# SUPPORTING YOU

## LIVING WITH PROSTATE CANCER

This booklet contains information to help and empower you during your cancer treatment journey









**The information in this booklet is also available in audio format, narrated by Tony Collier (patient) and Dr Manreet Randhawa (Clinical Oncologist). Please see page 3 for more information.**

**This booklet is intended for patients who have been prescribed NUBEQA® (darolutamide).**

### Reporting side effects

For more information, please refer to the Patient Information Leaflet. If you get any side effects, talk to your doctor, pharmacist, or nurse. This includes any possible side effects not listed in the package leaflet. You can also report side effects directly via the Yellow Card Scheme at https://yellowcard.mhra.gov.uk/ or search for MHRA Yellow Card in the Google Play or Apple App Store. By reporting side effects, you can help provide more information on the safety of this medicine.

ORION PHARMA

BAYER

NUBEQA® (darolutamide) 300 mg tablets

This patient booklet has been developed and fully funded by Bayer PLC.

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# SUPPORTING YOU
## LIVING WITH PROSTATE CANCER

You have been given this booklet to help you understand your diagnosis, learn what it means for you, and guide you through your treatment journey. We hope it will provide reassurance, answer some of your questions, and help you feel more informed and confident as you move through this stage of care.

### KEY

The contents of this book have been colour-coded to help you identify the information which is relevant to your diagnosis:

- non-metastatic castration-resistant prostate cancer (nmCRPC)
- metastatic hormone-sensitive prostate cancer (mHSPC)
- nmCRPC and mHSPC

**For more information, please refer to the Patient Information Leaflet and/or your doctor, nurse or pharmacist.**



This document has been produced by Bayer PLC, in conjunction with a patient and a dedicated steering committee comprised of healthcare professionals.

**SCAN ME FOR THE AUDIO VERSION**

**The information in this booklet is also available in audio format, narrated by Tony Collier (patient) and Dr Manreet Randhawa (Clinical Oncologist). Please scan the QR code to listen to the audio. You can listen along, or refer to the timestamps in the contents table on this page to hear about specific sections discussed in this booklet.**

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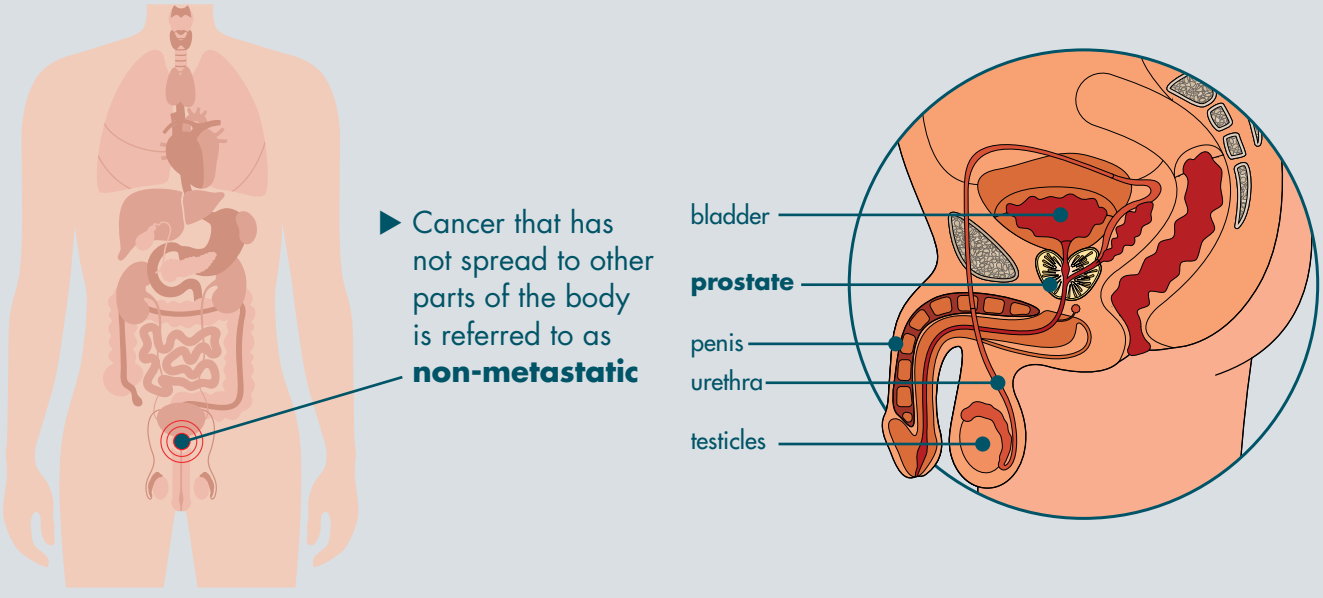
**SUPPORTING YOU** LIVING WITH PROSTATE CANCER

# UNDERSTANDING **YOUR DIAGNOSIS:**

## Non-metastatic castration-resistant prostate cancer (nmCRPC)[1]



**Non-metastatic castration-resistant prostate cancer (nmCRPC)** is a form of prostate cancer that is **no longer controlled by hormone therapy**. This type of cancer, which started in the prostate (a gland near the bladder), has not spread to other parts of the body.




