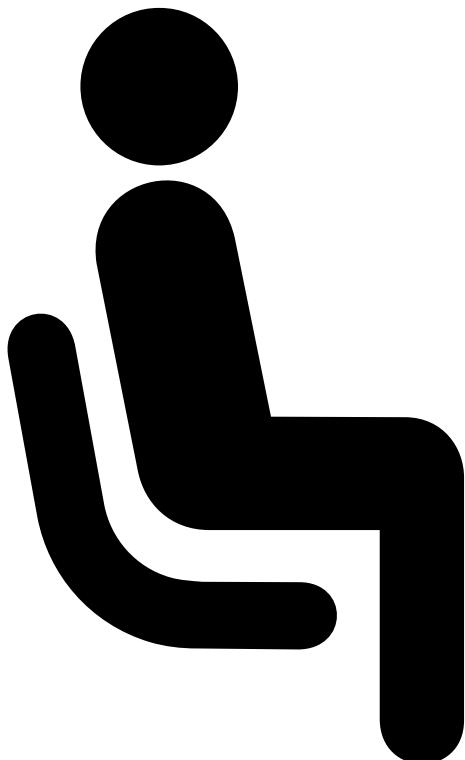


Advanced prostate cancer: Managing symptoms and getting support



**PROSTATE
CANCER UK**

About this booklet

This booklet is for anyone who has prostate cancer that has spread to other parts of the body (advanced prostate cancer), and who has 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 further 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:

 Our Specialist Nurses

 Our publications

 Watch online at prostatecanceruk.org

The photos in this booklet are of people affected by prostate cancer. The quotes are not the words of the people in the photos.

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What is advanced prostate cancer?

Advanced prostate cancer 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).

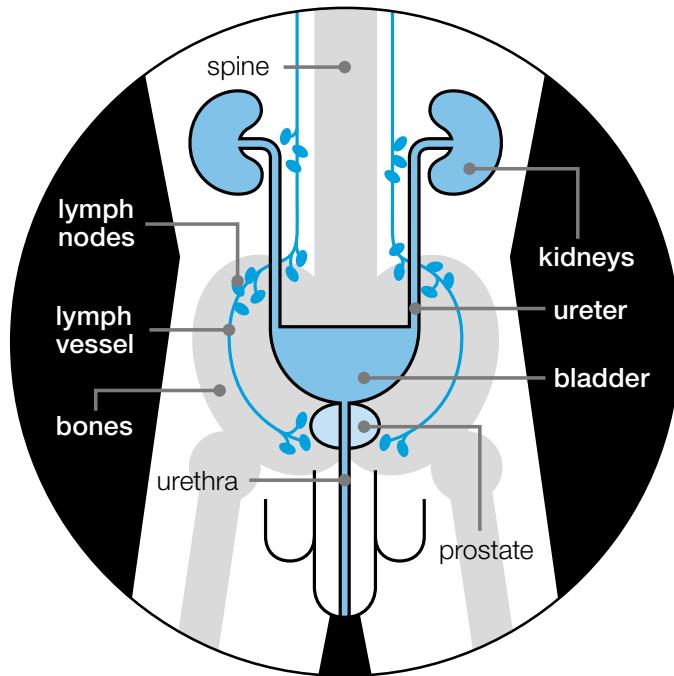
You might hear cancer that has spread called metastatic prostate cancer, secondary prostate cancer, secondaries, metastases or mets. It is still prostate cancer, wherever it is in the body.

It's not possible to cure advanced prostate cancer. But treatments can help keep it under control and manage any symptoms (see page 31).

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 with advanced prostate cancer will die from their cancer. Treatments can help keep it under control, often 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 help keep the cancer under control for longer.

Speak to your doctor about your own situation and any questions or concerns you have.

It can be very difficult living with the uncertainty of cancer, but there is support available. This includes help with managing symptoms, as well as emotional and practical support (see page 42).

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. But the cancer might spread further over time, causing symptoms that affect you more. 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

Having treatment for prostate cancer can cause side effects.

But this booklet doesn't talk about side effects of treatment.

You can read more about side effects and how to manage them in our other booklets and fact sheets, or on our website at prostatecanceruk.org/information. 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, having a shower or preparing food
- social activities, such as seeing friends and family
- sleeping (insomnia)
- concentrating
- 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
- treatments for prostate cancer
- stress, anxiety or depression
- symptoms of advanced prostate cancer, such as pain or anaemia
- other health problems
- not sleeping well
- 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 life can make a big difference.

