# Advanced prostate cancer

Managing symptoms and getting support



## **About this booklet**

This booklet is for anyone with prostate cancer that has spread to other parts of the body (advanced or metastatic prostate cancer) and who have symptoms such as fatigue or bone pain. Your partner, family or friends might also find it helpful.

We describe the symptoms you might get and the treatments available to help manage them. There's also information about emotional and practical support. And we mention other places where you can find more information.

This booklet is a general guide but everyone's experience of advanced prostate cancer is different. Ask your doctor, nurse, or someone else in your medical team for more details about your care and the support available to you. You can also speak to our Specialist Nurses, in confidence, on 0800 074 8383 or chat to them online.

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

- Our Specialist Nurses
- Our publication
- Sections for you to fill in
- Watch online at prostatecanceruk.org



## **Contents**

About this booklet	4 7		
		Health and social care professionals you might see	33
		Dealing with advanced prostate cancer  Relationships  Daily life with advanced prostate cancer	42
More information from us	57		
Other useful organisations	58		
About us	63		

# What is advanced prostate cancer?

This is cancer that has spread from the prostate to other parts of the body. It develops when prostate cancer cells move through the blood or the lymphatic system (see below).

It's also known as metastatic prostate cancer, secondary prostate cancer, secondaries, metastases or mets. It is still prostate cancer, wherever it is in the body.

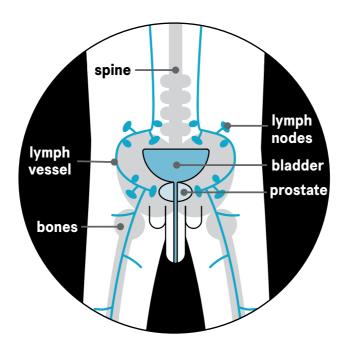
Advanced prostate cancer is not the same as locally advanced prostate cancer. Locally advanced prostate cancer is cancer that has started to break out of the prostate or has spread to the area just outside the prostate, but not the rest of the body.

It's not possible to cure advanced prostate cancer. But treatments can help keep it under control and manage any symptoms (see page 29).

## Where can prostate cancer spread to?

Prostate cancer can spread to any part of the body, but it most commonly spreads to the bones and lymph nodes (see diagram on page 5). Prostate cancer cells can move to other parts of the body through the blood stream. Or they can spread to lymph nodes near the prostate and travel through the lymph vessels. Lymph nodes (sometimes called lymph glands) and lymph vessels are part of your lymphatic system and are found throughout your body. The lymphatic system is part of your immune system, which helps the body fight infection.

Prostate cancer can also spread to or press on the tube that carries urine through the penis (urethra), the bladder, the tubes that carry urine from the kidneys to the bladder (ureters) and your lower bowel (rectum).



Prostate cancer may spread to other parts of the body including the lungs and liver. But this is less common. It's sometimes called secondary cancer in the lungs and liver. Macmillan Cancer Support has more information about secondary cancers in the lungs and liver.

#### Watch our video online

You might find it helpful to watch our video, What is advanced prostate cancer? It explains what advanced prostate cancer is, how prostate cancer can spread around the body, and the problems it might cause.

Watch it online at prostatecanceruk.org/advanced-video

## What is my outlook?

Some men want to know how well their treatment will control their cancer, and for how long it will control it. This is sometimes called your outlook or prognosis. But not all men want to know this.

It isn't possible to cure advanced prostate cancer. But not all men will die from their cancer. Treatments can help keep it under control, usually for several years. Treatments can also help manage any symptoms. How long treatment will keep your cancer under control, or manage any symptoms, will be different for each person.

No one can tell you exactly what your outlook will be as it will depend on many things such as where the cancer has spread to, how quickly it has spread, and how well you respond to treatment. Some men may not respond well to one treatment, but may respond better to another. And when your first treatment stops working, there are other treatments available that can bring the cancer back under control.

It can be very difficult living with the uncertainty of cancer and how long your treatments will work for, but there are people and organisations who can support you on your journey.

This includes help with managing symptoms, as well as emotional and practical support.

Speak to your doctor or nurse about your

concerns you have.

own situation and any questions or



## What symptoms might I get?

The symptoms you have will depend on where the cancer has spread to and how quickly it is growing. You might only get a few symptoms and they might not affect you every day. There are treatments available to help manage symptoms and other things that can help.

#### This section includes information about:

- fatigue (extreme tiredness)
- pain
- urinary problems
- bowel problems
- broken bones (fractures)
- sexual problems
- lymphoedema (swelling)
- anaemia (low levels of red blood cells)
- metastatic spinal cord compression (MSCC)
- hypercalcaemia (high levels of calcium)
- eating problems and weight loss.

#### Side effects from treatment

We don't go into a lot of detail about side effects from treatments. You can read more about these and how to manage them in our other booklets and fact sheets, or on our website at





You could also speak to our **Specialist Nurses**.

## **Fatigue**

Fatigue is a feeling of extreme tiredness that doesn't go away, even after you rest. It is very common in men with advanced prostate cancer. Many men are surprised by how tired they feel and by the impact this has on their lives. Fatigue can make it difficult to do some things, including:

- everyday tasks, such as getting dressed, or preparing food
- social activities, such as seeing friends and family
- sleeping (insomnia)
- concentrating and remembering things
- understanding new information and making decisions.

Fatigue can also affect your mood. It might make you feel sad, depressed, or anxious. You may feel guilty or frustrated that you can't do the things you normally do. It can also affect your relationships.

Fatigue can be caused by lots of things, such as:

- prostate cancer itself and the treatments you have
- stress, anxiety or depression, especially if it affects your sleep
- symptoms of advanced prostate cancer, such as pain or anaemia
- other health problems
- · lack of physical activity.



## What can help?

There are lots of things you can do to improve or manage your fatigue. Small changes to your lifestyle can make a big difference. This could include the following.

- Be as physically active as you can this can help improve your energy levels, sleep, mood and general health.
- Get help with anything that is worrying you (see page 40).
- Plan activities for when you usually have more energy maybe first thing in the morning, or after a rest.
- Make time to rest and relax.
- Deal with any problems sleeping try to relax before bed and avoid drinks with caffeine, such as tea and coffee.
- Eat a well-balanced diet.
- Try complementary therapies alongside your usual treatment.
- Ask for help if you need it.

#### Support for fatigue

Our **Specialist Nurses** can talk to you in depth about your experience of fatigue, and the impact it's having on your day-to-day life. They can also discuss ways to help you better manage your fatigue, such as behaviour and lifestyle changes. Visit prostatecanceruk.org/fatigue

There's also more information on ways to manage fatigue in our fact sheet, **Fatigue and prostate cancer.** 

Our fatigue diary can help you manage your fatigue. You can plan your week to decide what activities are important to you and help you work out what makes your fatigue better or worse. You can download our fatigue diary at **prostatecanceruk.org/shop** 



## **Pain**

Pain is a common problem for men with advanced prostate cancer, although some men have no pain at all. The cancer can cause pain in the areas it has spread to. If you do have pain, it can usually be relieved or reduced with the right treatment and management.

Pain is more common in men whose prostate cancer has spread to their bones. The cancer can damage or weaken the bone, which may cause pain. But not all men with cancer in their bones will get bone pain.

Bone pain is a very specific feeling. Some men describe it as feeling similar to a toothache but in the bones, or like a dull aching or stabbing. It can get worse when you move and can make the area tender to touch. Each man's experience of bone pain will be different. The pain may be constant, or it might come and go. How bad it is can also vary and may depend on where the affected bone is.

