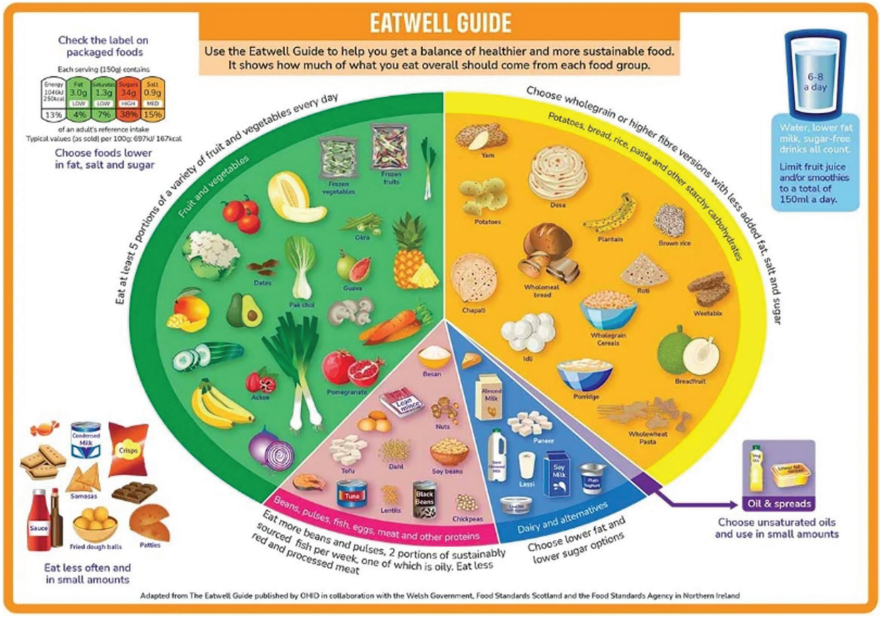
Eating high fat foods can increase weight and obesity is linked to a higher risk of dying from prostate cancer or getting more aggressive forms of the disease

A low-fat diet will help 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

- 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 increase your weight and the risk of prostate cancer
- 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
- The NHS advises cancer patients to follow a balanced, varied diet based on the ***Eatwell Guide*** to maintain weight and energy



Regular exercise

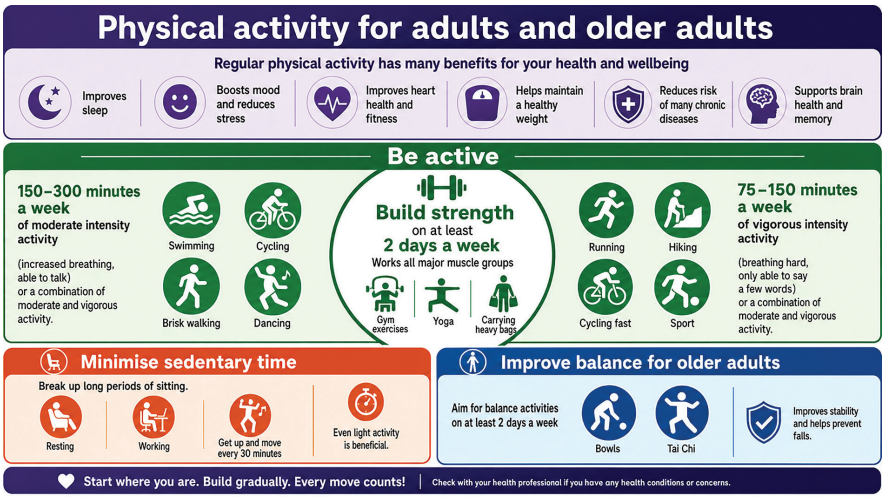
Regular exercise can improve heart health, bone health, decrease the risk of diabetes, reduce anxiety and fatigue, and reduce obesity. Aim to be active at least 3-5 times a week

- 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 each 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
- Activities such as vacuuming, dusting, cleaning, washing the floor or car, and doing DIY around the house are good ways to challenge yourself
- Some virtual games consoles include sports such as skiing, boxing or tennis and provide a challenging workout at home, and can be fun at the same time
- Using a step counter (pedometer or on a smartwatch) may help you check your progress when walking to see how much distance you have covered
- Keep an exercise diary or journal
- 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; 7 double (50mls) measures of spirits (40% ABV)



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

TRAVEL & PROSTATE CANCER 19

There are many reasons men choose to travel before, during and after cancer. Whether it is for a holiday or a family emergency, travelling home or abroad with a cancer diagnosis may require extra planning and preparation

Initial Considerations

- Are you fit to travel?
- 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?