**This is what the term nmCRPC means:**

**nm** Non-metastatic
The cancer **has NOT spread** to other parts of the body

**CR** Castration-resistant
The cancer is **still growing** despite low testosterone levels

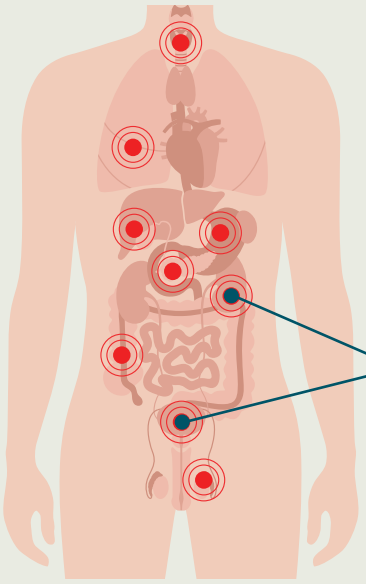
**PC** Prostate cancer
Cancer that starts in the **prostate gland**

# UNDERSTANDING **YOUR DIAGNOSIS:**

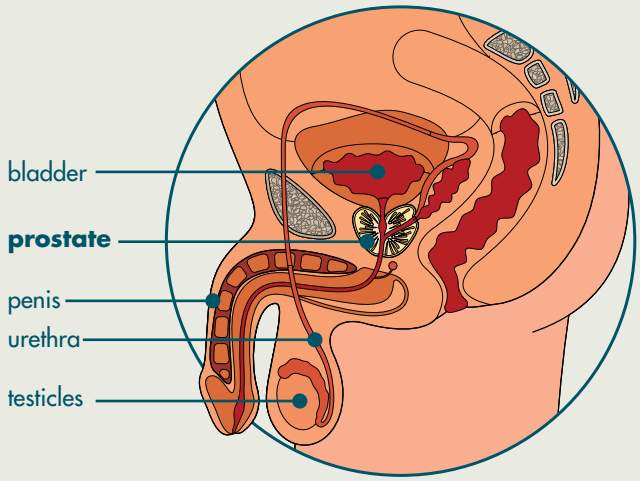
## Metastatic hormone-sensitive prostate cancer (mHSPC)[2]



**Metastatic hormone-sensitive prostate cancer (mHSPC)** is a type of cancer that started in the prostate (a gland near the bladder), but has also spread to other areas. This cancer is **still controlled by hormone therapy**. However, adding an additional treatment will help block/slow the progress of the cancer.



▶ Cancer that has spread to other parts of the body is referred to as **metastatic**




**This is what the term mHSPC means:**

**m** Metastatic

The cancer **has spread** to other parts of the body

**HS** Hormone-sensitive

The cancer is **controlled by** medical or surgical treatment to lower testosterone

**PC** Prostate cancer

Cancer that starts in the **prostate gland**

# PROSTATE-SPECIFIC ANTIGEN (PSA)[3]



## What is PSA?

PSA is a protein produced by both normal and prostate cancer cells. Prostate cancer and some other non-cancerous conditions can cause PSA levels in the blood to rise.

## About PSA monitoring

### Why is it done?

- To see how your treatment is working
- To spot early signs that the cancer may be worsening
- To guide any further tests or treatment

### How often will it be done?

Timing depends on your treatment, and your treatment team will tell you your schedule.

Whilst on darolutamide, you will have regular PSA tests and blood pressure checks, at first monthly, then usually every two to three months.

### What can the results mean?

A stable or falling PSA is reassuring. A rising PSA does not always mean the cancer is worsening, but you may need further checks.



For more information on PSA testing, please talk to your doctor.

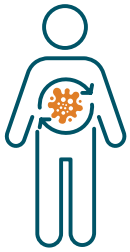
# HOW HAS MY DOCTOR DECIDED WHAT **TREATMENT TO RECOMMEND?**



Certain features of your prostate cancer can be used to guide treatment choices and help your doctor decide which treatment to recommend. These include:



- **Your prostate-specific antigen (PSA) blood test level.** A continuous rise in your PSA level can be the first sign that your cancer has begun to grow and spread again.[3]



- **How quickly your prostate cancer is likely to grow/spread.** This is assessed by carrying out a biopsy, where sample of cells is taken from your prostate. By looking at your cancer cells, doctors can assess how quickly it is likely to grow/spread using a scoring system called the **'Gleason score' or 'Grade Group'**.[10]
- **How big your cancer is and if, where, or how far it has spread.** Doctors use the **'TNM' staging system** to describe the size and spread of cancers.[10]

If you would like to understand more about scoring systems and what they mean for your diagnosis, please visit **this page** or scan the QR code.

*Please note: This page is not developed or monitored by Bayer PLC.*



## Can I be involved in deciding my treatment plan?

Treatment choices are based on more than test results. They also depend on your age, overall health, symptoms, and personal preferences. Every patient is different, and it is important that you are actively involved in decisions about your care.

You should feel included in "shared decision-making" with your healthcare team and you have the right to ask questions, and also challenge things you are unsure about. Your voice matters.

Before discussing treatment plans with your healthcare team, doing some of your own research can help you clarify what is important to you. Healthcare professionals (HCPs) will have their own recommendations regarding your treatment; being informed can make conversations easier and more balanced.

**Remember:** It is okay to ask, question, and take the time you need to make the decisions that feel right for you.

## Option grid to support treatment decisions

You/your healthcare team can use an option grid, such as the one below, to show the advantages and disadvantages of different treatment options in one place. It can help you compare options, understand what matters to you, and have more balanced discussions with your healthcare team.

| Treatment Option | What is it? | Potential Benefits | Potential Risks |
|---|---|---|---|
| Darolutamide + androgen deprivation therapy (ADT) | Androgen receptor inhibitor + hormone therapy | | |
| Darolutamide + ADT + docetaxel | Androgen receptor inhibitor + hormone therapy + chemotherapy | | |
| | | | |
| | | | |

## NOTES

Please note down what is most important to you to preserve your quality of life, and any concerns or queries pertaining to these that you may wish to speak to your HCP about.