You might get other types of pain. For example, if the cancer presses on a nerve, this can also cause pain. This might be shooting, stabbing, burning, tingling or numbness.

Pain can also be a symptom of a more serious condition called metastatic spinal cord compression (MSCC) (see page 25).

## What can help?

By trying different treatments, or combinations of treatments, pain from cancer can usually be managed well. You shouldn't have to accept pain as a normal part of having cancer. If you have pain, speak to your doctor or nurse. The earlier pain is treated, the easier it will be to control.

Different types of pain are treated in different ways. Treatments to control pain include:

- treatments for the cancer itself, such as hormone therapy, steroids, chemotherapy or radiotherapy
- Pain-relieving drugs, pain-relieving radiotherapy, bisphosphonates surgery to support damaged bone and other treatments.

Other things that might help you manage your pain include:

- complementary therapies (see page 32)
- getting emotional support (see page 36)
- treatments for other causes of pain, such as antibiotics to treat infection
- keeping a pain diary to help you describe the pain to your doctor or nurse - download one from our website at prostatecanceruk.org/pain-diary
- eating a healthy diet and doing regular gentle exercise.

To find the best way to deal with your pain, you might have a pain assessment at your GP surgery or the hospital and be referred to a palliative care specialist. Palliative care specialists provide treatment to manage pain and other symptoms of advanced cancer (see page 34).

Read more about ways to control pain in our fact sheet, **Managing pain** in advanced prostate cancer.

## **Urinary problems**

You might get urinary problems if the cancer is pressing on your urethra or has spread to areas around the prostate, such as the urethra and bladder. These might include:

- problems emptying your bladder
- leaking urine (incontinence)
- blood in your urine
- kidney problems.

Some treatments for prostate cancer, such as surgery or radiotherapy, can also cause urinary problems. Find out more about ways to manage these problems in our fact sheet, **Urinary problems after prostate**cancer treatment.

Urinary problems can also be caused by an infection or an enlarged prostate. If you have urinary problems, speak to your doctor or nurse. There are lots of things that can help.

## **Problems emptying your bladder**

If the cancer is pressing on your urethra or the opening of your bladder, you may find it difficult to empty your bladder fully. This can sometimes cause urine retention, where urine is left in your bladder when you urinate. There are several things that can help, including the following.

- Drugs called alpha-blockers. These relax the muscles around the opening of the bladder, making it easier to urinate.
- A catheter to drain urine from your bladder. This is a thin, flexible tube that is passed up your penis into your bladder, or through a small cut in your abdomen (stomach area).
- An operation called a transurethral resection of the prostate (TURP)
  to remove the parts of the prostate that are pressing on the urethra.

#### **Acute urine retention**

This is when you suddenly and painfully can't urinate at all – it needs treating straight away. Acute retention isn't very common in men with advanced prostate cancer. But if it happens, call your doctor or nurse, or go to your nearest accident and emergency (A&E) department. They may need to drain your bladder using a catheter.

#### Leaking urine

Cancer can grow into the bladder and the muscles that control urination, making the muscles weaker. This could mean you leak urine or need to urinate urgently. Ways to manage leaking urine include:

- absorbent pads and pants
- pelvic floor muscle exercises
- medicines called anti-cholinergics
- a catheter
- surgery.

Your treatment options will depend on how much urine you're leaking and what treatments are suitable for you. Your GP may refer you to an NHS continence service, run by specialist nurses and physiotherapists. You can get more advice and support about incontinence products from www.continenceproductadvisor.org

If you find you need to rush to the toilet a lot and sometimes leak before you get there, find out where there are public toilets before you go out. Get our Urgent toilet card to show to staff in shops or restaurants - this should make it easier to ask to use their toilet. Order one on our website at prostatecanceruk.org

Read more about treatments for leaking urine in our fact sheet, Urinary problems after prostate cancer treatment.

Rarely, problems emptying your bladder or leaking urine may be caused by a condition called metastatic spinal cord compression (MSCC) (see page 25).

#### **Blood in your urine**

Some men notice blood in their urine (haematuria). This may be caused by bleeding from the prostate. It can be alarming, but can usually be managed, so tell your hospital doctor or nurse if you have this.

Your doctor might ask you to stop taking medicines that thin your blood, such as aspirin or warfarin. Speak to your doctor or nurse before you stop taking any drugs. You might also be able to have radiotherapy to shrink the cancer and help to stop the bleeding.

#### **Kidney problems**

The kidneys remove waste products from your blood and produce urine. Prostate cancer may block the tubes that carry urine from the kidneys to the bladder (ureters). This can affect how well your kidneys work Prostate cancer and some treatments can also make it difficult to empty your bladder (which can lead to urine retention). This can stop your bladder and kidneys from draining properly, which can cause kidney problems.

Severe kidney problems can lead to high levels of waste products in your blood, which can be harmful. Symptoms include tiredness and lack of energy, feeling sick, swollen ankles and feet, and poor appetite. If you have any of these symptoms tell your doctor or nurse. A blood test can check how well your kidneys are working.

Treatments that can help to drain urine from the kidneys include:

- a tube put into one or both kidneys to drain urine into a bag outside your body (nephrostomy)
- a tube (called a stent) put inside one or both ureters to allow urine to flow from the kidney to the bladder
- radiotherapy to shrink the cancer and reduce the blockage.

If you have kidney problems caused by urine retention, you may need a catheter to drain urine from your bladder.

#### **Getting support for urinary problems**

Urinary problems might affect your independence and how you feel about yourself. If you're finding them hard to deal with, speak to your doctor or nurse.

## **Bowel problems**

Men with advanced prostate cancer can get bowel problems for a variety of reasons.

- Radiotherapy to treat prostate cancer. These might start during treatment, or they can develop months or years later.
- Pain-relieving drugs such as morphine and codeine can cause constination. Don't stop taking them but speak to your doctor or nurse if you have any problems.
- Becoming less active, changes to your diet, and not drinking enough fluids can also cause constipation.
- You might get bowel problems if your prostate cancer has spread to your bowel, although this isn't very common.
- Problems emptying your bowels or leaking from your back passage might sometimes be caused by a rare condition called metastatic spinal cord compression (MSCC) (see page 25).

#### Bowel problems can include:

- passing more wind than usual, which may sometimes be wet (flatulence)
- passing loose and watery bowel movements (diarrhoea)
- difficulty emptying your bowels (constipation) or a feeling that your bowels haven't emptied properly

- needing to empty your bowel more often, or having to rush to the toilet (faecal urgency)
- pain in your abdomen (stomach area) or back passage
- being unable to empty your bowels (bowel blockage)
- bleeding from your back passage or blood in your stools.
- leaking from your back passage (faecal incontinence) this is very rare.

Speak to your doctor or nurse if you have any of these symptoms. There are treatments available that may help.

## What can help? Lifestyle changes

Speak to your doctor or nurse about whether changing your diet could help with these problems. They may refer you to a dietitian, who can help you make changes to your diet.

If you have constipation, eating more high-fibre foods may help. These include fruit such as prunes, wholemeal bread, wholegrain breakfast cereals and porridge. Drink plenty of water – aim for about two litres (eight glasses) a day. Gentle exercise such as going for a walk can also help with constipation.

If you have diarrhoea, eating less fibre for a short time might help, but the evidence for this is not very strong. Low-fibre foods include white rice, pasta and bread, potatoes without the skins, cornmeal, eggs and lean white meat. Avoiding spicy food and eating fewer dairy products, such as milk and cheese, may also help. Make sure you drink lots of water to replace the liquid your body is losing.

