Advanced prostate cancer
Managing symptoms
and getting support
About this booklet

This booklet is for men who have prostate cancer that has spread to other parts of the body (advanced 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.

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
- Sections for you to fill in
- Watch online at prostatecanceruk.org

The photos in this booklet are of people personally 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, such as the bones.

You might hear cancer that has spread called metastatic prostate cancer, secondary prostate cancer, metastases, mets or secondaries. 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 most commonly spreads to the bones and lymph nodes (see diagram on page 6). Prostate cancer cells can move to other parts of the body through the blood stream. Or they can spread to the lymph nodes near the prostate and then travel through the lymph vessels to other parts of your body. Lymph nodes and lymph vessels are part of your lymphatic system, and are found throughout your body. The lymphatic system is part of your body’s 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**
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 what problems it might cause. Watch it online at prostatecanceruk.org/advanced-video
What is my outlook?

Some men want to know how effective treatment is likely to be in controlling 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.

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 to manage symptoms, and emotional and practical support.
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

This booklet doesn’t talk about side effects of treatments for prostate cancer. You can read more about side effects and how to manage them in our other booklets and fact sheets, or 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. And 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.

Talk to your doctor or nurse. They can help you understand what might be making your fatigue worse and help you find ways to manage your fatigue.

Keep active. Physical activity can help to improve your energy levels, sleep, mood and general health. Start doing what you can and build up slowly.

Get help with emotional problems. Feeling down can make you feel less energetic, and worrying can affect your sleep and make your fatigue worse.

Plan ahead and take things slowly. You might not have enough energy to do everything you used to do. But if you plan ahead, you can try to do the things that are most important to you.

Keep a fatigue diary. If you notice a pattern in your energy levels you could plan to do your most tiring activities when you have the most energy.

Ask for help. Think about which activities you want to do for yourself, and which ones other people could do for you.

Make time to relax. This can help with the stress of having cancer treatment, and with fatigue. Try to find time to relax every day, for example by doing breathing exercises or listening to music.
Complementary therapies. Therapies like acupuncture or massage may be used alongside medical treatment (see page 35).

Eat and drink well. This can boost your energy levels.

Sort out your sleep. Not sleeping well can make your fatigue worse. There are lots of things you can do to improve your sleep.

Our Specialist Nurses provide a telephone-based fatigue support service to help men manage fatigue (see page 47). Read more about ways to improve or manage fatigue in our fact sheet, Fatigue and prostate cancer.

I found exercise was the best thing to combat fatigue. It motivates you, and keeps your spirits up and stress levels down.

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.

The most common cause of pain is cancer that has spread to the bones. If prostate cancer spreads to the bone, it can damage or weaken the bone and may cause 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. Every 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?**
With the right treatment, cancer pain can usually be managed. 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 or chemotherapy
- treatment for the pain, such as pain-relieving drugs, radiotherapy, bisphosphonates (see page 35), transcutaneous electrical nerve stimulation (TENS), or a nerve block.
Other things that might help you manage your pain include:
• keeping a pain diary to help you describe the pain to your doctor or nurse
• looking into complementary therapies (see page 35)
• eating a healthy diet or taking regular gentle exercise
• getting emotional support (see page 43).

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 appointment with me. 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, 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 treatment for prostate cancer**.

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 is called urine retention. 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 the 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. Read more in our fact sheet, **Transurethral resection of the prostate (TURP)**.

**Acute urine retention**

This is when you suddenly and painfully can’t urinate – 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 can put you in touch with your local NHS continence service. This is run by specialist nurses and physiotherapists. They can give you advice and support about treatments and products that can help. The Continence Product Advisor website has information about incontinence products.

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 from 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 (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 the kidney to drain urine into a bag outside your body (nephrostomy)
- a tube (called a stent) put inside the ureter 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 the bladder.

**Getting support for urinary problems**

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

**Bowel problems**

Bowel problems can include:
- difficulty emptying your bowels (constipation)
- passing loose and watery bowel movements (diarrhoea)
- needing to rush to the toilet (faecal urgency)
- leaking from your back passage (faecal incontinence)
- pain around your abdomen (stomach area) or back passage
- being unable to empty your bowels (bowel obstruction)
- passing a lot of wind (flatulence).

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 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 mobile, 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**

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 lots of high fibre foods can 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) of water 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. Low fibre foods include white rice, pasta and bread, potatoes (without the skins), cornmeal, eggs and lean white meat. Drink plenty of fluids, but avoid alcohol, coffee and fizzy drinks. 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.