# **UNDERSTANDING** YOUR TREATMENT (nmCRPC)

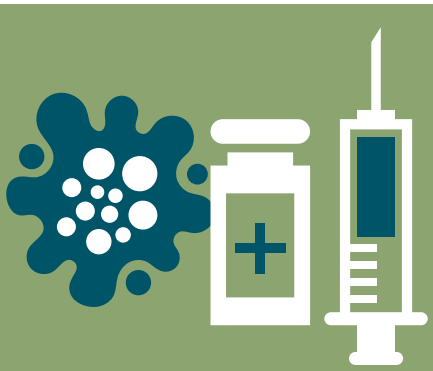
Your clinician will discuss with you which treatment regime is most appropriate for your prostate cancer diagnosis. The following medications are used to treat nmCRPC.



| | |
|---|---|
| **Androgen deprivation therapy (ADT)[4]** | In people with prostate cancer, **male hormones** (also called **androgens**) can make cancer cells grow faster. **Androgen deprivation therapy (ADT)** is sometimes known as **'hormone therapy'**. ADT is a treatment that either stops your body from making male hormones or stops male hormones from reaching the cancer cells. ADT is usually given by injection or tablets. Some men are offered an operation to remove the testicles or parts of the testicles instead. ADT treatment will usually continue for the rest of your life. |
| **Darolutamide[5,6]** | **Darolutamide** works by blocking the ability of cancer cells to respond to testosterone. It sticks to proteins called **'androgen receptors'** on the cancer cells which stops testosterone from binding to the cells. This helps to help delay cancer cell growth. |

## For patients with nmCRPC, darolutamide is given in combination with ADT.[5,6]

The clinical trial of 1,509 patients with nmCRPC showed that fewer patients with prostate cancer had died 3 years after treatment with darolutamide + ADT as compared to patients who were treated with ADT alone.



# UNDERSTANDING YOUR TREATMENT (mHSPC)

Your clinician will discuss with you which treatment regime is most appropriate for your prostate cancer diagnosis. The following medications are used to treat mHSPC.

| | |
|---|---|
| **Androgen deprivation therapy (ADT)**[4] | In people with prostate cancer, **male hormones** (also called **androgens**) can make cancer cells grow faster. **Androgen deprivation therapy (ADT)** is sometimes known as **'hormone therapy'**. ADT is a treatment that either stops your body from making male hormones or stops male hormones from reaching the cancer cells. ADT is usually given by injection or tablets. Some men are offered an operation to remove the testicles or parts of the testicles instead. ADT treatment will usually continue for the rest of your life. |
| **Darolutamide**[6–8] | **Darolutamide** works by blocking the ability of cancer cells to respond to testosterone. It sticks to proteins called **'androgen receptors'** on the cancer cells which stops testosterone from binding to the cells. This helps to help delay cancer cell growth. |
| **Docetaxel**[9] | **Docetaxel** is a type of chemotherapy that can help to stop the growth and spread of cancer cells. |

## Treatment combinations

Your doctor may recommend you receive treatment with two (doublet therapy) or three (triplet therapy) of these medications.

### Doublet therapy is darolutamide + ADT.[7]

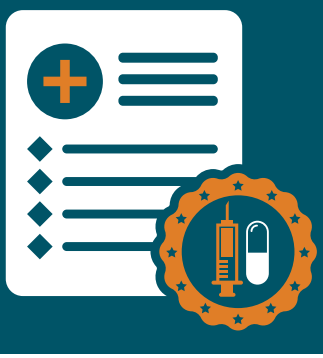
The clinical trial of 669 patients with mHSPC showed that patients who were treated with darolutamide + ADT had a longer time before the cancer began to spread again as compared to patients who were treated with ADT alone.

This is an important sign that the treatment could help patients live longer.



### Triplet therapy is darolutamide + ADT + docetaxel.[8]

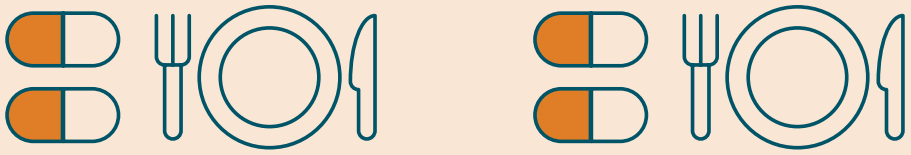
The clinical trial of 1,306 patients with mHSPC showed that fewer patients with prostate cancer had died 4 years after treatment with darolutamide + ADT + docetaxel as compared to patients who were treated with ADT + docetaxel alone.



# TAKING YOUR MEDICINES FOR **PROSTATE CANCER**

**Darolutamide** is a tablet, and your healthcare provider will tell you how to take it. Usually, this means taking two tablets (300 mg each) swallowed whole, twice a day with food.[11]

## 2 TIMES A DAY WITH FOOD



**MORNING WITH FOOD** **EVENING WITH FOOD**

(Tablets not actual size)

In some patients, the dose of darolutamide may be different.[11] Please refer to your prescription or healthcare professional for details on how to take darolutamide. If you miss a dose, take the missed tablets as soon as possible before your next scheduled dose, and:[11]

- Return to your normal routine the following day
- Do not take two doses together to make up for a missed dose

**Androgen deprivation therapy (ADT)** is given as an injection, implanted under the skin, or as an oral treatment, depending on the specific drug that you are prescribed. You should continue taking ADT during your treatment with darolutamide unless advised otherwise by your healthcare professional.[4]

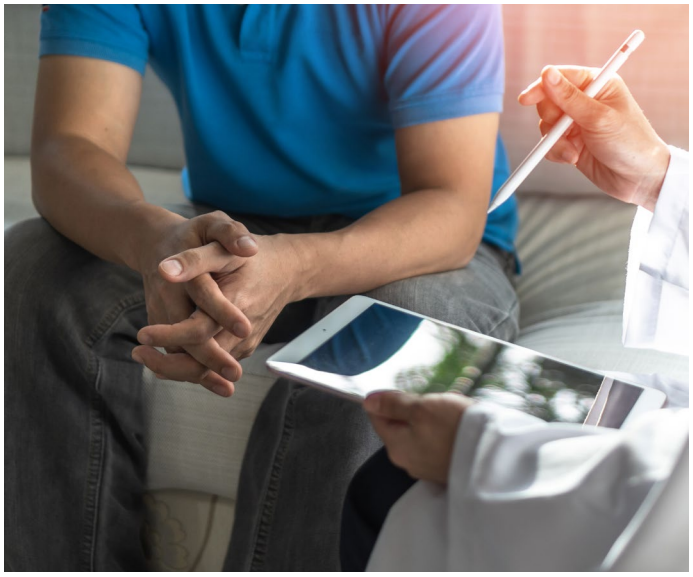
**Docetaxel** is given through a drip into a vein in your arm (also called an intravenous infusion). If you receive docetaxel, your doctor will provide more information on how this is given (usually up to 6 cycles every 3 weeks).[9]

## Other medicines you may take with your treatment for prostate cancer[9]

Your healthcare team will provide any additional medication you may need to help you manage the side effects of chemotherapy.