Travel insurance

- This may be difficult so start to look for appropriate insurance providers early
- Travel insurance with a cancer diagnosis may be more costly
- Check whether you already have cover
- Travel insurance may be a benefit with some bank accounts, credit cards or home insurance
- There are 2 types of travel insurance:
  - Single trip – covers you for 1 trip and you need a new policy each time you travel
  - Annual or multi-trip – covers you for more than 1 trip in a given year
- If you already have travel insurance and are diagnosed with cancer during the cover period, you will need to let the insurance company know
- 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
- Ask around. Your hospital key worker or someone at a local prostate cancer support group may make a recommendation based on experience

UK European Health Insurance Card (EHIC) / UK Global Health Insurance Card (GHIC)

- The UK GHIC allows you to get necessary state healthcare in the European Economic Area and some other countries, on the same basis as a resident of that country
- This means that you have the right to access certain medical treatments as a resident of that country would receive at the same price – it may be free or you may need to pay
- The UK GHIC has replaced the existing UK EHIC. If you have an existing and valid UK EHIC, you will still be able to use it
- When your UK EHIC expires, you will need to apply for a UK GHIC
- The UK GHIC is free and valid for 5 years
- The UK GHIC and EHIC are NOT an alternative to travel insurance - you still need a UK EHIC / UK GHIC because your insurance company might not cover the cost of treatment that the card covers. If you then try to claim in full, the insurance company might say you should have had the UK EHIC or UK GHIC
- These cards ONLY cover emergency care in the EU country you are visiting. They do not cover the cost of bringing you back to the UK

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
- Carry a list of any allergies you may have
- If you have mobility problems, take your Blue Badge with you
- You may be able to get help whilst travelling on trains in the UK
    - this includes help getting on and off trains, carrying up to 3 items of luggage or getting around the station
    - book help in advance 24 hours a day via the Passenger Assistance website or on freephone 0800 022 3720 (select option 1)

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 while travelling
- 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/being accused of smuggling drugs
- 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
- If your medications need to be kept cool, carry them in a cool bag and check ahead with the airline and where you are staying as to whether a fridge is available

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
- Other options for incontinence such as urethral control devices, body worn urinal devices, condom sheath catheters or petal sheaths should also be carried in your hand luggage where possible
- If you are performing self-catheterisation, it is useful to carry a doctor's letter explaining this
- Pack spares of all your equipment
- If you suffer with urine leakage, consider wearing washable underwear whilst travelling, such as Men's Maximum Absorbency H-Fly Boxer Brief supplied by iMEDicare Pelvic Health Naturally. These discreet, stay in place pants come in varying degrees of absorbency and protect the skin until it is convenient to change



Wearever Boxer Brief

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 breaks to stretch your legs and walk around
    - Drink plenty of water regularly
    - Minimise your intake of alcohol
    - Break up long journeys to avoid fatigue and exhaustion
    - Taking eye masks and face mists

- 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 50 offers approximately 98% protection against UV rays
  - Protect your lips using 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 between 11am and 3pm when the sun is at its strongest
- 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 that 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
- Avoid restaurants and hotels offering buffets
- 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
- Take small snacks and meals that you can carry easily, such as granola bars, trail mix, sandwiches and wraps for your journey

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
- Consider translating your medical information and taking this with you when travelling abroad
- 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

SEX & PROSTATE CANCER 20

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
- Many of the treatments such as surgery or radiotherapy can affect sexual function, thereby affecting libido and desire

What causes the problems with erections?

- Prostate biopsies can temporarily affect erectile function. They tend to be mild and transient and 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 to years later
- Radiotherapy can also damage nerves and blood vessels responsible for healthy erections, and it can take longer to recover
- 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?

- 80-90% of the fluid in semen is made by the prostate and seminal vesicles. Consequently, when they are removed at surgery, you will no longer make any semen, and 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

Why do I leak urine during sex?