Information and support
Living with 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. You could also ask your GP to refer you to your local continence service. Their specialist nurses can give you further 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 control damage to the bones and relieve bone pain (see page 34). 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 in men whose cancer has caused bone thinning. 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 there is an area of bone that has been badly damaged, surgery might help to strengthen it. A metal pin or plate is put inside the bone. 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. Speak to your doctor, nurse or physiotherapist about what you can and can’t do.

The National Osteoporosis Society provides more information about fragile bones.
Sexual problems

Dealing with advanced prostate cancer can have an impact on your sex life. You might lose interest in sex or not have enough energy for it. Getting an erection relies on your desire for sex (libido), which can be affected by your thoughts and feelings. So feeling low, anxious or tired can also affect your sex life.

All types of hormone therapy can reduce your desire for sex, and affect your ability to get or keep an erection. Other treatments for prostate cancer, such as surgery or radiotherapy, can also cause erection problems.

What can help?

You can get free medical treatment and support for sexual problems on the NHS. 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’re on hormone therapy and have lost your desire for sex (libido), 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 your PSA level is low and steady, and start it again if your PSA rises. 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.

Your sex life might not be the same as it was before cancer, and you may need some support accepting this. You don’t have to give up on having pleasure, closeness or fun. You could explore other ways to be intimate, such as hugging and holding each other.
If you have a partner, talking about sex, your thoughts and feelings can help you both deal with any changes.

If you are in a relationship you may need time alone together, whatever your situation. If you are in a hospital, hospice or have carers coming to your house, make sure they know when you need some private time together.

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

Read more about managing relationships on page 51. 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 body’s immune system, carrying fluid called lymph around your body. If it is blocked, the fluid can build up and cause swelling (lymphoedema). Prostate cancer can cause the blockage, and so can some treatments such as surgery or radiotherapy. Lymphoedema can occur 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). 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, who can show you how to manage the swelling. They are often based in hospices.

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 aeroplane journeys, may help with leg lymphoedema.

- **Using compression bandages** or stockings can help to 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 practical or emotional support, speak to your nurse or GP. Your GP can also refer you to a 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 may develop a condition called anaemia. This is when your blood can’t carry enough oxygen to meet your body’s needs. Symptoms include feeling tired or weak, being out of breath and looking pale.

Anaemia is caused by a drop in the number of red blood cells, which means not enough oxygen is carried 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.

Sometimes anaemia is caused by a lack of 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. Which 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 constipation – see page 19 for ways to manage this. If you have very low levels of red blood cells, you may need a blood transfusion. This can be a quick and effective way of treating anaemia.

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

**Metastatic spinal cord compression (MSCC)**

Metastatic spinal cord compression (MSCC) happens when cancer cells grow in or near to 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. The risk of MSCC is highest if the cancer has already spread to the spine. Speak to your doctor or nurse for more information about your risk.

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, or go to the toilet. It might get worse when you are lying down. It may wake you at night or stop you from sleeping.

- A narrow band of pain around your abdomen (stomach area) or chest that can move towards your lower back, buttocks or legs.

- Pain that moves down your arms or legs.

- Weakness in 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.

**Don’t wait**
It is very important to seek medical advice immediately if you think you might have MSCC. The sooner you have treatment, the lower your risk of long-term problems. Don’t wait to see if it gets better and don’t worry if it’s an inconvenient time, such as the evening or weekend. At its worst, MSCC can cause paralysis, which could mean you can’t walk or use your arms or legs normally. Getting treatment straight away can lower the risk of this happening, or of it being permanent.

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

**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. This isn’t common in men with advanced prostate cancer. But if it happens, it’s important that it’s treated so it doesn’t develop into 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 to treat hypercalcaemia. They are very effective at lowering 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. Read more in our fact sheet, Bisphosphonates for advanced prostate cancer.

Once your calcium levels are back to normal, you will have regular blood tests to keep an eye on them. 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 have a poor appetite. 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 regularly. If you’re struggling to eat because of nausea (feeling sick), try to avoid strong smelling foods. 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.
Treatments for advanced prostate cancer

Men who’ve recently been diagnosed with advanced prostate cancer are usually offered hormone therapy, sometimes with chemotherapy.