## I am on other medications, is that OK?[11]

Your doctor or healthcare professional will check if you are taking any additional medication, including any complementary medicines or weight loss drugs. Sometimes, they may need to make changes to the doses of your medicines or switch your medicines to other options.



# WHAT DO I NEED TO KNOW ABOUT **SIDE EFFECTS?**[11]



All treatments can cause side effects, but not everyone will experience them in the same way. Some people may experience few or no side effects, while others may experience more. The type and severity of side effects can vary from person to person.

**You will be regularly monitored for side effects while on treatment. However, please do contact your healthcare team (doctor, pharmacist or nurse) if you would like to discuss any side effects you are experiencing or if you have any questions/concerns throughout your treatment journey.**

Many side effects can be managed more effectively when treated early. So, speak to your doctor or nurse as soon as possible about any new or changing symptoms. Your healthcare team will give you contact numbers for the hospital. Save these numbers in your phone or keep them somewhere safe. If you feel unwell or need advice, you can call at any time of the day or night.

## Darolutamide (when given together with androgen deprivation therapy (ADT) and docetaxel):

More than 1 in 10 people on darolutamide experience:

- Rash
- High blood pressure
- Changes in liver function tests (this can be detected in blood tests as high levels of substances that are produced by the liver)

Some patients may experience side effects of chemotherapy (docetaxel) and have to stop their chemotherapy cycles. However, they can still continue with darolutamide if they are tolerating this drug.



## Darolutamide (when given together with ADT):

### More than 1 in 10 people on darolutamide experience:

- Fatigue (a deep, ongoing lack of energy that does not always improve with rest.
  You may feel weaker than usual or find everyday tasks harder to manage)
- Changes in liver function tests (this can be detected in blood tests as high levels of substances that are produced by the liver)
- Increased risk of infection (this can be detected in blood tests as a reduced number of white blood cells)
- Anaemia (reduced number of red blood cells)

### Up to 1 in 10 people on darolutamide experience:

- Pain in muscles and bones, especially arms and legs
- Rash
- Bone fractures
- Heart disease or heart failure



You may also experience other side effects such as **hot sweats/flushes** and **brain fog**. ADT can also be associated with loss of muscle mass, loss of body hair, **loss of libido, impotence, penile shortening or shrinkage, mood swings and male breast swelling (or gynaecomastia).**[12,13]

You should contact your doctor immediately if you experience any of the following serious side effects:[11]

- Chest pain, pain in other parts of the body (spreading from your chest to your arms, jaw, neck, back and tummy), feeling lightheaded or dizzy, sweating, shortness of breath, feeling sick (signs of heart disease caused by blockage of the blood vessels in the heart).
- Breathlessness after activity or at rest, tiredness most of the time, feeling lightheaded or fainting and swelling of the ankles and legs (signs of heart failure).
- Seizures

Please contact your doctor if you have any of the following symptoms that do not go away or keep coming back over time, as they can occasionally be related to signs of liver injury:[11]

- Feeling sick (nausea)
- Vomiting
- Abdominal discomfort
- Yellowing of the skin or eyes
- Darkening of the urine
- Loss of appetite



## An important note on fertility and pregnancy

Please be aware that darolutamide could reduce male fertility. The following advice should be followed while taking and 1 week after stopping darolutamide:

- **Use a condom or another highly effective method of birth control** to prevent pregnancy, if you are having sex with a woman who can become pregnant
- **Use a condom** to protect the unborn baby, if you are having sex with a pregnant woman

**Please talk to your doctor if you have concerns.**

## Reporting side effects

If you get any side effects, talk to your doctor, pharmacist or nurse. This includes any possible side effects not mentioned in this or any other leaflet given to you by a doctor.

It is important that you talk to your healthcare team if you experience any side effects. This includes any not already mentioned in this patient information booklet.

You can also report side effects directly via the Yellow Card Scheme at https://yellowcard.mhra.gov.uk/ or search for MHRA Yellow Card in the Google Play or Apple App Store. By reporting side effects, you can help provide more information on the safety of this medicine.

# LIVING WELL WITH PROSTATE CANCER

Living with prostate cancer can be challenging, especially when facing uncertainty or difficult symptoms. Your healthcare team can guide you and provide contact details for organisations that provide practical, emotional and medical guidance.

**You also play an important role in your own care. Taking steps to look after your physical and emotional wellbeing can make a real difference in how you feel day to day.**

Below are some suggestions on how to help manage the common symptoms and side effects of prostate cancer.[14,15]

## Pain



- Keep a pain diary to share with your doctor
- Pain can often be reduced with medication. Your doctor or nurse can help you identify suitable treatments

## Fatigue



- Stay as active as you can, even short walks can help
- Eat a balanced, nourishing diet
- Try to get enough rest and good-quality sleep
- Plan rest breaks into your day
- Ask for help when needed

## High blood pressure



- You can help by eating well, staying active, and reducing salt and alcohol
- Your doctor may suggest medicines, lifestyle changes, or monitoring

## Urinary problems



- Pelvic floor exercises can help – ask your nurse for more information
- There are also tools such as 'Squeezy' that can help you do pelvic floor exercises.