Things you might want to try include:

- being as physically active as you can – this can help improve your energy levels, sleep, mood and general health
- getting help with emotional problems
- planning activities for when you usually have more energy – maybe first thing in the morning, or in the afternoon after a rest
- making time to rest and relax
- dealing with any problems sleeping – try to relax before bed and avoid drinks with caffeine, such as tea and coffee, as these can keep you awake
- eating a well-balanced diet
- trying complementary therapies alongside your usual treatment
- asking for help if you need it, for example with shopping or jobs around the house.

Support for fatigue

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 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**.



“

I found exercise was a good way to manage my fatigue. It motivated me and helped keep my spirits up.

A personal experience

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 cancer has spread to their bones. The cancer can damage or weaken the bones, which may cause pain. But not all men with cancer in their bones will get bone pain. A bone scan can show whether areas of your bones have been weakened. The areas that show up on a scan are sometimes called 'hot spots'.

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 26).

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:

- treatment for the cancer itself, such as hormone therapy, steroids, chemotherapy or a type of internal radiotherapy called radium-223 (Xofigo®)
- treatment for the pain, such as pain-relieving drugs, pain-relieving radiotherapy, bisphosphonates (see page 35), surgery to support damaged bone, transcutaneous electrical nerve stimulation (TENS), or a nerve block.

Other things that might help you manage your pain include:

- complementary therapies (see page 36)
- getting emotional support (see page 42)
- 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 and be referred to a palliative care specialist. Palliative care specialists provide treatment to manage pain and other symptoms of advanced cancer (see page 38).

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



“

I kept a pain diary and took it to my appointments. This made it easier to describe my pain.

A personal experience

Urinary problems

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

- 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. Read more 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 – it needs treating straight away. Acute urine retention isn't very common in men with advanced prostate cancer. But if it happens 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 treatments and 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 26).

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.

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) using an ultrasound machine
- surgery to insert a tube (called a stent) 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 how you feel about yourself. If you're finding them hard to deal with, speak to your doctor or nurse.

Bowel problems

You might get bowel problems if your prostate cancer has spread to your bowel, although this isn't very common. If you have bowel problems, these are more likely to be caused by previous radiotherapy to your prostate, or by some medications.

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)
- 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.

Men with advanced prostate cancer can get bowel problems for a variety of reasons. Radiotherapy to the prostate and surrounding area can cause bowel problems. You might start to get these during treatment, or they can develop months or years later.

Pain-relieving drugs such as morphine and codeine can cause constipation. 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 may also get bowel problems if prostate cancer spreads to your lower bowel (rectum), but this isn't common. If it happens, it can cause symptoms including constipation, pain, bleeding and, rarely, being unable to empty your bowels. Problems emptying your bowels or leaking from your back passage might sometimes be caused by a condition called metastatic spinal cord compression (MSCC, see page 26). But this is rare.

What can help?

Lifestyle changes

Ask your doctor or nurse if changing your diet could help. They may refer you to a dietitian, who can help you make changes.

If you have constipation, eating high-fibre foods can help. These include fruit, wholemeal bread, wholegrain breakfast cereals and porridge. Drink plenty of water – about 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 may help, but the evidence for this isn't 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.



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 you have constipation or bowel obstruction caused by prostate cancer, they might recommend radiotherapy to the bowel. If your bowel becomes very blocked, you may need to have surgery. But this is rare.

Information and support

Bowel problems can be difficult to talk about. But health professionals are used to discussing these problems and can help you find ways to deal with them. You could also ask your GP to refer you to an NHS continence service. They 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, **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. This can be hard to accept.

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 35). Read more in our fact sheet,



Radiotherapy for advanced prostate cancer.

Your doctor may offer you drugs called bisphosphonates (see page 35). 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**.



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 you may not be able to do some physical activities, 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.

When you're on hormone therapy and have lost your desire for sex, this might not come back. Some treatments may still help with your erections, even if your sex drive is low.

If you're on long-term hormone therapy, you may be able to have intermittent hormone therapy. This is where you stop hormone therapy when the level of prostate specific antigen (PSA) in your blood is low and steady, and start it again if your PSA rises. PSA is a protein produced by normal cells in the prostate and also by prostate cancer cells. Your sex drive may improve while you're not having hormone therapy. But it can take several months and some men don't notice any improvement. Read more in our booklet, **Living with hormone therapy: A guide for men with prostate cancer**.