- This is called climacturia and unintentional leakage during penetration is common in the early months after treatments for prostate cancer
- It may not be noticeable to you or your partner, and infection-free urine is not harmful, but can be annoying
- The amount that leaks can be as little as a few drops to 1-2 tablespoons
- Be open and discuss this issue with your partner. Consider some of the strategies listed to manage this:
    - Limit your fluid intake within a few hours of intercourse
    - Empty your bladder before sex
    - Place a towel under you
    - Place a lubricant on your penis to disguise the moisture. This may also help with penetration
    - Consider sex in the shower so that any urinary leakage washes away
    - Wear a condom

- Consider sexual positions that reduce the amount of pressure on the abdomen and therefore leakage, such as standing, or on your hands and knees
- Try a variable tension penile loop. This is a soft, adjustable, silicone loop placed around the base of the penis before sex to reduce leakage
- Regular pelvic floor exercises

Will having prostate cancer affect the size of my penis?

Some men report a decrease in the length of the penis of 1-2cm, 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. Possible reasons for shortening include:

- Part of the urethra is removed at the time of surgery, along with the prostate. This causes the base of the penis to withdraw into the body – called 'turtling'
- Damage to the nerves and blood vessels during surgery
- Without regular erections, there is less blood flowing to the penis thus starving the tissues of oxygen, which causes scar tissue (fibrosis). This makes the penis less elastic

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 increasing the flow of blood to the penis may help and for most men, the problem returns to normal over time. It is well recognised that regular exercise and stretching keeps the body flexible, mobile and supple. Similarly increasing blood flow to the penis, through penile rehabilitation using drugs, or the correct use of vacuum pumps such as SOMAerect STF can help achieve erections and preserve penile length. The earlier you start penile rehabilitation, the better the recovery after surgery

Tips to help with sexual difficulties

- If you are on continuous hormone injections, then discuss the possibility of intermittent hormone treatment 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 you 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, cialis or spedra. 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 who experience low desire
- 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 must only leave it on for a maximum of 30 minutes before it causes damage to the tissues. Vacuum pumps work well when used correctly, are relatively cost-effective, have less side effects than oral tablets, and can be used in combination with other treatments. Medical grade pumps can be used several times a day sexually or

therapeutically; consider it a gym work out for your penis. One complaint of vacuum pump use is that men find their penis becomes cold and semi-rigid. This can be minimised if the correct ring size and type is used

- 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 intercourse 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, eating healthy regular meals 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 programme of penile rehabilitation after surgery using drugs or vacuum pumps can help erections to recover more quickly and can include any of the erectile dysfunction treatment options alone or in combination. The programme will involve a certain number of 'artificial erections' per week after surgery, which is not necessarily for intercourse but for better penile health

Can I masturbate if I have prostate cancer?

Yes. Beyond the enjoyment and pleasure of masturbating, it can also help with penile rehabilitation to strengthen erectile function and increase blood flow to the penis