Read more in our fact sheet, **Diet and physical activity for men with prostate cancer**.

#### Medicines or treatments

If you have constipation, your doctor or nurse may prescribe laxatives to help you empty your bowels. If your bowel becomes blocked, you may need to have surgery. But this is rare.

#### Information and support

Bowel problems can be distressing and difficult to talk about. But health professionals are used to discussing these problems and can help you find ways to deal with them. If you have bowel incontinence, you could also ask your GP to refer you to an NHS continence service. Their specialist nurses can give you support and information on products that can help. Macmillan Cancer Support has more information about coping with bowel problems.

## **Broken bones**

The most common place for prostate cancer to spread to is the bones. The cancer can damage bones, making them weaker. And some types of hormone therapy can also make your bones weaker. You might hear this called bone thinning. If bone thinning is severe, it can lead to a condition called osteoporosis. This can increase your risk of broken bones (fractures).

Read more about bone thinning and hormone therapy in our booklet, Illustrate Living with hormone therapy: A guide for men with prostate cancer.

Damage to the bones can make it difficult or painful to move around. You may not be able to do some of the things that you used to do because you're in pain, or because you might be more likely to break a bone.

## What can help?

You might be given radiotherapy to slow down the growth of the cancer. This can help slow down damage to the bones and relieve bone pain (see page 30). Read more in our fact sheet, **Radiotherapy for advanced prostate cancer**.

Your doctor may offer you drugs called bisphosphonates. These can strengthen the bones and help prevent broken bones. Bisphosphonates can also be used to treat pain caused by cancer that has spread to the bones. Read more in our fact sheet, **Bisphosphonates for advanced** prostate cancer.

Your doctor or nurse may suggest you take vitamin D and calcium supplements to help keep your bones healthy and strong. Read more in our fact sheet, **Diet and physical activity for men with prostate cancer**.

If an area of bone is badly damaged, you may be able to have surgery. A metal pin or plate is put inside the bone to strengthen it and reduce the risk of it breaking. Or a type of cement can be used to fill the damaged area. Surgery isn't suitable for all men with advanced prostate cancer. This will depend on where the damaged bone is, and other things such as whether you are well enough for surgery. If you have an operation, you may have radiotherapy afterwards to help stop the cancer growing in that area.

Even though it can be hard to accept that you may not be able to do some activities you enjoy, staying active can help with your general health and your ability to move around. It could also help to keep you strong and prevent falls that could cause broken bones. Speak to your doctor, nurse or physiotherapist about what you can and can't do.

The Royal Osteoporosis Society has more information about weak bones.



## Sexual problems

Dealing with advanced prostate cancer can have an impact on your sex life. There are lots of different reasons why this might happen. For example, hormone therapy can reduce your desire for sex (your libido) and affect your ability to get or keep an erection. Other treatments that you may have had in the past, such as surgery or radiotherapy, can also cause erection problems. Feeling low, anxious or tired can affect your sex life too.

#### What can help?

Men with prostate cancer can get free treatment and support for sexual problems on the NHS. Treatments for erection problems include tablets, vacuum pump, injections, pellets and cream. Because getting an erection also relies on your thoughts and feelings, tackling any worries or relationship issues as well as having medical treatment can help. Speak to your GP, nurse or hospital doctor to find out more. They can offer you treatment or refer you to a specialist service.

If you had an active sex life before you were diagnosed with prostate cancer, your sex life is unlikely to be the same now. You may need some support dealing with these changes. There are still many ways to have pleasure, closeness and fun. If you have a partner, talking about sex, your thoughts and feelings can help you both deal with any changes. If you're in a relationship you may need time alone together, whatever your situation. If you're in a hospital, hospice or have carers coming to your house, let them know when you need private time.

If you have a catheter to help manage urinary problems, it's still possible to have sex. Speak to your nurse about this.

Read more about managing relationships on page 42. Read more about ways to manage sexual problems in our booklet, **Prostate cancer and your sex life**.

## Lymphoedema

If the cancer spreads to the lymph nodes it could lead to a condition called lymphoedema - caused by a blockage in the lymphatic system. The lymphatic system is part of your immune system, carrying fluid called lymph around your body. If it is blocked, the fluid can build up and cause swelling (lymphoedema). Prostate cancer itself, as well as some treatments such as surgery or radiotherapy, can cause a blockage. This can happen months or even years after treatment.

Lymphoedema in prostate cancer usually affects the legs, but it can affect other areas, including the penis or scrotum (the skin around your testicles), and the abdomen (stomach area). Symptoms in the affected area can include:

- swelling
- pain, discomfort or heaviness
- inflammation, redness or infection
- · tight or sore skin.

Lymphoedema can affect your daily life. You might be less able to move around and find it harder to carry out everyday tasks. Some men worry about how the affected area looks and feel anxious about other people seeing it.

## What can help?

Speak to your nurse or GP if you have any symptoms. There are treatments that can help to manage them. Treatments aim to reduce or stop the swelling and make you more comfortable. They are most effective if you start them when you first get symptoms. If you have lymphoedema, you may be referred to a specialist lymphoedema nurse or physiotherapist, who can show you how to manage the swelling. They are often based in hospices or hospitals.

There are a variety of things that might help.

- Caring for the skin, such as regular cleaning and moisturising, can help to keep your skin soft and reduce the chance of it becoming cracked and infected.
- Special massage (manual lymphatic drainage) can help to increase the flow of lymph. Your nurse might be able to show you or a partner, family member or friend how to do this.
- Gentle exercise may help to improve the flow of lymph from the affected area of the body. For example, doing simple leg movements, similar to those recommended for long flights, may help with leg lymphoedema.
- Using compression bandages or stockings can encourage the lymph to drain from the affected area. Your nurse will show you how to use them.
- Wearing close-fitting underwear or Lycra cycling shorts may help control any swelling in your penis or scrotum.
- Try to maintain a healthy weight as being overweight can make lymphoedema harder to manage. Read more in our fact sheet,
   Diet and physical activity for men with prostate cancer.

Living with lymphoedema can be difficult. If you need any support, speak to your nurse or GP. You could also refer yourself to an NHS counsellor to help you deal with how you're feeling.

Macmillan Cancer Support and the Lymphoedema Support Network provide more information and can put you in touch with local support groups.

## **Anaemia**

Some men with advanced prostate cancer develop a condition called anaemia. This is caused by a drop in the number of red blood cells or haemoglobin (a protein found in red blood cells). This means your blood doesn't carry enough oxygen around the body. Anaemia can happen when your bone marrow is damaged – either by the prostate cancer or by treatment such as hormone therapy, chemotherapy, radiotherapy or drugs such as Olaparib. Symptoms include feeling tired or weak, being out of breath and looking pale.

Sometimes anaemia is caused by not enough iron in your diet. You might be more at risk of this if you have problems eating, or if you are bleeding.

## What can help?

Speak to your doctor or nurse if you have symptoms of anaemia. You will have a blood test to check your levels of red blood cell and haemoglobin. The treatment you are offered will depend on what's causing your anaemia.

Your doctor may recommend you take iron supplements to help with anaemia. These can cause bowel problems such as constipation or diarrhoea – see page 17 for ways to manage bowel problems. If your red blood cell levels are very low, you may need a blood transfusion. This can be a quick and effective way of treating anaemia.

Macmillan Cancer Support and Cancer Research UK have more information about anaemia.