For more information, please visit **this page** or scan the QR code.[16]

*Please note: This page is not developed or monitored by Bayer PLC.*

- If needed, your doctor or nurse can provide medicines or suggest surgery that could help
- If you are leaking urine, your healthcare team can advise on the use of absorbent pads

## Managing symptoms and side effects of prostate cancer



For tips on how to maintain a healthy diet and stay active, please see page 16

## Nausea, eating problems and weight loss



- Your doctor may be able to give you anti-sickness drugs or steroids
- Try to eat small, frequent meals and drink plenty of fluids. Avoid strong smells and eat in well-ventilated spaces

## Bowel problems



- For constipation, try to eat high-fibre foods (e.g., wholemeal bread, prunes) and do gentle exercise
- For diarrhoea, reduce fibre and avoid spicy foods and dairy
- Drink plenty of fluids (especially water)
- Your doctor may recommend medications or dietary changes

## Swelling (also called lymphoedema)



- Early treatment is key. Let your healthcare team know as soon as you notice symptoms
- Treatments include compression garments, gentle exercise, and skin care
- Keeping your skin clean and moisturised helps prevent complications

## Managing long-term effects of hormone therapy[12,17]

Hormone therapy is an important part of your treatment and may allow people with prostate cancer to live longer. However, male hormones, such as testosterone, have many roles within your body. So, when they are removed or reduced by hormone therapy this has an impact on other parts of the body. Not all people will experience these side effects. Your healthcare team will monitor you regularly and work with you to manage these conditions if they develop.

Hormone therapy can cause:

- Increased weight (particularly around the waist)
- Increased cholesterol levels
- Changes in your body's ability to manage blood sugar
- Bone thinning

Talk to your team about how often you should have general health checks. You may be weighed, have your blood pressure checked, and have blood tests to check for diabetes and measure your cholesterol levels. If you experience bone thinning, you may be offered a type of x-ray called a DEXA scan. You may also be offered vitamin and mineral supplements or medicines.

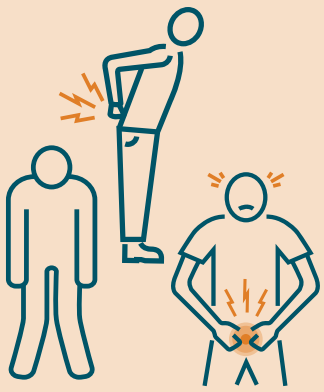
You can help by ensuring you have a healthy balanced diet, limiting the amount of salt you eat, cutting down on alcohol, stopping smoking and remaining as active as you can.

## What symptoms would be an emergency?[14]

Some symptoms may require urgent attention. These include:

- A sudden inability to empty your bladder, causing pain and discomfort
- Severe back pain that does not go away, is getting worse over time, or wakes you up at night
- Sudden difficulty walking or feeling unsteady on your feet,
- Weakness, numbness, tingling, or loss of sensation in your arms and legs

If you experience these symptoms, contact your doctor immediately or go to A&E, as you will need to be assessed.



## A patient's voice

*I seem to have suffered a full range of side effects from hormone based therapies. From hot sweats/flushes that diminished over time to loss of libido and erectile function but the hardest for me, as a club athlete, was fatigue.*

*I was given a massive boost when my Oncologist encouraged me to keep on running. He was 100% correct as unintuitive as that might sound.*

*I found complimentary therapies, in my case acupuncture, also helped.*

*My wife and I were very grateful to be able to access psychosexual therapy. It taught us a lot about our sexual relationship and helped us cope with the impact on my sexuality.*

**Tony Collier**
Ambassador, Fundraiser, Volunteer and Awareness Speaker, Prostate Cancer UK
Trustee and Vice Chair, Tackle Prostate Cancer

# MAINTAINING A **HEALTHY ROUTINE**

If you can, it is important to try to maintain a healthy routine. Below are some tips which may help you to eat well, exercise and look after your physical and emotional wellbeing.

## Eating well

Eating a healthy diet can help to improve energy levels, maintain strength and manage weight. Try to get a balance of the right nutrients in your diet over the course of the day or week.

- **Carbohydrates** provide your body with energy for physical activity and should be around one third of what you eat. Try to include whole grains where possible
- **Fruit and vegetables** provide vitamins, minerals and fibre and should make up more than one third of your diet
- **Proteins** are essential to help you maintain a healthy immune systems. Protein-rich foods include fish, poultry, nuts and nut butters or lentils




## Physical activity

It can be hard to think about exercise when you are dealing with prostate cancer, but taking steps to become more active can help.

Being active before and during treatment can improve recovery, reduce fatigue, boost mood, and support a healthy weight.

Aim for regular, moderate to vigorous exercise, enough to get slightly out of breath if possible, but start at your own pace and build up safely.

Ask your hospital/healthcare team about any physiotherapy or exercise programmes they may have available.



- Go for a short walk
- Do gentle stretching exercises
- Meet up with a friend or family member to exercise
- Do some light gardening or cleaning
- Take stairs where possible

For more advice on physical activity, visit the following pages or scan the QR code.[18]

- Exercise video
- The exercise clinic
- Physical activity, weight and prostate cancer

*Please note: These pages are not developed or monitored by Bayer PLC.*

**Always talk to your doctor or healthcare team before making any changes to your diet or exercise regime.**



## Emotional wellbeing

Living with prostate cancer can affect not only your body, but also how you feel emotionally. You don't have to face this alone – support is available.

Many people find it helpful to connect with others who understand what they're going through.

Local and national support groups, such as those offered by Prostate Cancer UK, Macmillan Cancer Support, and other cancer charities, can provide a safe space to share, listen, and feel supported.

The tips on the right may also help.