If you had sex 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 49. 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 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, which 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 or radiotherapy. 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.

What can help?

Speak to your doctor or nurse if you have symptoms of anaemia. You will have a blood test to check your red blood cell levels. The treatment you're 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 isn't common, 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 may wake you at night or stop you from sleeping.
- 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.

These symptoms can also be caused by other conditions, but it's still important to get medical advice straight away in case you do have MSCC. If your doctor or nurse isn't available, go to your nearest accident and emergency (A&E) department.

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

Don't wait

It is very important to seek medical advice immediately 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 – ideally within 24 hours. 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:

- bone pain
- tiredness, weakness or lack of energy
- loss of appetite
- difficulty emptying your bowels (constipation)
- confusion
- 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 can 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
- 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 (see page 32). 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

Hormone therapy will be a life-long treatment for most men with advanced prostate cancer.

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 can cause side effects – speak to your doctor or nurse about ways to manage these. Read more



in our fact sheet, **Hormone therapy**, and our booklet,

Living with hormone therapy: A guide for men with 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 could take part in, or speak to our Specialist Nurses. Read more on our website at prostatecanceruk.org/clinical-trials



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.

Radiotherapy to the prostate isn't suitable for all men with advanced prostate cancer. If it isn't suitable for you, you might be offered a type of radiotherapy to help manage symptoms instead (see page 35).

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:

- more hormone therapy
- more chemotherapy
- radium-223 (Xofigo®)
- clinical trials (see page 32).

More hormone therapy

Your prostate cancer may respond well to other types of hormone therapy, such as abiraterone (Zytiga®), enzalutamide (Xtandi®), apalutamide (Erleada®), steroids or oestrogens, or to a combination of treatments.

More chemotherapy

If you've had hormone therapy on its own as a first treatment, you might be offered a chemotherapy drug called docetaxel (Taxotere[®]). This may help some men to live longer, and can help to improve and delay symptoms. If you've already had docetaxel, you might be offered more docetaxel or another chemotherapy drug called cabazitaxel (Jevtana[®]).

Radium-223 (Xofigo[®])

This is a type of internal radiotherapy that may be an option if your cancer has spread to your bones and is causing pain. A radioactive liquid is injected into your arm and collects in bones that have been damaged by the cancer. It kills cancer cells in the bones and helps some men to live longer. It can also help to reduce bone pain and delay some symptoms, such as bone fractures. Read more in our



fact sheet, **Radiotherapy for advanced prostate cancer**.



Read more about all of these treatments in our fact sheet,

Treatment options after your first hormone therapy.

Treatments to help manage symptoms

Treatments to help manage symptoms caused by advanced prostate cancer include:

- pain-relieving drugs
- radiotherapy
- bisphosphonates.

Pain-relieving drugs

There are lots of different types of pain-relieving drugs, such as tablets, patches and injections. Your doctor or palliative care nurse will help you find what's best for you.



Some men worry about becoming addicted to pain-relieving drugs. But this is uncommon in men with prostate cancer. Read more in our fact sheet, **Managing pain in advanced prostate cancer**.

Radiotherapy

Radiotherapy can help control symptoms by slowing down the growth of the cancer. Radiotherapy to help control symptoms is sometimes called palliative radiotherapy.

The most common type of radiotherapy used to reduce symptoms is external beam radiotherapy. This uses high-energy X-ray beams targeted at the area being treated from outside the body. It can help to manage symptoms such as pain, blood in your urine or discomfort from swollen lymph nodes. It's also used to treat metastatic spinal cord compression (see page 26).

You might have slightly more pain during treatment, and for a few days afterwards, but this should soon get better. It can take a few weeks for radiotherapy to have its full effect.

If your prostate cancer is causing bone pain, you may be offered radium-223 to help reduce the pain and delay some other symptoms (see page 34).



Read more in our fact sheet, **Radiotherapy for advanced prostate cancer**.