## Metastatic spinal cord compression (MSCC)

Metastatic spinal cord compression (MSCC) happens when cancer cells that have spread from the prostate grow in or near the spine and press on the spinal cord. MSCC is rare, but you need to be aware of the risk if your prostate cancer has spread to your bones or has a high risk of spreading to your bones. Your risk of MSCC is highest if the cancer has already spread to your spine. Speak to your doctor or nurse for more information about your risk of MSCC.

MSCC can cause any of the following symptoms.

- Pain or soreness in your lower, middle or upper back or neck. The pain may be severe or get worse over time. It might get worse when you cough, sneeze, lift or strain, go to the toilet, or lie down. It also may get worse when you are sitting, standing or moving. It may wake you at night or stop you from sleeping.
- Tenderness or pain in your spine when touched.
- Muscle pain or cramping when you walk or exercise.
- A narrow band of pain around your chest or abdomen (stomach area) that can move towards your back, buttocks or legs.
- Pain that moves down your arms or legs.
- Weakness or loss of control of your arms or legs, or difficulty standing or walking. You might feel unsteady on your feet or feel as if your legs are giving way. Some people say they feel clumsy.
- Numbness or tingling (pins and needles) in your legs, arms, fingers, toes, buttocks, stomach area or chest that doesn't go away.
- Problems controlling your bladder or bowel. You might not be able to empty your bladder or bowel, or you might have no control over emptying them.

Read more in our fact sheet, **Metastatic spinal cord compression (MSCC)**.

#### Don't wait

It is very important to seek medical advice straight away if you think you might have MSCC. Don't wait to see if your symptoms get better and don't worry if you think it's an inconvenient time, such as the evening or weekend. If you are diagnosed with MSCC, you should start treatment as soon as possible. MSCC could affect your ability to walk and move around if it isn't treated quickly. Getting treatment early can reduce the risk of long-term problems.

## **Hypercalcaemia**

Hypercalcaemia is a high level of calcium in your blood. Calcium is usually stored in the bones, but the cancer can cause calcium to leak into the blood. It is very rare but can sometimes affect men with advanced prostate cancer. If it happens, it's important to treat it so that you don't develop a more serious condition.

Hypercalcaemia doesn't always cause symptoms, but it can cause:

- difficulty emptying your bowels (constipation)
- confusion
- bone pain
- · tiredness, weakness or lack of energy
- loss of appetite
- feeling and being sick (nausea and vomiting)

- pain in your lower stomach area
- feeling more thirsty than usual
- needing to urinate often (frequency).

These symptoms can be quite common in men with advanced prostate cancer and might not be caused by hypercalcaemia. Tell your doctor or nurse if you have any of these symptoms. They may do some tests to find out what is causing them, including a blood test to check the level of calcium in your blood.

## What can help?

You may have to go into hospital or a hospice for a couple of days. You will be given fluid through a drip in your arm. This will help to flush calcium out of your blood and bring your calcium levels down.

Drugs called bisphosphonates can help treat hypercalcaemia by lowering the level of calcium in your blood. They usually start to work in two to four days. If your blood calcium levels are still high, you may be given another dose of bisphosphonates after a week. You'll usually stop treatment once your calcium levels are back to normal. Read more in our fact sheet, **Bisphosphonates for advanced prostate cancer**.

Once your calcium levels are back to normal, you'll have regular blood tests to check your calcium levels stay low, and to make sure you're not missing any important minerals that your body needs. Tell your doctor or nurse if your symptoms come back.

Cancer Research UK has more information about hypercalcaemia.

## **Eating problems and weight loss**

Some men with advanced prostate cancer have problems eating, or don't feel very hungry. You might feel or be sick. These problems may be caused by your cancer, or by your treatments. Being worried about things can also affect your appetite.

Problems eating or loss of appetite can lead to weight loss and can make you feel very tired and weak. Advanced prostate cancer can also cause weight loss by changing the way your body uses energy.

## What can help?

If you feel sick because of your treatment, your doctor can give you anti-sickness drugs. Steroids can also increase your appetite and are sometimes given along with other treatments.

Try to eat small amounts often. If you're struggling to eat because of nausea (feeling sick), try to avoid strong-smelling foods. Cold foods tend to smell less, or it may help if someone cooks for you. Try to eat when you feel less sick, even if it's not your usual mealtime. Fatty and fried foods can make sickness worse. Drink plenty of water, but drink slowly and try not to drink too much before you eat.

Tell your doctor if you lose weight. They may refer you to a dietitian who can provide advice about high calorie foods and any supplements that might help. It can be upsetting for your family to see you losing weight, and they may also need support. Macmillan Cancer Support and Marie Curie provide support and information about eating problems in advanced cancer.

## What treatments can I have?

Men with advanced prostate cancer may be offered different treatments to help with different things. Some treatments aim to keep the cancer under control, while others aim to help manage symptoms caused by the cancer. The following pages have more information about different treatments.

## Treatments to control advanced prostate cancer

If you've just been diagnosed with advanced prostate cancer, you may be offered the following treatments:

- chemotherapy with hormone therapy
- hormone therapy alone
- radiotherapy
- clinical trials.

## **Chemotherapy with hormone therapy**

Chemotherapy uses anti-cancer drugs to kill cancer cells, wherever they are in the body. It won't get rid of your prostate cancer, but it aims to shrink it and slow down its growth. You might be offered chemotherapy at the same time as, or soon after, you start having hormone therapy. This helps many men to live longer and may help delay symptoms such as pain.

You need to be quite fit to have chemotherapy. This is because it can cause side effects that are harder to deal with if you have other health problems. Read more in our fact sheet, **Chemotherapy**.

## Hormone therapy

Prostate cancer usually needs the hormone testosterone to grow. Hormone therapy works by either stopping your body from making testosterone, or stopping testosterone from reaching the cancer cells. This usually causes the cancer to shrink, wherever it is in the body. Hormone therapy can also help control symptoms of advanced prostate cancer, such as bone pain. Hormone therapy will be a life-long treatment for most men with advanced prostate cancer.

Hormone therapy can cause side effects - speak to your doctor or nurse about ways to manage these. Read more in our fact sheet, Mormone therapy, and our booklet, Living with hormone therapy: A guide for men with prostate cancer.

#### Radiotherapy to the prostate

Some men who have just been diagnosed with advanced prostate cancer may be offered external beam radiotherapy as part of their first treatment. This is where high-energy X-ray beams are directed at the prostate from outside the body. The X-ray beams damage the cancer cells and stop them from dividing and growing. Read more in our fact sheet, Radiotherapy for advanced prostate cancer.

#### **Clinical trials**

There are clinical trials looking at new treatments for men with advanced prostate cancer and new ways to use existing treatments. Clinical trials aren't suitable for everyone and there may not be any in your area. You can ask your doctor or nurse if there are any trials you Occupied could take part in, or speak to our **Specialist Nurses**.

## Further treatments to control the cancer

Your first treatment may help keep your cancer under control. But over time, the cancer may change and start to grow again. If this happens you might be offered other treatments, including:

- a different type of hormone therapy
- a different type of chemotherapy
- radium-223 (Xofigo<sup>®</sup>, a type of internal radiotherapy)
- clinical trials (see page 30).

Read more about all of these treatments in our fact sheet, Treatment options after your first hormone therapy.

## **Treatments to help manage symptoms**

There are treatments to help manage symptoms caused by advanced prostate cancer.

- Pain-relieving drugs, including tablets, patches and injections.
- Radiotherapy, either external beam radiotherapy or radium-223.
- · Bisphosphonates, to help strengthen weak or thin bones.