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
ARPIs	Androgen Receptor Pathway Inhibitors
AS	Active Surveillance
ASAP	Atypical Small Acinar Proliferation
BPH	Benign Prostatic Hyperplasia
CNS	Clinical Nurse Specialist
CPG	Cambridge Prognostic Group
CRPC	Castrate-resistant prostate cancer
CT	Computerised Tomography
DHT	Dihydrotestosterone
DIY	Do-It-Yourself
DNA	Deoxyribonucleic Acid
DRE	Digital Rectal Examination
DVLA	Driving and Vehicle Licensing Agency
DVT	Deep Vein Thrombosis
eGFR	estimated Glomerular Filtration Rate
ECG	Electrocardiogram
EBRT	External Beam Radiation Therapy
EHIC	European Health Insurance Card
GHIC	UK Global Health Insurance Card
GnRH	Gonadotrophin-releasing hormone
GPH	Giant Prostatic Hyperplasia
Gy	Gray
HDR	High Dose Rate brachytherapy
HGPIN	High-Grade Prostatic Intraepithelial Neoplasia
HIFU	High Intensity Focused Ultrasound
HNA	Holistic Needs Assessment
HNPCC	Hereditary Non-Polyposis Colorectal Cancer
HTCS	Healthcare Travel Costs Scheme
IMRT	Intensity-Modulated Radiation Therapy
IRE	Irreversible Electroporation
INR	International Normalised Ratio
LDR	Low Dose Rate brachytherapy
LHRH	Luteinising hormone releasing hormone
MDT	Multi-Disciplinary Team
MRI	Magnetic Resonance Imaging
NICE	National Institute of Clinical Excellence
PARP	poly(ADP-ribose) polymerase
PET	Positron Emission Tomography
PHI	Prostate Health Index
PIN	Prostatic Intraepithelial Neoplasia
PI-RADS	Prostate Imaging – Reporting and Data System
PRECISE	Prostate Cancer Radiologic Estimation of Change in Sequential Evaluation
PSA	Prostate Specific Antigen
PSMA	Prostate Specific Membrane Antigen
PTS	Patient Transport Services
ReSPECT	Recommended Summary Plan for Emergency Care and Treatment
SABR	Stereotactic Ablative Body Radiotherapy
SMDT	Specialist Multi-Disciplinary Meeting
SPF	Sun Protection Factor
TRUS	Transrectal Ultrasound Guided
TURP	Transurethral Resection of the Prostate
TWOC	Trial Without Catheter
UCR	Urgent Cancer Referral
UV	Ultraviolet Rays
2WW	Urgent Cancer Referral (2-week wait)
VED	Vacuum Erection Device
WW	Watchful Waiting

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.
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 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
Cryotherapy	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 ionising radiation
Gynaecomastia	Enlargement of breast tissue in men, which can be a side effect of ADT
Haematospermia	Blood in the semen
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 contrast (dye)
Multidisciplinary Team	A team of health professionals who are involved in your care. This includes urologists, oncologists, radiologists, histopathologists, clinical nurse specialists and a co-ordinator
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 a 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 can be used to see if the cancer has come back after treatment
Prognosis	A term used to predict the course of the cancer and to help patients plan for the 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	An 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

Transperineal Biopsy	Sampling of the prostate through the perineum, which can be done under local or general anaesthetic
Transrectal Biopsy	Biopsies of the prostate taken via the back passage under local 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

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
CRUK 2RP
PO Box 81666
London E15 9LJ
General enquiries Tel: 0300 123 1022
Email for general enquiries: supporter.services@cancer.org.uk
www.cancerresearch.org

Cancer Support UK
Provides practical & emotional support to people with cancer
Cancer Support UK
The Old Church, 89b Quicks Road, Wimbledon SW19 1EX
Tel: 020 3983 7616
Email: hello@cancersupportuk.org
www.cancersupportuk.org

iMEDicare Pelvic Health naturally
UK & Ireland's leading Medical device distributor in the field of urology & continence management/ treatment
Unit 11, Shakespeare Industrial Estate
Shakespeare Street
Watford WD24 5RR
General enquiries Tel: 01923 237 795
Mobile: 07841 579499
Customer services: csm@imedicare.co.uk

Macmillan Cancer Support
Provides financial, emotional, practical advice & support for people with cancer & their loved ones
The Forge (Head Office), 3rd Floor, Bronze Building,
105 Sumner Street, London SE1 9HZ
Macmillan Support Line Tel: 0808 808 0000
www.macmillan.org.uk

Marie Curie
The UK's leading end of life charity providing nursing & hospice care & information on all aspects of dying
Marie Curie (Head Office), One Embassy Gardens
8 Viaduct Gardens, London SW11 7BW
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: 0800 082 1616
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

Date	My PSA	Date	Comments

MY NOTES

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» AVAILABLE ON NHS PRESCRIPTION



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24 HOUR LEAKAGE

BIODERM

The **BioDerm** male external penile glans petal sheath device is ideal for men with a retracted penile anatomy or who's body shape make's fitting a conventional penile sheath difficult. A hydrocolloid adhesive provides a strong skin friendly seal around the urethra directing urine to the leg or bed bag of your choice.

» AVAILABLE ON NHS PRESCRIPTION



BIODERM XLS (OVAL)

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CHOOSE LIFE – NOT LEAKS!

MyPelvicHealth.co.uk

01923 23 77 95

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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 MBE 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.

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