Your first treatment may help keep your cancer under control. But over time, the cancer may change and it may start to grow again. If this happens you might be offered another type of hormone therapy or chemotherapy. Or you might be offered another treatment, such as radium-223 (Xofigo®), or treatment on a clinical trial. There are also specific treatments to help manage symptoms caused by advanced prostate cancer, including pain-relieving drugs, radiotherapy and bisphosphonates.

The following pages have more information about different treatments.

Hormone therapy

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

Prostate cancer needs the male hormone testosterone to grow. Hormone therapy works by stopping your brain from telling your body to make testosterone, or by stopping testosterone from reaching the cancer cells. This causes the cancer to shrink, wherever it is in the body. It can also help control the symptoms of advanced prostate cancer, such as bone pain. Read more in our fact sheet, Hormone therapy.
If your first hormone therapy stops working, there are other treatments that can help keep the cancer under control for longer, such as different types of hormone therapy and chemotherapy. Read more in our fact sheet, **Treatment options after your first hormone therapy**.

Hormone therapy can cause side effects, such as hot flushes, loss of desire for sex (libido), problems getting or keeping an erection (erectile dysfunction), and extreme tiredness (fatigue). Speak to your doctor or nurse about ways to manage these side effects. If your cancer is under control, you may be able to have intermittent hormone therapy. This is where you stop hormone therapy when your PSA level is low and steady, and start it again if your PSA rises. Your side effects may improve while you’re not having hormone therapy. Read more about managing side effects in our booklet, **Living with hormone therapy: A guide for men with prostate cancer**.

**Chemotherapy**

Chemotherapy uses anti-cancer drugs to kill cancer cells, wherever they are in the body. You might be offered chemotherapy at the same time as your first hormone therapy. This helps many men to live longer and may help delay symptoms such as pain. And you might be offered chemotherapy if your cancer is no longer responding to your hormone therapy. This may help some men to live longer, and can help to improve and delay symptoms.

Chemotherapy may cause side effects, such as a higher risk of infections, feeling breathless, tired or weak, and bleeding and bruising more easily than normal. You need to be quite fit to have chemotherapy because the side effects can be harder to deal with if you have other health problems. Read more in our fact sheet, **Chemotherapy**.
Clinical trials
There are clinical trials looking at new treatments for men with advanced prostate cancer and new ways of using existing treatments. Not all men are able to take part in a clinical trial and there may not be any trials available in your area. You can ask your doctor or nurse if there are any clinical trials you could take part in, or speak to our Specialist Nurses. Read more in our fact sheet, A guide to prostate cancer clinical trials.

Pain-relieving drugs
Pain-relieving drugs include 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 it’s uncommon for men with prostate cancer to become addicted to pain-relieving drugs. Read more in our fact sheet, Managing pain in advanced prostate cancer.

The specialist palliative care team worked out what I needed and recommended treatments to reduce my pain.
A personal experience
Radiotherapy

Radiotherapy can help control symptoms by slowing down the growth of the cancer. This is sometimes called palliative radiotherapy. 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 experience an increase in pain during, and for a few days after, treatment but this should soon improve. It usually takes a few weeks for radiotherapy to have its full effect.

There are two types of radiotherapy used to reduce symptoms.

• **External beam radiotherapy**
  This is where high-energy X-ray beams are directed at the area of pain from outside the body. Radiotherapy for advanced prostate cancer uses less radiation overall than radiotherapy for earlier stages of prostate cancer. The course of treatment is also often shorter. It’s sometimes called short-course radiotherapy.

• **Radioisotopes**
  A very small amount of a radioactive liquid is injected into a vein in your arm and collects in bones that have been damaged by prostate cancer. It kills the cancer cells in the bones, but doesn’t damage many surrounding healthy cells. A radioisotope called radium-223 (Xofigo®) can help reduce bone pain. It can also help some men live longer and delay some symptoms, such as bone fractures.

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

Bisphosphonates are drugs that are sometimes used to help relieve and prevent further bone pain in men with advanced prostate cancer. Bisphosphonates can also be used to manage bone thinning caused by hormone therapy, or to help prevent and slow down further bone damage. They can also be used to treat a condition called hypercalcaemia (see page 27). 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.

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, as part of the care they provide. 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 have advice about finding a therapist.

Macmillan Cancer Support and Cancer Research UK have more information about different therapies and important safety issues to think about when choosing a therapy.
Work out who your main contact or ‘key worker’ is. It’s important to know who to contact if you’ve got questions and worries.

A personal experience
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 palliative care.