Read more in our fact sheets, Managing pain in advanced prostate cancer, Radiotherapy for advanced prostate cancer and Bisphosphonates for advanced prostate cancer.



#### **Complementary therapies**

Complementary therapies may be used alongside medical treatment. They include acupuncture, massage, yoga, meditation, reflexology and hypnotherapy. Some people find they help them deal with cancer symptoms and side effects of treatment, such as tiredness or hot flushes. But the evidence for most complementary therapies isn't very strong.

Some complementary therapies have side effects or may interfere with your cancer treatment. So make sure your doctor or nurse knows about any complementary therapies you're using or thinking of trying. And make sure that any complementary therapist you see knows about your cancer and treatments.

Some complementary therapies are available through hospices, GPs and hospitals. But if you want to find a therapist yourself, make sure they are properly qualified and belong to a professional body. The Complementary and Natural Healthcare Council has advice on finding a therapist at www.cnhc.org.uk

Macmillan Cancer Support and Cancer Research UK have more information about different therapies and important safety issues to think about when choosing a therapy.

# Health and social care professionals you might see

You might see a range of different professionals to help manage your symptoms and offer emotional and practical support. Some may have been treating you since your diagnosis. Others provide specific services or specialise in providing treatment to manage symptoms (palliative care).

If you have questions or concerns at any time, speak to someone in your medical team. They can explain your diagnosis, treatment and side effects, listen to your concerns, and help you get support.

## Your multi-disciplinary team (MDT)

This is the team of health professionals involved in your care. Your MDT may include the following.

- Specialist nurse. A nurse who specialises in caring for men with prostate cancer. They provide care and advice and can offer emotional support and practical information.
- Urologist. A surgeon who specialises in treating problems with the urinary system, which includes the prostate.
- Oncologist. A doctor who specialises in treating cancer using treatments other than surgery, including radiotherapy, hormone therapy and chemotherapy.
- Therapeutic or specialist radiographer. A health professional who plans and gives radiotherapy.

## Your GP, practice nurse and district nurse

Your GP, practice nurse, and district or community nurse will work with other health professionals to co-ordinate your care, refer you to local services and offer you support and advice. They can visit you in your home and also help support your family. They might also care for you if you go into a nursing home or hospice.

## Palliative care team

This includes specialist doctors and nurses who provide treatment to manage pain and other symptoms of advanced cancer. You might hear this called symptom control or supportive care. They work in hospitals and hospices, and they might be able to visit you at home. Your hospital doctor, nurse or GP can refer you to a palliative care team.

Palliative care can be provided at any stage of advanced prostate cancer and isn't just for men in the final stages of life. Men with advanced prostate cancer might have palliative care for many months or years.

People who work in palliative care may include the following.

- Palliative care nurses. You might hear your palliative care nurse called a Macmillan nurse. But not all palliative care nurses are Macmillan nurses.
- Marie Curie nurses. They provide care, practical advice and emotional support to people in the last few months or weeks of life. They visit people at home and can provide care overnight if you need it.
- Consultant in palliative care. These are doctors that specialise in treating symptoms that the cancer and its treatment may be causing you. They can provide care at hospitals or visit people at their home.

## **Hospices**

Hospices provide a range of services for men with advanced prostate cancer, and their family and friends. They can provide treatment to manage symptoms as well as emotional, spiritual, psychological, practical and social support. This can be in a hospice centre or at your home.

Hospices don't just provide care for people at the end of their life. Some people go into a hospice for a short time to get their symptoms under control, then go home again. For example, they might give you drugs called bisphosphonates if you have hypercalcaemia, or a blood transfusion if you have anaemia.

Hospice care is free for patients and the people looking after them. Most hospices are happy to tell you about the services they provide and show you around.

Your GP, hospital doctor or district nurse can refer you to a hospice service. Find out more about services in your area from Hospice UK.

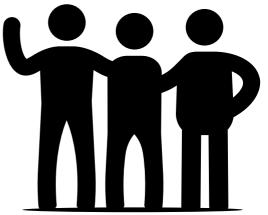
## **Hospitals**

Most men with advanced prostate cancer will need to stay in hospital at some point. Some men will go into hospital to help get their symptoms under control. Other men have to go into hospital if their symptoms suddenly get worse. This can be distressing or upsetting, but it may be the best way to get the care you need. If you're admitted to hospital, this may just be for a few days or it might be for longer.

## Other professionals who can help

Your doctor, nurse or GP can refer you to these professionals.

- Physiotherapists can help with mobility and provide exercises to help improve fitness or ease pain. This can help you stay independent for longer.
- Counsellors, psychologists or psychotherapists can help you and your family work through any difficult feelings and find ways of coping. You can get free counselling through your hospital or GP or refer yourself to an NHS counsellor. Visit www.nhs.uk/counselling to find out more.
- Dietitians can give you advice about healthy eating, which might help if you're having problems with eating, fatigue and staying a healthy weight.
- Occupational therapists can provide advice and access to equipment and adaptations to help with daily life. For example, help with dressing, eating, bathing or using the stairs.
- Social services and social workers, can provide practical and financial advice and access to emotional support. The telephone number for your local social services department will be in the phonebook under the name of your local authority, on their website and at the town hall.



# Dealing with advanced prostate cancer

Being diagnosed with prostate cancer can change the way you think and feel about life. It's normal to feel scared, worried, stressed, helpless or even angry. Lots of men with prostate cancer get these kinds of thoughts and feelings. But there's no 'right' way to feel and everyone reacts in their own way.

Finding out about things you can do to help yourself can make you feel more in control. Families can also find this a difficult time and they may need support and information too. They may want to read our booklet,

When you're close to someone with prostate cancer: A guide for partners and family.

# How can I help myself?

Everyone has their own way of dealing with their feelings. Give yourself time. Don't put yourself under pressure to be positive if that's not how you feel. There will be good days and bad days – make the most of the days you feel well and find ways to get through the bad days.

# Look into your treatment options

Find out about the different treatments you could have. Bring a list of questions to your doctor or nurse. And ask about any side effects so you know what to expect and how to manage them. This will help you decide what's right for you.

#### Talk to someone

Share what you're thinking – find someone you can talk to. It could be someone close, or someone trained to listen, like a counsellor or your doctor or nurse. People involved in your care should be able to help with any questions or concerns you might have.

"It is helpful to chat with other men. A shared experience lets you know that you're not on your own." A personal experience

# Set yourself some goals

Set yourself goals and plan things to look forward to – even if they're just for the next few weeks or months.

# Look after yourself

Take time out to look after yourself. When you feel up to it, learn some techniques to manage stress and to relax – like breathing exercises or listening to music. If you're having difficulty sleeping, talk to your doctor or nurse.

# Stay a healthy weight

Some men put on weight while they are on hormone therapy, often around the waist. Being very overweight might make hormone therapy less effective and make it harder to deal with some of the side effects. If you're on hormone therapy, you're at risk of bone thinning and broken bones. Being underweight or very overweight, can increase this risk further. For tips on how to stay a healthy weight, read our fact sheet,

Diet and physical activity for men with prostate cancer.

## Eat a healthy, balanced diet

Eating well is good for your general health and can help you feel more in control. Certain changes to your diet can also help with some side effects of treatment. For more information, read our fact sheet, **Diet and physical activity for men with prostate cancer**.

If you're on hormone therapy, you may need extra calcium or vitamin D to protect your bones. This is because hormone therapy can cause bone thinning, which may increase your risk of broken bones. Speak to your doctor or nurse about this. Drinking lots of alcohol can also increase your risk of broken bones, so try not to drink more than the recommended amount.