Bisphosphonates

Bisphosphonates are drugs that are sometimes used to help strengthen bones that have become weak or thin. This may be caused by cancer that has spread, but can also happen if you're having hormone therapy. Bisphosphonates can also be used to



treat bone pain if other pain-relieving treatments aren't helping, or to treat hypercalcaemia (see page 28). Read more in our fact sheet, **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.** This is a nurse who specialises in caring for men with prostate cancer. You may also hear them called a urology nurse specialist or a clinical nurse specialist (CNS). They provide care and advice, and can offer emotional support and practical information.
- **Urologist.** This is a surgeon who specialises in treating problems with the urinary system, which includes the prostate.
- **Oncologist.** This is a doctor who specialises in treating cancer using treatments other than surgery, including radiotherapy, hormone therapy and chemotherapy.
- **Therapeutic or specialist radiographer.** This is a health professional who plans and gives radiotherapy. They may also do follow-up checks to see how well the treatment has worked.

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 and offer you support and advice. They can also refer you to local services. 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.

If you're feeling depressed or anxious, speak to your GP. They might suggest anti-depressants.

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 also provide emotional, physical, practical and spiritual support for you and your family. 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 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. This will depend on your local services. For example, in some areas palliative care nurses are funded by a local hospice, rather than by Macmillan.

- **Marie Curie nurses.** Marie Curie nurses 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. Your district nurse might be able to arrange a Marie Curie nurse for you. Services vary depending on where you live. In some areas, a hospice may provide this care rather than Marie Curie nurses.

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.

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.

Most hospices have nurses who can visit you at home, and some provide day care. This means you can use their services while still living at home.

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. This may just be for a few days or it might be for longer. Some men may 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.

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.
- **Counsellors, psychologists or psychotherapists** can help you and your family find ways of coping. Many hospitals have counsellors who specialise in helping people with cancer. You can also get free counselling on the NHS without a referral from your GP. Visit www.nhs.uk/counselling to find out more.
- **Dietitians** can give you advice about healthy eating, which might help with fatigue and staying a healthy weight. They can also help if you are losing weight or having problems eating.
- **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**, including **social workers**, can provide practical and financial advice and access to emotional support. They can give you advice about practical issues such as arranging for someone to support you at home. What's available varies from place to place.



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**Find out who your main contact or key worker is so you know who to contact if you have questions or worries.
Talk about things and get support.**

A personal experience

Dealing with advanced prostate cancer

Some men say being diagnosed with prostate cancer changes the way they think and feel about life. You might feel scared, worried, stressed, helpless or even angry. At times, 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.

This section suggests some things you can do to help yourself and people who can help. 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 prostate cancer, but you may find some of the following suggestions helpful.

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.

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.

Eat a healthy, balanced diet

We don't know for sure whether any specific foods have an effect on prostate cancer. But eating well can help you stay a healthy weight, which may be important for men with prostate cancer. It's also good for your general health and can help you feel more in control. Certain changes to your diet may 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.

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 this 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 56).

Get more ideas about how to look after yourself from Macmillan Cancer Support, Maggie's, Penny Brohn UK, or your nearest cancer support centre. You can also find more ideas in our booklet,



Living with and after prostate cancer: A guide to physical, emotional and practical issues.



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The hospice staff have visited us at home, and we have been there too. They gave me some counselling, which has helped us get back on our feet.

A personal experience

Who else can help?

Your medical team

It may be useful to speak to your nurse, doctor, GP or someone else in your medical team. They can explain your diagnosis, treatment and side effects, listen to your concerns, and put you in touch with other people who can help.



Our Specialist Nurses

Our Specialist Nurses can help with 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 support service

Our one-to-one 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 to 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. Some groups also hold meetings online. 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 sexual support service

 This is a chance for you, or your partner, to talk to a Specialist Nurse with an interest in sexual problems after treatment for prostate cancer. They can talk to you about the impact of treatment on your sex life and relationships, and discuss possible treatments or ways to deal with these changes.

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 experiences 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.

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 provide a range of services, including 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. Spiritual beliefs aren't necessarily religious, but might help you make sense of life or your cancer. You may find that your beliefs offer you great comfort or support. Or you might start to question your current beliefs.



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. Or sometimes it can make relationships feel more difficult and 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.

What can help?

Talking to those close to you can help everyone deal with tensions. 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 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 contact 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, Carers UK and Carers Trust
- 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.

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-to-door 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**.



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Going on holiday helps me forget my cancer for a while. If I feel well enough, I don't hesitate.

A personal experience

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. But 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. It's not something you have to do, but planning your care can help make sure you get the care you want.

People sometimes 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.