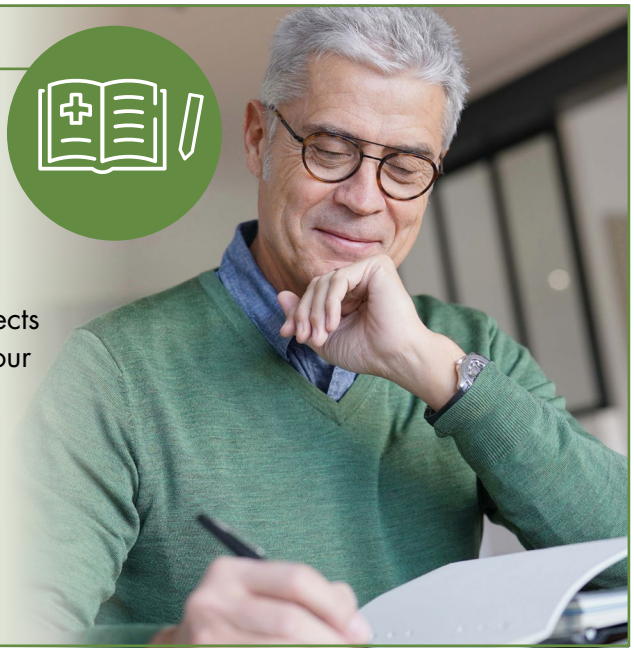
- Talk to people you are close to
- Be kind and caring to yourself
- Try to find things that help you relax
- Try to get plenty of sleep
- Make plans for events that are important to you and your loved ones



## Keeping a journal

You may find it helpful to keep a daily or weekly journal. This can have many benefits such as:

- Building a routine of when you take your medicines, how you are improving your diet and making time for regular exercise
- Showing you how far you've come in managing the effects of prostate cancer and your treatments, and boosting your confidence in living with prostate cancer going forward
- Creating a sense of wellbeing and being an active part of your journey
- Supporting you in communicating your thoughts to loved ones, family, friends, your partner and also your healthcare team

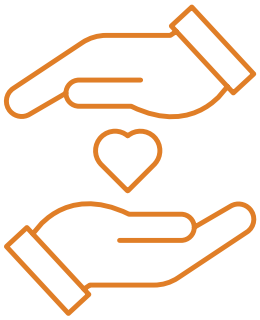


**Complementary therapies can help manage symptoms and improve wellbeing. Talk to your healthcare team about whether or not these may be beneficial for you.**

# IMPACT OF PROSTATE CANCER ON **RELATIONSHIPS WITH FAMILY AND FRIENDS**

Living with advanced prostate cancer can affect your relationships with family and friends. You might find it difficult to talk about your diagnosis, and that's completely understandable. You may worry about saying the wrong thing, causing distress, or not knowing how much to share. It can feel overwhelming.

There are many reasons why opening up might feel difficult:



- You may still be coming to terms with your own diagnosis
- You might want to protect your loved ones from worrying or feeling afraid
- Medical language around prostate cancer can be complex and hard to explain, especially to children or older family members
- You might not feel confident talking about emotions, especially if you come from a background or culture where health/emotional issues aren't usually discussed



While it's natural to want to shield those close to you, avoiding conversations can sometimes create distance or confusion. Opening up, even a little, can help build trust and strengthen support around you. Just telling one person can make a big difference.

You don't have to do this alone. Your healthcare team can help you find the words or provide written information to guide conversations. They may also be able to refer you to:

- Counselling or family support services
- Resources designed specifically to help explain cancer to people with different ages, cultures or backgrounds
- Local or online support groups

If you have a partner, it is important to remember they may also need emotional support. Caring for someone with prostate cancer can be stressful, and partners can sometimes feel overlooked. Encourage them to talk about how they feel and seek help if needed. Organisations such as Tackle Prostate Cancer offer guidance, peer support, and resources specifically for partners.[19]

There are also resources available to help you discuss your cancer diagnosis with children. For more advice, **visit this link** or scan the QR code.



## Changes to your sex life

Prostate cancer and its treatment can affect your sex life, and how you feel about yourself. Whether you're single or in a relationship, and whatever your sexuality, it is important to find ways to deal with changes in your sex life that are right for you.

Not everyone will have the same symptoms from cancer or the same side effects from therapy, but some changes you might have are:[13]

- Less desire for sex (low libido)
- Problems getting or keeping an erection (treatments are available for erection problems, e.g., vacuum pumps and medications)
- Changes to the size of your penis and testicles
- Changes to ejaculation and orgasm (e.g., 'dry orgasms' with no ejaculate)
- Changes in your looks, such as loss of muscle definition and body hair, and breast swelling
- Urinary incontinence during sex

It isn't always easy to talk about sex and relationships, but it can help to share any worries you may have with your partner. Free treatment and support for sexual problems is available on the NHS. Speak to your healthcare team for more information.

### Psychosexual support

Changes to sexual function, desire and intimacy can be distressing for both you and your partner. Psychosexual therapy can help you and your partner manage these changes, improve communication and regain confidence.

Early support can help you maintain intimacy and improve quality of life. Speak to your healthcare team if you would like more information on access to psychosexual therapists or sexual health specialists.

### LGBTQ+

Prostate cancer affects LGBTQ+ individuals in many of the same ways as heterosexual men, but there can be some other factors to consider too. It can help to tell your doctor or nurse about your sexuality, particularly if you have specific issues you want to talk about. Issues that might impact LGBTQ+ individuals with prostate cancer include:[14,15]

- Problematic anal intercourse
- Altered sexual function in relation to receptive anal and neovaginal intercourse
- Changes to a patient's role in sex

There are support groups which provide a safe place to share experiences and provide emotional comfort, support and practical information.

**Please see page 23 for websites which have further information on sex, intimacy and relationships that might be useful.**

# CARING FOR SOMEONE WITH CANCER

Looking after a loved one with cancer can be rewarding, but it is also hard work and can be stressful. You may feel overwhelmed by the responsibility or by the number of things that you have to help with. It is important that you reach out for help if you need it.