# Stop or reduce smoking

Smoking increases the risk of health problems such as heart disease, stroke and some other cancers. It may also be harmful for men with prostate cancer. Smoking also increases your risk of bone thinning. If you're having hormone therapy for your prostate cancer, you're at risk of bone thinning, but stopping smoking will help reduce your overall risk. For more information on stopping smoking visit the NHS website at www.nhs.uk/smokefree

# Be as active as you can

We don't know for sure if physical activity can help slow the growth of prostate cancer. But it can help with some side effects of hormone therapy, such as weight gain, fatigue, sexual problems and feelings of anxiety and depression. Certain exercises might also help reduce muscle loss and reduce your risk of broken bones. Even a small amount of physical activity can help. Take things at your own pace – you could start by taking a short walk or doing some gentle exercise like swimming or yoga. For more information, read our fact sheet, Diet and physical activity for men with prostate cancer.

# Sort out any problems

If something in particular is worrying you, then tackling it can help. For example, if you're having trouble with symptoms or side effects, speak to your doctor or nurse about ways to manage them.

If you are worried about the future, then making plans – such as thinking about your future care – might help you feel more in control (see page 50).

Find more ways organisations can support you at Macmillan Cancer Support, Maggie's Centres, Penny Brohn UK, or your nearest cancer support centre. You can also find more ideas in our booklet, <a href="Living">Living</a> with and after prostate cancer: A guide to physical, emotional and practical issues.

# Who else can help? Our Specialist Nurses

Our **Specialist Nurses** can help with any questions and explain your diagnosis and treatment options. They have time to listen, in confidence, to any concerns you or those close to you have.

# Our one-to-one peer support service

Our one-to-one peer support service is a chance to speak to someone who's been there and understands what you're going through. They can share their experiences and listen to yours. You can discuss whatever's important to you. We'll try to match you with someone with similar experiences.

# **Our online community**

Our online community is a place to talk about whatever's on your mind – your questions, your ups and your downs. Anyone can ask a question or share an experience.

## **Support groups**

At support groups, men get together to share their experiences of living with prostate cancer. You can ask questions, share worries and know that someone understands what you're going through. Some groups have been set up by health professionals, others by men themselves. Many also welcome partners, friends and relatives.

# Our fatigue support

Fatigue is a common symptom of prostate cancer, and a side effect of some treatments. Our **Specialist Nurses** can talk to you in depth about your experience of fatigue and how it affects your day-to-day life. They can also discuss ways to help you better manage your fatigue, such as behaviour and lifestyle changes.

# **Hospices**

You may be able to get support from your local hospice or community palliative care team. Hospices don't just care for people at the end of their life – you may be able to use their services while living at home. They can help with pain management, emotional and spiritual support, practical and financial advice, and support for families. Your GP, doctor or nurse can refer you to a hospice service and will work closely with these teams to support you.

# **Spiritual support**

You might begin to think more about spiritual beliefs as a result of having prostate cancer. You could get spiritual support from your friends, family, religious leader or faith group.

To find out more about any of the above, visit prostatecanceruk.org/get-support or call our **Specialist Nurses** on **0800 074 8383**.



# Relationships

Having cancer can often bring you closer to your partner, family or friends. But sometimes it can make relationships feel more difficult. Some days may feel harder than others.

The cancer and your treatment might mean that your partner or family need to do more for you, such as helping you get up, get dressed, wash and eat. Or they might take on tasks that you can't do any more, such as managing finances or doing jobs around the house. These changing roles can sometimes be difficult for both you and your family to deal with. You might not feel comfortable becoming more dependent, and they might have problems coping or feel very tired.

Some people may be unsure how to act around you and might find it difficult to talk about your cancer. They could be worried about upsetting you, or about becoming upset themselves. Sometimes it can help if you let them know whether you want to talk about it or not.

"We talk more now and that has brought us closer together."

A personal experience

# What can help?

Talking to those close to you can help everyone come to terms with your situation. But talking may not always be easy. If you'd like help with relationship problems, your nurse or GP can put you in touch with a counsellor, and your local hospice may have a family support team. You can also refer yourself if you prefer. You could also try contacting organisations such as Relate or the College of Sexual and Relationship Therapists.

# **Talking to children**

It can be difficult and upsetting to talk to children or grandchildren about your cancer, whatever their age. Not everyone chooses to talk about their prostate cancer. Everyone is different and it's okay to keep things private. But if you do decide to tell your family it usually helps to be honest with them. Keeping things from them might only make them worry more.

Children can often sense that something is wrong even if they don't understand it. They may also notice that things at home have changed, such as their day-to-day routine. This can be confusing, especially for younger children. Charities such as Macmillan Cancer Support and Winston's Wish have more information about how to talk to children when a parent or grandparent has cancer. Fruit Fly Collective also has information, and activity kits to order for children of all ages. You could also ask your GP or specialist nurse for advice or call our

#### **Specialist Nurses.**

If you're worried about talking to teenagers or adult children about cancer, find a time and place that feels right for everyone to talk. Everyone reacts differently when they're told that someone they love has cancer, but they may be shocked, upset or even angry. They may also have questions, which you might not always know the answers

to. It's okay to be honest and say if you don't know something. Some people find it helps talking to a counsellor, either together as a family or individually. Your doctor or nurse can tell you more about counselling services for yourself, and for your family. Your hospital and local hospice will also have support and information for partners and family members.



#### Supporting someone with advanced prostate cancer

If someone close to you has advanced prostate cancer you might be able to offer him a great deal of support. But looking after someone with advanced prostate cancer can be difficult. It's important to look after yourself and get support if you need it.

- Talk to someone. Sharing your worries and fears can make you feel less alone. You could talk to a family member or a close friend, or someone trained to listen, like your GP or a counsellor.
- Connect with other carers. You might find it helpful to talk to other people in similar situations. You can search for local carers groups on the Carers UK website.
- Take time for yourself. Take time to relax and rest so that you don't get too tired and can cope in the long run.
- Accept help from friends and family. Don't feel that you have to cope with everything on your own. Try to accept help from other people.
- Look after your health. If you feel unwell, tired or low, talk to your GP.
- Ask for help. Practical, financial and emotional support is available from social services and charities. Talk to your GP about what support is available in your area, or speak to our Specialist Nurses.

Macmillan Cancer Support have more information about caring for someone with advanced cancer. You can also read our booklet,

When you're close to someone with prostate cancer: A guide for partners and family.





# Daily life with advanced prostate cancer

Advanced prostate cancer can affect whether you're able to work or carry out everyday tasks. But there is advice and support available.

# Work and money

Advanced prostate cancer and the side effects of treatments can make it more difficult for you to work. You might decide to work part-time or stop working altogether. If your partner is caring for you, they might not be able to work as much.

A lot of men and their partners worry about how they will cope financially. It's a good idea to get advice about your own situation. You may be entitled to sick pay if you are employed, or to retire early and start receiving your pension. You may also be entitled to claim certain benefits. In the UK, there's a law to say that cancer is a disability. So even if you feel well or don't have symptoms that are bothering you, remember that the law protects your rights, including at work.

You can find out more about benefits and other types of financial help from other organisations, including:

- www.gov.uk
- Macmillan Cancer Support and Carers UK
- Citizens Advice
- a benefits adviser at your local council or hospital
- an independent financial adviser.

# At home

You might find everyday tasks more difficult. If you need help, speak to your GP or your local council. The council's social services department may provide a range of support services, such as practical and financial advice and access to emotional support. Social services can assess your needs and those of your carer, if you have one. They can work out what services can help, and provide information about support available in your area. Some services may be free. Or you may need to pay towards them.