Your multi-disciplinary team (MDT)

This is the team of health professionals involved in your care. Your MDT is likely to include a specialist nurse, oncologist, urologist, radiologist, therapeutic radiographer, and a palliative care doctor or nurse. It may also include other health professionals, such as a dietitian or physiotherapist. Services can vary depending on where you live.

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 may be the health professional you’ve seen the most. They provide care and can offer advice on managing symptoms of prostate cancer and the side effects of treatment. They also provide emotional support.

Urologist

A urologist is a surgeon who specialises in treating problems with the urinary and reproductive systems, which includes the prostate. They can carry out biopsies to help diagnose prostate cancer, and usually treat prostate cancer using surgery to remove the cancer (radical prostatectomy). Surgery won’t be an option if you have advanced prostate cancer, but a urologist may be involved in planning your treatment and managing side effects.
**Oncologist**
An oncologist is a doctor who specialises in treating cancer using treatments other than surgery, including external beam radiotherapy, hormone therapy and chemotherapy.

**Radiologist**
A radiologist specialises in understanding medical scans and images, such as MRI scans, to diagnose and monitor prostate cancer. They will look at the scans and images taken by a radiographer and explain these to the rest of your medical team.

**Therapeutic or specialist radiographer**
Also called radiotherapy radiographers. They specialise in giving radiotherapy to treat cancer. Some radiographers may also give you check-ups to see if your treatment is working and causing any side effects.

**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.

**Palliative care team**
This includes specialist doctors and nurses who provide treatment to manage pain and other symptoms of advanced cancer. They also provide emotional, physical, practical and spiritual support for you and your family. 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.

**Macmillan nurse**
You might hear your palliative care nurse called a Macmillan nurse. But not all palliative care nurses are Macmillan nurses. And Macmillan nurses aren’t always palliative care nurses. This will depend on your local services.

**Marie Curie nurse**
Marie Curie nurses provide care to people in the last few months or weeks of life. They visit people at home and often provide care overnight. They also offer practical advice and emotional support to you and your family. They help to give partners and family members a break so that they can rest. 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, family members 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.

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

A personal experience

**Hospitals**

Many men with advanced prostate cancer stay in hospital at some point. Some men decide to 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.

- **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. Your social services department or your GP should be able to arrange for an occupational therapist to visit you.

- **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. Your GP, hospital doctor or nurse might be able to refer you to some services. You can also contact your local social services department yourself. Their telephone number will be in the phonebook under the name of your local authority, on their website and at the town hall.
It is helpful to chat with other men. A shared experience lets you know that you’re not on your own.

A personal experience
Dealing with advanced prostate cancer

Living with advanced prostate cancer can be hard to deal with emotionally as well as physically. Symptoms and treatments can be draining and make you feel unwell. And some treatments, including hormone therapy, can affect your emotions.

You may feel a wide range of emotions, including sadness, anxiety, helplessness, anger and fear. Some men having hormone therapy find that they cry more easily or have low moods. Your emotions might change very quickly (mood swings). There are things you can do to help yourself and people who can help you.

Men with advanced prostate cancer might also be at risk of depression, especially if they have symptoms such as pain or fatigue. If you are feeling down or hopeless, or have little interest or pleasure in doing things, you might be depressed. Speak to your GP or nurse – there are things that can help.

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. You may find some of the following suggestions helpful.
**Talk to someone**
Share what you’re thinking – find someone you can talk to. A lot of men find that talking about how they feel can help. Some men get support from talking to their family and friends. But not everyone will want to share their feelings with those close to them.

You might find it easier to talk to someone trained to listen, like a counsellor or your doctor or nurse. Your GP, nurse or other people involved in your care should be able to answer any questions or concerns you might have.

**Look into your treatment options**
Find out about the different treatments that are available to you. 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.

**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.

**Eat a healthy, balanced diet**
Eating well is good for your general health. A healthy diet can help with some side effects of treatment. For more information, read our fact sheet, **Diet and physical activity for men with prostate cancer.**
**Be as active as you can**

Keeping active can improve your physical strength and fitness, and can lift your mood. It can also help with some side effects of treatment. Even a small amount of physical activity can help. Take things at your own pace. 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 are having trouble with symptoms or side effects, speak to your doctor or nurse about ways to manage them.

If you are worrying about the future, then making plans – such as thinking about your future care – might help you feel more in control (see page 59).