Patients with prostate cancer may experience mood swings or changes in emotions, which is a normal response to diagnosis and treatment, though some treatments (such as hormone therapy) may affect these further.

Understanding that these mood changes can occur can help you respond with patience and support. Encourage open conversations, offer reassurance, and seek help from the healthcare team if needed. **Support is also available for you, as a carer, to manage your own wellbeing.**

**Being a carer for someone can mean:**

- Providing emotional support
- Helping with everyday tasks, such as making sure they take their medicines as advised by their doctor and are eating well
- Driving or accompanying them to appointments
- Talking to their healthcare team on their behalf
- Helping with washing and dressing; modifying things at home may help the person you're caring for keep some independence

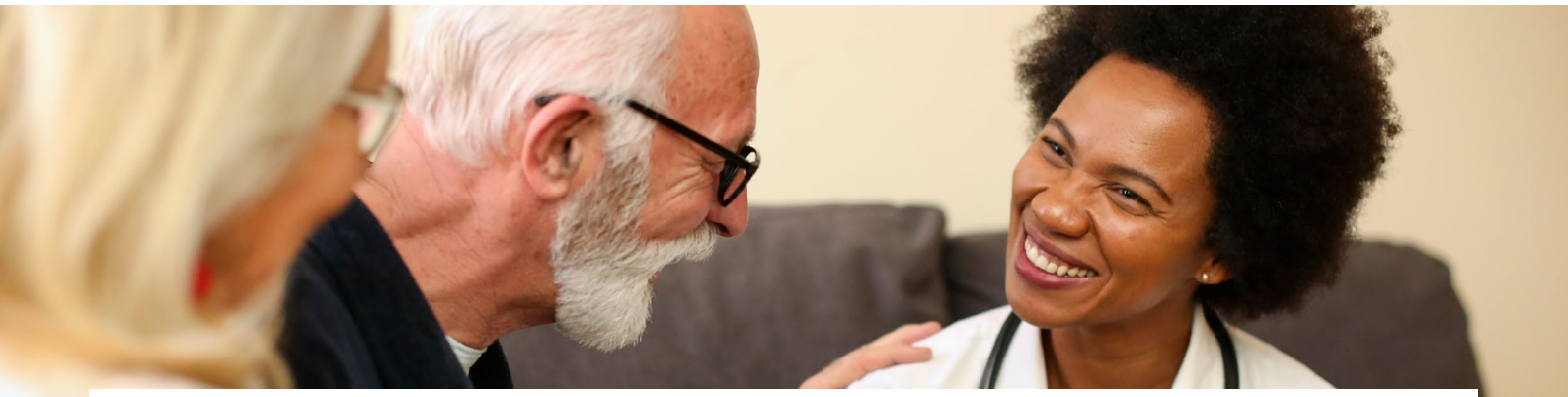


**As a carer, it is important to look after yourself:**

- Taking care of yourself means that you will be in a good place to care for your loved one
- Having someone to talk to, such as a family member or friend, may help you cope. You can also talk to your GP
- You may be able to share the caring with family or friends. It might be hard to accept help from others, but it can help
- Seek professional support if you need it – different health, social care and mental health professionals can help provide emotional support and give practical advice
- **Macmillan Cancer Support** offers a community forum and support line for carers, as well as information on prostate cancer. Available at: https://macmillan.org.uk



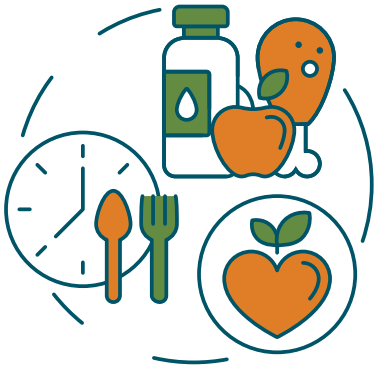
# TALKING WITH YOUR **HEALTHCARE TEAM**



It's completely normal to feel unsure about how to talk to your doctor or nurse about your concerns. Your healthcare team is there to help, and no question or concern is too small to bring up.

- Consider bringing a family member, partner or friend to your appointments
- Write down any questions you might have before your appointment
- Bring a pen and paper to your appointments so you can make notes, and/or ask if you can record the discussions to help you remember important information
- Don't be afraid to ask for support when you need it; your healthcare team may be able to signpost you to online resources, patient support groups or other suitable healthcare professionals
- Your doctor may ask about particular areas of your life, before discussing how darolutamide will fit into your current lifestyle







Take an active role in your care. Self-advocate by asking questions, doing your research, and sharing your preferences. Remember, your healthcare team is there to help with any concern, big or small.

# WHAT **HEALTHCARE PROFESSIONALS** MIGHT I SEE?



The main healthcare professionals who will be involved in your care are a medical oncologist, urologist, clinical oncologist, GP, nurse, and pharmacist. This is what each of these people specialise in:

- A **medical oncologist** is a specialist doctor who treats cancer using medicines
- A **urologist** is a specialist doctor who treats conditions affecting the urinary tract, including the prostate
- A **clinical oncologist** a specialist doctor who treats cancer and other conditions using radiation and/or medicines (those who deliver radiotherapy can also be termed radiation oncologists)
- Your **GP** will support you after your diagnosis and referral to a specialist by providing ongoing monitoring, management of side effects and telling you that other support is available if required
- **Nurses** have a vital role in providing support and information, and coordination of care. Specialist nurses may be the healthcare professional who you see the most. Some nurses are also able to prescribe medicines
- A **pharmacist** will focus on helping you manage your medications and support your overall wellbeing. Some pharmacists are able to prescribe as well as dispense medicines

Through the course of your care, other healthcare professionals (e.g., nutritionists and exercise professionals) may also be involved to help address any additional needs you may have.