# **Equipment and changes to your home**

An occupational therapist may be able to advise you about practical things to make it easier to live at home. For example, they may suggest making some changes to your home, or special equipment to help with everyday tasks. Your social services department or your GP can refer you to an occupational therapist.

## Help at home

You may be able to get help from a home care worker. Home care workers include care assistants, for help with housework and shopping, and personal care assistants, for help with tasks like getting washed and dressed.

## Respite care

If you need ongoing care from your partner, family member or a friend, respite care allows them to have a break. A professional will take over your care for a short time. Examples of respite care include:

- a sitting service, where someone stays with you in your home for a few hours
- a short stay in a residential home or hospice
- a carer who comes into your home for a few days.

## If you live alone

Dealing with advanced prostate cancer can be hard at times, particularly if you live on your own. Don't be afraid to ask for help if you need it. You could speak to your GP or nurse. If you have friends or neighbours nearby, they may be able to help, both practically and emotionally. See page 47 for more information about support you can get at home.

Joining a local support group can also be a good way of meeting people with similar experiences. For details of your nearest support group, ask your doctor or nurse or visit our website at prostatecanceruk.org/get-support

# **Driving and public transport**

There are various schemes available to help with transport. These include the Blue Badge scheme for parking, the Motability Scheme for help with leasing a car, and cheap or free travel on public transport. Contact your local council for details.

If you're having trouble getting around, ask your nurse or GP about local transport services. For example, the British Red Cross offer a door-todoor transport service.

If you drive, you don't need to tell the Driver and Vehicle Licensing Agency (DVLA) - or the Driver and Vehicle Agency (DVA) in Northern Ireland - that you have prostate cancer. But you should tell them if:

- · your medication causes side effects likely to affect safe driving
- your doctor is concerned about your fitness to drive
- you develop any problems with the brain or nervous system
- you can only drive vehicles with special adaptations or certain types of vehicle.

If you're unsure, speak to your doctor. You can find out more from the official government website, **www.gov.uk**. You should also tell your insurance company about your prostate cancer to make sure you're properly covered.

#### **Travel**

Holidays can be a great way to relax. Having advanced prostate cancer shouldn't stop you going away, but there are things you might want to consider. For example, it can be more difficult to get travel insurance.

Read more in our fact sheet, **Travel and prostate cancer**.



# Planning for the future

You might find that making plans helps you feel more prepared for what the future may hold. It can also reassure you about the future for your family.

Some men find it difficult or upsetting to think about what will happen if their cancer progresses and they come to the end of their life. Although it might be very hard, it's a good idea to talk about your wishes with those close to you so that they understand what is important to you. It can be helpful to have these conversations and start making plans well ahead of time. It's important to write your wishes down so that if you become too unwell to make decisions, your healthcare team and family should know what you want.

# Planning your future care

It can help to think about what care you would like to receive in the future. For example, you may need to decide how and where you'd prefer to be cared for and whether there are any treatments you don't want to have. This is called advance care planning. Planning your care can help to make sure you get the care you want.6 But not everyone wants to think about what care they want in the future, and it's not something you have to do.

People often find the thought of planning for their future treatment and care overwhelming. But the options may be more straightforward than you think, and there's lots of support available. We've listed some of the options below.

# Writing down your wishes

An advance statement (or anticipatory care plan in Scotland) is a general statement about anything that is important to you in relation to your future health and wellbeing. It can include:

- things that are important to you or that you'd like other people to know about your life, including information about your identity and religious or cultural beliefs
- your wishes about the type of care you want, for example if you have a daily routine you'd like to stick to
- who you would like to be involved in making decisions about your care, if you're unable to make them yourself
- where you would prefer to be cared for for example, at home, in a hospice or at hospital
- where you would prefer to die.

Your doctor will take your advance statement into account when making any decisions about your care. But they don't legally have to follow what your advance statement says, and your doctor might not always be able to follow your wishes. You can find more information and download an advance statement from the Compassion in Dying website.

# **Deciding not to have certain treatments**

An advance decision to refuse treatment (ADRT), known in Scotland as an advance directive to refuse treatment, allows you to record any treatments you don't want to have in certain situations. You might hear it called a living will.

An advance decision or advance directive is used if there's ever a time when you are unable to make a decision for yourself, or if you can't communicate what you want. For example, if you are unconscious or very sleepy in your final days.

You can't use an advance decision or advance directive to ask for a specific treatment or to ask for your life to be ended.

If you wish to make an advance decision or advance directive, you must do this in writing. Make sure your doctor, nurse and family know about it. This means they can follow your wishes.

You can download a free advance decision form and find lots of free support to help you complete it, at <a href="www.compassionindying.org.uk">www.compassionindying.org.uk</a>. It's a good idea to speak to your partner or family about what to include in your advance decision. And ask your doctor or nurse if you're not sure about something.

You can change your advance decision or advance directive at any time. It's a good idea to read it regularly to make sure it is still what you want. Whatever you decide, your doctor or nurse will still try to make sure you are comfortable and not in pain.

"We have talked about the end.

Now that's done, we can move on to living each day as it comes."

A personal experience

# **Support in making decisions**

Thinking about your wishes and making decisions can be difficult. Here are some things that may help, but you don't have to make any decisions if you don't want to.

 Talk to your doctor or nurse so they know your wishes when planning your care. They'll keep a record of your decisions.

- Talk to your family about what you want and help them understand your wishes. Let them know if you change your mind.
- Read more about making decisions about your care from Compassion in Dying, Age UK, Marie Curie and the NHS website.
- Read more about making an advance decision on Compassion in Dying's website at www.compassionindying.org.uk

## Appointing someone to make decisions for you

You, your loved ones, and your doctor or nurse will usually make decisions about your care together. But you can choose one or more people to make decisions for you if you're unable to – for example, if you are unconscious. The people you chose won't be able to make any final decisions about your care, but they should be involved in conversations with health professionals about your care. They should be someone you trust, like a family member or friend. This person is known as an attorney, and the legal document is known as a lasting power of attorney.

There are two types of lasting power of attorney, and you might choose someone different as each one.

- A property and financial affairs lasting power of attorney can make decisions about money and property.
- A health and welfare lasting power of attorney can make decisions about your health, personal care and welfare.

Age UK and Compassion in Dying provide information about making a lasting power of attorney. You can find more information and the forms you need to fill in on the official government website, **www.gov.uk** 

Read more about planning your future care on our website at **prostatecanceruk.org/plan-ahead** 

# **Practical things** Making a Will

By making a Will you can decide who will get your money, property and possessions after you die. If you die without making a Will, the government can decide who gets these things. You don't need a solicitor to make a Will, but using one makes sure your Will is made properly and is valid.

Age UK and Macmillan Cancer Support have more information about making a Will.

"Dad had already thought about his Will, but he decided to update it and talked to us all about it. I think that helped him feel in control of the situation."

A personal experience

# Making a funeral plan

Some people want to be involved in decisions about their own funeral, such as whether they will be buried or cremated, or what music and readings to have. Some people take comfort in making these plans. But other people prefer not to think about this.

If you do want to think about your funeral, you could discuss your wishes with your family, or write them down for them. Some people include instructions for their funeral in their Will. You can get more information about planning a funeral from Age UK and www.gov.uk

# Worries about dying from prostate cancer

Not all men with advanced prostate cancer will die from prostate cancer and men often live with advanced prostate cancer for several years. But you might have questions about what will happen if your cancer progresses and you're approaching the end of your life. It can help to know what to expect and how you can get the support you need. This can also make things easier for your family and friends.