Deciding not to have certain treatments

An advance decision to refuse treatment (ADRT), known in Scotland as an advance directive, 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 www.compassionindying.org.uk. 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 can make decisions about your care and 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 for 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. The Law Society can help you find a solicitor.

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 42).

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 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 **prostatecanceruk.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**

Contact 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**



**Speak to our
Specialist Nurses**
0800 074 8383*
prostatecanceruk.org

Other useful organisations

Age UK

www.ageuk.org.uk

Telephone: 0800 678 1602

Information for older people on a range of subjects including health, finances and lifestyle.

Bladder and Bowel UK

www.bbuk.org.uk

Telephone: 0161 214 4591

Impartial 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.

British Red Cross

www.redcross.org.uk

A wide range of support and services, from medical equipment loans and home assistance to help with transport. Find your local Red Cross in the phonebook or online.

Cancer Research UK

www.cancerresearchuk.org

Telephone: 0808 800 4040

Information about prostate cancer and clinical trials.

Carers Trust**www.carers.org****Telephone: 0300 722 9600**

Information and support for carers.

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 Bureau in the phonebook or online.**College of Sexual and Relationship Therapists****www.cosrt.org.uk****Telephone: 020 8106 9635**

Information about sexual and relationship therapy, and details of therapists who meet national standards.

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.

Continence Product Advisor

www.continenceproductadvisor.org

Unbiased information on products for different continence problems, written by health professionals.

Cruse Bereavement Support

www.cruse.org.uk

Telephone: 0808 808 1677

Support and information for people after the death of someone close.

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.

The DLF (previously known as the Disabled Living Foundation)

www.livingmadeeasy.org.uk

Telephone: 0300 999 0004

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

Dying Matters (Hospice UK)**www.dyingmatters.org**

Information about planning for the future and advice on talking about dying.

Fruit Fly Collective**www.fruitflycollective.com**

Support for adults and children when a parent has cancer. Includes online information for adults, activity kits to order for children, and animated films to help parents talk to children about cancer.

GOV.UK**www.gov.uk**

Information about UK government services, including benefits, employment, and money matters.

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.

Maggie's

www.maggies.org

Telephone: 0300 123 1801

Drop-in centres for cancer information and support, and an online support group.

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.

Penny Brohn UK

www.pennybrohn.org.uk

Telephone: 0303 3000 118

Runs courses and offers physical, emotional and spiritual support for people with cancer and those close to them.

Relate

www.relate.org.uk

Information, advice and relationship counselling and sex therapy in England, Wales and Northern Ireland.

Relationships Scotland

www.relationships-scotland.org.uk

Telephone: 0345 119 2020

Information, relationship counselling and sex therapy in Scotland.

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.

The Law Society

www.lawsociety.org.uk

Telephone: 020 7320 5650

Help finding a solicitor in England and Wales.

The Law Society of Northern Ireland

www.lawsoc-ni.org

Telephone: 028 9023 1614

Help finding a solicitor in Northern Ireland.

The Law Society of Scotland

www.lawscot.org.uk

Telephone: 0131 226 7411

Help finding a solicitor in Scotland.

Turn2us

www.turn2us.org.uk

Telephone: 0808 802 2000

Help to access money that's available through benefits, grants and other help.

Winston's Wish

www.winstonswish.org.uk

Telephone: 08088 020 021

Practical support and guidance for bereaved children and their families. Information about helping children when a relative is ill.

About us

Prostate Cancer UK has a simple ambition: to stop men dying from prostate cancer – by driving improvements in prevention, diagnosis, treatment and support.

At Prostate Cancer UK, we take great care to provide up-to-date, unbiased and accurate facts about prostate diseases. We hope these will add to the medical advice you have had and help you to make decisions. Our services are not intended to replace advice from your doctor.

References to sources of information used to produce this booklet are available at prostatecanceruk.org

This publication was written and edited by:

Our Health Information team.

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- Tom Fish, Research Radiographer, Poole Hospital NHS Foundation Trust
- Jennifer Noel, Information Manager, Compassion in Dying
- Our Specialist Nurses
- Our volunteers.

Tell us what you think

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



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Patient Information Forum

- Like us on Facebook: Prostate Cancer UK**
- Follow us on Twitter: @ProstateUK**

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To be reviewed November 2023

**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.

Prostate Cancer UK is a registered charity in England and Wales (1005541)
and in Scotland (SC039332). Registered company number 02653887.