## Carrying a patient alert card

You will be given a patient alert card when you start on darolutamide. This will list the exact medications for your prostate cancer diagnosis and what doses you are taking. It is important to carry this card with you, in your wallet or bag, so that first responders and other healthcare professionals have easy access to this vital information during an emergency. This information will help them to provide you with appropriate treatment quickly.



# **RESOURCES**, AND WHERE TO FIND MORE INFORMATION AND SUPPORT

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## General information on prostate cancer

### ▶ Prostate Cancer UK

Has lots of information on many aspects of prostate cancer, with educational guides and support materials that you can download.
**https://www.prostatecanceruk.org**

### ▶ Cancer Research UK

Provides lots of in-depth information about prostate cancer and different treatments.
**www.cancerresearchuk.org**

### ▶ The Infopool

The Infopool is a free online resource providing clear, up-to-date information and support for people with prostate cancer.
**https://www.theinfopool.co.uk/**

### ▶ Movember

Focusing on men's health, the website includes an initiative called True North, which provides information and support on the prostate cancer journey.
**https://uk.movember.com and https://truenorth.movember.com**

### ▶ Prostate Scotland

Prostate Scotland aims to inform, support, campaign and advance on prostate disease in Scotland.
**https://www.prostatescotland.org.uk/**

### ▶ Maggie's

A charity that provides free expert care and support in centres across the UK and online.
**https://www.maggies.org/**

## Support groups and community forums

### ▶ Tackle Prostate Cancer

Runs a network of support groups for prostate cancer.
**https://tackleprostate.org/**

### ▶ Orchid

Offers a helpline and website support for cancers.
**https://orchid-cancer.org.uk**

### ▶ Macmillan Cancer Support

Offers a support line for patients and their loved ones, as well as information on prostate cancer.
**https://macmillan.org.uk**

### ▶ PCaSO: Prostate Cancer Knowledge Empowers

PCaSO's "Knowledge Empowers" booklet is a free, easy-to-read guide giving clear information about prostate cancer, treatments, and what to expect; ideal for newly diagnosed men and their families.
**https://pcaso.org/forms-leaflets/PCaSO_Knowledge_Empowers_Oct_2024.pdf**

## Diet management

For more information on maintaining a healthy, balanced diet, you can visit:

### ▶ What makes up a healthy, balanced diet?

**https://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/healthy-eating-and-cancer/what-is-a-healthy-balanced-diet**

### ▶ Diet and prostate cancer

**https://prostatecanceruk.org/prostate-information-and-support/living-with-prostate-cancer/your-diet-and-physical-activity**

### ▶ How to eat a balanced diet

**https://www.nhs.uk/live-well/eat-well/how-to-eat-a-balanced-diet/eating-a-balanced-diet/**

### ▶ Healthy eating and cancer

**https://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/healthy-eating-and-cancer**

## LGBTQ+ support

### ▶ Out with Prostate Cancer

Primarily for LGBTQ+ individuals, this group offers support, shared experiences and practical information on living with prostate cancer.
**https://outwithprostatecancer.org.uk/**

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# ABBREVIATIONS

| | |
|---|---|
| ADT | Androgen deprivation therapy |
| A&E | Accident and emergency |
| GP | General practitioner / doctor |
| HCP | Healthcare professional |
| LGBTQ+ | Lesbian, gay, bisexual, transgender, queer/questioning, intersex, asexual or other |
| mHSPC | Metastatic hormone sensitive prostate cancer |
| nmCRPC | Nonmetastatic castration resistant prostate cancer |
| PSA | Prostate-specific antigen |

# GLOSSARY

| | |
|---|---|
| Androgen deprivation therapy (ADT) | Sometimes known as 'hormone therapy', ADT is a treatment that either stops your body from making male hormones or stops male hormones from reaching the cancer cells. It is usually given by injection or tablets although some men are offered an operation to remove the testicles or parts of the testicles instead. |
| Darolutamide | Darolutamide works by blocking the ability of cancer cells to respond to testosterone. It sticks to proteins called 'androgen receptors' on the cancer cells which stops testosterone from binding to the cells. This helps to help delay cancer cell growth. Darolutamide is given as an oral treatment (tablet). |
| Docetaxel | A type of chemotherapy that can help to stop the growth and spread of cancer cells. Docetaxel is given through a drip into a vein in your arm. |
| Metastatic hormone-sensitive prostate cancer (mHSPC) | A type of cancer that started in the prostate (a gland near the bladder), but has also spread to other areas. This cancer is still controlled by hormone therapy. |
| Non-metastatic castration-resistant prostate cancer (nmCRPC) | A form of prostate cancer is no longer controlled by hormone therapy. This type of cancer, which started in the prostate (a gland near the bladder), has not spread to other parts of the body. |
| Prostate-specific antigen | PSA is a protein produced by both normal and prostate cancer cells. Prostate cancer and some other non-cancerous conditions can cause PSA levels in the blood to rise. |

# NOTES

Please note any thoughts regarding your treatment, or any questions you may have for your next appointment.

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Please note any thoughts regarding your treatment, or any questions you may have for your next appointment.

# SUPPORTING YOU

## LIVING WITH PROSTATE CANCER

This booklet contains information to help and empower you during your cancer treatment journey









**Reporting side effects**

This booklet is intended for patients who have been prescribed NUBEQA® (darolutamide).

For more information, please refer to the Patient Information Leaflet. If you get any side effects, talk to your doctor, pharmacist, or nurse. This includes any possible side effects not listed in the package leaflet. You can also report side effects directly via the Yellow Card Scheme at https://yellowcard.mhra.gov.uk/ or search for MHRA Yellow Card in the Google Play or Apple App Store. By reporting side effects, you can help provide more information on the safety of this medicine.

ORION PHARMA

BAYER

NUBEQA® (darolutamide) 300 mg tablets

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