# **Coming to terms with things**

If you're approaching the end of your life, this might be hard for you and your family to accept. Even if you've been living with prostate cancer for years, it can still be a shock. Some men feel upset, alone, or angry. Some men worry about their family and friends. It can be difficult to talk to your family about what's happening.

Give yourself time – it can take a while to process what's happening. Some men want time by themselves or with a family member or close friend. There are things you can do to help yourself and people who can support you (see page 37).

#### What to expect

Some men find that they get more symptoms in their last months and weeks. Others find that existing problems get worse. For more information about what to expect visit prostatecanceruk.org/dying-from-prostate-cancer

# **Getting access to care**

Towards the end of your life, your doctor or nurse will try to manage any pain and other symptoms. They will try to give you emotional, physical, practical and spiritual support. And provide support for your family and for people looking after you. This is sometimes called palliative or supportive care.

You might be looked after in a hospice, hospital, care home, or your own home. Where you're looked after will depend on what you need, what you prefer, and the services in your local area.

Your GP can refer you for palliative care and end of life care. Even if your doctor or nurse doesn't bring this up, you can still ask them about it. They can explain the services in your area and what support might be suitable.

To find out more about any of the above, visit prostate-canceruk.org/dying-from-prostate-cancer

**Or speak to our Specialist Nurses.** 

# More information from us

#### **The Tool Kit**

The Tool Kit information pack contains fact sheets that explain how prostate cancer is diagnosed, how it's treated and how it may affect your lifestyle. Each treatment fact sheet also includes a list of suggested questions to ask your doctor. Call our Specialist Nurses for a personally tailored copy.

#### Leaflets and booklets

We have a range of other leaflets and booklets about prostate cancer and other prostate problems.

#### To order publications:

All our publications are free and available to order or download online. To order them:

- call us on 0800 074 8383
- visit our website at prostatecanceruk.org/publications

# **Chat to one of our Specialist Nurses**

If you want to talk about prostate cancer or other prostate problems, call our Specialist Nurses in confidence. You can also text **NURSE** to **70004**, or you can email or chat online with our nurses on our website. Visit **prostatecanceruk.org/get-support** 



Chat to one of our Specialist Nurses 0800 074 8383\* prostatecanceruk.org

<sup>\*</sup> Calls are recorded for training purposes only. Confidentiality is maintained between callers and Prostate Cancer UK.

# Other useful organisations

#### **Bladder and Bowel UK**

www.bbuk.org.uk

Telephone: 0161 214 4591

Information and advice about bladder and bowel problems.

#### **British Association for Counselling & Psychotherapy**

www.bacp.co.uk

Telephone: 01455 883 300

Information about counselling and details of therapists in your area.

#### Cancer Research UK

www.cancerresearchuk.org Telephone: 0808 800 4040

Information about prostate cancer and clinical trials.

#### **Carers UK**

www.carersuk.org

Telephone: 0808 808 7777

Information and advice for carers, and details of local support groups.

#### Citizens Advice

www.citizensadvice.org.uk

Telephone: 0800 144 8848 (England), 0800 702 2020 (Wales)

Advice on a range of issues including financial and legal matters.

Find your nearest Citizens Advice online.

#### Citizens Advice Scotland

www.cas.org.uk

Telephone: 0800 028 1456

Advice on a range of issues including financial and legal matters.

Find your nearest Citizens Advice online.

#### **Advice NI**

#### www.adviceni.net

Telephone: 0800 915 4604

Advice for residents of Northern Ireland on a range of issues including financial and legal matters.

#### **Compassion in Dying**

#### www.compassionindying.org.uk

Telephone: 0800 999 2434

Information on your rights to make choices about your end of life care. Free advance decision forms and support to complete one.

#### **Complementary and Natural Healthcare Council**

www.cnhc.org.uk

Telephone: 020 3327 2720

Details of complementary therapists who meet national standards.

#### **Disability Rights UK**

# www.disabilityrightsuk.org

Telephone: 0330 995 0400

Practical information about disability rights and benefits, and keys for accessible toilets across the UK.

#### **Living made Easy**

#### www.livingmadeeasy.org.uk

Telephone: 0300 999 0004

Expert advice about equipment and aids to help people live as independently as possible.

#### **Fruit Fly Collective**

#### www.fruitflycollective.com

Support for adults and children when a parent has cancer.

#### **Hospice UK**

#### www.hospiceuk.org

Telephone: 020 7520 8200

Information about hospice care, including a database of hospice and palliative care providers.

#### Lymphoedema Support Network

#### www.lymphoedema.org Telephone: 020 7351 4480

Information and support for people with lymphoedema, including details of support groups.

#### **Macmillan Cancer Support**

#### www.macmillan.org.uk

Telephone: 0808 808 0000

Practical, financial and emotional support for people with cancer, their family and friends.

#### **Marie Curie**

# www.mariecurie.org.uk

Telephone: 0800 090 2309

Runs hospices throughout the UK and a free nursing service for people in their own home.

#### Mind

#### www.mind.org.uk

Telephone: 0300 123 3393

Information and support for mental health issues such as depression or anxiety.

#### **Royal Osteoporosis Society**

www.theros.org.uk

Telephone: 0808 800 0035

Information and support for people with weak bones.

#### **Samaritans**

www.samaritans.org **Telephone: 116 123** 

Confidential, judgement-free emotional support, 24 hours a day, by telephone, email, letter or face to face.



# **About us**

We're Prostate Cancer UK. We're striving for a world where no one dies from prostate cancer.

We work to give everyone the power to navigate prostate cancer, by providing up-to-date, unbiased and accurate information about prostate diseases. But we're not here to replace your doctor. Always get advice from a healthcare professional to help you make decisions that are right for you.

References used in this booklet are available at prostatecanceruk.org

This publication was written and edited by our Health Information team.

It was reviewed by:

- Peter Hoskin, Clinical Oncologist, Mount Vernon Cancer Centre and The Christie NHS Foundation Trust
- Nicola Lancaster, Macmillan Metastatic Prostate Cancer Clinical Nurse Specialist, Darent Valley Hospital
- Philip Reynolds, Consultant Therapeutic Radiographer in Prostate Cancer, Clatterbridge Cancer Centre NHS Foundation Trust
- Deborah Victor, Uro-Oncology Clinical Nurse Specialist, Royal Cornwall Hospital
- · Our Specialist Nurses
- · Our volunteers.

#### Tell us what you think

If you have any comments about our publications, you can email: yourfeedback@prostatecanceruk.org

# Donate today – help others like you

Every year over 52,000 men get the life-changing news that they have prostate cancer. But thanks to our generous supporters, we're there to help men when they need us most. You can help more men get free, unbiased, confidential support by donating to us today:

- £10 could fund a call with one of our Specialist Nurses.
- £20 could give 40 men vital information through our handy

Mow your prostate: a quick guide.

To donate, visit prostatecanceruk.org/donate or call 0800 082 1616 or text PROSTATE to 70004†. And for other ways to support us, head to prostatecanceruk.org/get-involved

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





Chat to one of our **Specialist Nurses** 0800 074 8383\* prostatecanceruk.org

Trusted Information Creator

Patient Information Forum







© Prostate Cancer UK January 2025 | To be reviewed January 2028

Call our Specialist Nurses from Monday to Friday 9am - 5pm, Wednesday 10am - 5pm

\* Calls are recorded for training purposes only.

Confidentiality is maintained between callers and Prostate Cancer UK.