Get more ideas about how to look after yourself from Macmillan Cancer Support, Maggie’s Centres, 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**.
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 (see page 37). They can explain your diagnosis, treatment and side effects, listen to your concerns, and put you in touch with other people who can help.

If you’re feeling depressed or anxious, speak to your GP. They might suggest anti-depressants. It is important that you tell your GP about any other medicine or complementary therapies you are taking.

Our Specialist Nurses
Our Specialist Nurses can answer your questions and explain your diagnosis and treatment options. They’ve got time to listen, in confidence, to any concerns you or those close to you have.

Trained counsellors
Counsellors are trained to listen and can help you find your own ways to deal with things. Many hospitals have counsellors or psychologists who specialise in helping people with cancer – ask your doctor or nurse at the hospital if this is available. Your GP may also be able to refer you to a counsellor, or you can see a private counsellor. To find out more, contact the British Association for Counselling & Psychotherapy.

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. Our Specialist Nurses will try to match you with someone with similar experiences.
Our online community
Our free 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.

Local support groups
At local 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 local health professionals, others by men themselves. Many also welcome partners, friends and relatives.

I joined a support group and found speaking to other men with the same experiences valuable and rewarding.
A personal experience

Our fatigue support service
Our fatigue support service is a 10-week telephone service delivered by our Specialist Nurses. It can help if you have problems with extreme tiredness (fatigue), which is a common symptom of advanced prostate cancer. Fatigue can also be a side effect of some treatments for prostate cancer. The fatigue support service can help you make positive changes to your behaviour and lifestyle, which can improve your fatigue over time.
Hospices
You may be able to get support from your local hospice or community palliative care team. Hospices don’t just provide care for people at the end of their life – you may be able to use their services while still living at home. They provide a range of services, including treatment to manage pain. They can also offer 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 advanced prostate cancer. 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.

It’s important to get spiritual support if you need it. This could be from your friends, family, religious leader or faith community. If you have any religious practices that are important to you, such as a special diet or prayer time, tell your doctor or nurse. Most hospitals and hospices will have a chaplain who can talk to you about your concerns, whatever your religion, or even if you are not religious.

To find out more, visit prostatecanceruk.org/get-support or call our Specialist Nurses on 0800 074 8383.
Information and support
Macmillan Cancer Support and Cancer Research UK both provide information about dealing with cancer. You can also ask your GP or nurse about support in your area.

The charity Mind provides information and support for people with depression or anxiety. Samaritans offer a confidential listening service, allowing you to talk through your feelings at any time of day or night.
Relationships

Having cancer can often bring you closer to your partner, family or friends. But it can also put a strain on relationships.

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.

As a family, we’ve been very open about it. If anything I think it’s probably brought us closer together.

A personal experience
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 to talk to children or grandchildren about your cancer. It is usually best to be honest with them. Children can often sense that something is wrong even if they don’t understand it, and keeping things from them might only make them worry more. You could ask your GP or nurse for advice. The charities Macmillan Cancer Support and Winston’s Wish have more information about talking to children about cancer.

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 56 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
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 are able to 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 friends and family.

- **Look after your health.** If you’re feeling 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 a man with prostate cancer: A guide for partners and family.*
Advanced prostate cancer: Managing symptoms and getting support
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.

Diet and physical activity

A healthy diet and regular physical activity may help you feel more in control of your health. A healthy lifestyle can also help with some side effects of treatment. Read more in our fact sheet, Diet and physical activity for men with prostate cancer.

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 reduce your working hours, 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 take early retirement. You may also be entitled to claim certain benefits.

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
- your local Citizens Advice Bureau
- a benefits advisor at your local council or hospital
- an independent financial advisor.
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 adaptations to your home
An occupational therapist may be able to advise you about practical things that might make it easier to live at home. For example, they may suggest making some changes to your home, or special equipment that can 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, who can help with housework and shopping, and personal care assistants, who can help with tasks like getting washed and dressed.

Respite care
If you need ongoing care from a partner, family member or 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 in for a few days.
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 buying or 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 GOV.UK website. 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.
We have talked about the end. Now that's done, we can move on to living each day as it comes.
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 also help to write your wishes down so that if you become too unwell to make decisions, your healthcare team and your 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. But not everyone wants to think about what care they want in the future, and it’s not something you have to do.

There are lots of different ways you can plan ahead for your future treatment and care.

Writing down your wishes

An advance statement is a general statement about anything that is important to you in relation to your future health and wellbeing.
It can include some of the following:
- your wishes and preferences about the type of care you want
- who you would like to make decisions about your care, if you are 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 whether there are treatments you don’t want to have**

An advance decision or advance directive to refuse treatment (ADRT) allows you to record any treatments you don’t want to have in certain circumstances. For example, you might want to think about whether or not you’d want to have cardio pulmonary resuscitation (CPR) if your heart stopped. 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.
Speak to your partner, family, doctor and nurse about what to include. Your doctor can talk to you about this in more detail, and help you think carefully about the consequences of any decision. Whatever you decide, your doctor or nurse will still try to make sure you are comfortable and not in pain.

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.

**Support in making decisions**
Thinking about your wishes and making decisions can be difficult. You don’t have to make any decisions if you don’t want to. Here are some things that may help.

- 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.

**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 someone to make decisions for you if you’re unable to – for example, if you are unconscious. This person is known as an attorney, and the legal document is known as a lasting power of attorney.
You can choose one or more people to make decisions for you. They should be someone you trust, like a family member or friend.

There are two types of lasting power of attorney.

- 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 from the GOV.UK website.

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 that your Will is made properly and is valid.

Age UK and Macmillan Cancer Support have more information about making a Will. You can find a solicitor from the Law Society.
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 the GOV.UK website.

Macmillan Cancer Support and Marie Curie also produce a booklet for people in the final stages of life and their carers called End of life: a guide.
Worries about dying from prostate cancer
Not all men with advanced prostate cancer will die from prostate cancer and men will 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, it might be hard for you and your family to accept that you’re dying. 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 43).

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.

**Support for family and friends**
You might worry about your family and friends and how they are feeling. There’s support available for your family and friends too, including practical, emotional, and financial help. To find out more about any of the above, visit prostatecanceruk.org/get-support
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

Call 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

*Calls are recorded for training purposes only. Confidentiality is maintained between callers and Prostate Cancer UK.
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.bladderandboweluk.co.uk
Telephone: 0161 607 8219
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
Patient information from Cancer Research UK.
Carers Trust
www.carers.org
Telephone: 0300 772 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
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 8543 2707
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 3668 0406
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 Care**
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: 020 7250 8181
Practical information about disability rights and benefits, and keys for accessible toilets across the UK.

**Disabled Living Foundation**
www.dlf.org.uk
Telephone: 0300 999 0004
Expert advice about equipment and aids to help people live as independently as possible.

**Dying Matters**
www.dyingmatters.org
Telephone: 0800 021 4466
Information about planning for the future and advice on talking about dying.

**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 Centres**  
www.maggiescentres.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.

**Royal Osteoporosis Society**

www.theros.org.uk  
Telephone: 0808 800 0035  
Information and support for people with weak bones.

**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  
Telephone: 0300 100 1234  
Information, advice and relationship counselling and sex therapy. In Scotland, contact Relationships Scotland instead.

**Relationships Scotland**

www.relationships-scotland.org.uk  
Telephone: 0345 119 2020  
Information, advice and relationship counselling and sex therapy in Scotland.
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 in the production of this booklet are available at prostatecanceruk.org

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

It was reviewed by:
- Kate Bullen, Professor of Psychology, University of Brighton
- Christopher Eden, Professor of Urology and Consultant Urologist, Royal Surrey County Hospital NHS Foundation Trust
- Louisa Fleure, Prostate Cancer Advanced Nurse Practitioner, Guy’s and St Thomas’ NHS Foundation Trust, London
- Nikki Hawkins, Macmillan Consultant Cancer Practitioner, Gloucestershire Care Services NHS Trust
- Clare Lait, Macmillan Next Steps Community Specialist Physiotherapist, Gloucestershire Care Services NHS Trust
- Our Specialist Nurses
- Our Volunteers.
Donate today – help others like you

Did you find this information useful? Would you like to help others in your situation access the facts they need? Every year, over 47,000 men face a prostate cancer diagnosis. Thanks to our generous supporters, we offer information free to all who need it. If you would like to help us continue this service, please consider making a donation. Your gift could fund the following services:

- £10 could buy a Tool Kit – a set of fact sheets, tailored to the needs of each man with vital information on diagnosis, treatment and lifestyle.

- £25 could give a man diagnosed with prostate cancer unlimited time to talk over treatment options with one of our specialist nurses.

To make a donation of any amount, please call us on 0800 082 1616, visit prostatecanceruk.org/donate or text PROSTATE to 70004†. There are many other ways to support us. For more details please visit 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