Living with and after prostate cancer

A guide to physical, emotional and practical issues



PROSTATE CANCER UK

About this booklet

This booklet is for anyone living with and after prostate cancer. It's also for those who are having their prostate cancer monitored, rather than having treatment. Your partner, family and friends might also find it useful.

We've included information about the physical and emotional effects of prostate cancer and its treatment, and ways to manage them. We also discuss practical issues, such as work and money.

This booklet is a general guide and everyone's experience is different. You might find some parts of this booklet more useful than others. If you'd like more information, talk to your doctor or nurse. You can also speak to our Specialist Nurses, in confidence, on 0800 074 8383 or chat to them online.



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

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

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Living with and after prostate cancer

Living with prostate cancer can have a physical, emotional and practical impact on your life and the lives of those close to you. Even if you have stopped treatment you might still have side effects, or worry about your cancer coming back. It can be hard to move on and that is completely normal to feel.

Support from healthcare professionals

Healthcare professionals can support you before, during and after your prostate cancer treatment. One way is through regular check-ups. How often you have these will depend on the stage and grade of your prostate cancer, what treatment you're having or have had in the past, how well your treatment is working, and any side effects you have.

Your main contact (also known as key worker) may be a specialist nurse, also called a urology nurse specialist, clinical nurse specialist (CNS) or advanced nurse practitioner (ANP). Or they may be another health professional such as therapeutic radiographer or cancer support worker. They may be the healthcare professional you've had the most contact with during your treatment. They provide care and can offer advice on managing symptoms of prostate cancer and the side effects of treatment, and on how you can help yourself.

Let your doctor or nurse know if you notice any new symptoms, side effects or changes in how you feel. There may be ways to manage them, or you might need more tests to see if your cancer has spread or come back. If this happens, you may be offered treatment.

Don't worry about asking for help. If there's anything bothering you, tell your doctor or nurse, they are there to help support you.

You might want to write down any questions or concerns before your appointment, and take notes of what is said. Some men find it helpful to have someone with them at the appointment. It's hard to take everything in, ask questions and make notes all at the same time.

Read about getting care and support after treatment in our booklet, **Follow-up after prostate cancer treatment: What happens next?**

Make sure you have the details of someone to contact if you have any questions or concerns between check-ups, or if you notice any symptoms or changes in how you feel. Use the table below to record these details or to remind you what to ask about. You can ask your doctor or nurse to fill it in for you.

Problem or concern	Who to contact

Self-management

There's a lot you can do to look after your own health and wellbeing. This is sometimes called self-management. It could be watching what you eat, staying active, or learning other ways to look after yourself. It's also important to be aware of any changes in how you feel so you get the support you need from your doctor or nurse. There are tips on self-management throughout this booklet.

You might want to get some ideas and learn how to make it easier to manage things yourself.

- Charities such as Macmillan Cancer Support, Maggie's and Penny Brohn UK run free courses for people living with cancer.
- You may find it helpful to attend a support group, where you can share your experiences and get support from others. Find an in-person or online support group at **www.tackleprostate.org/supportgroups**
- You can ask your specialist nurse, therapeutic radiographer, GP surgery or local support group if they run training courses or invite healthcare professionals to give talks.

We have a range of services to help you reach out to others who have experienced prostate cancer such as:

- **our One-to-One Peer Support service,** where you can speak to someone who understands what you're going through
- **our online community,** a place to ask questions or share experiences.



Physical effects of prostate cancer

Prostate cancer and its treatment can affect your body and physical health. Lots of treatments for prostate cancer cause short-term or long-term side effects, which can often be managed or treated. If you notice any changes, or have any concerns, speak to your doctor or nurse to make sure you get the help you need.

We have fact sheets on the different treatments for prostate cancer that include information about possible side effects. These are free and available to order or download online (see page 45). Or you can contact our **Specialist Nurses**.

If you have prostate cancer that's spread to other parts of the body (advanced prostate cancer), you can read more about managing symptoms in our booklet, **Advanced prostate cancer: Managing symptoms and getting support**.

Extreme tiredness (fatigue)

Fatigue is different from normal tiredness. Fatigue is a feeling of extreme tiredness that doesn't go away, even after you rest.

Fatigue can make it hard to carry out your daily activities. All treatments for prostate cancer can cause fatigue. Your fatigue is likely to be worse if you have hormone therapy, radiotherapy, chemotherapy or more than one treatment at the same time.

If your fatigue is caused by your treatment, it may improve when you finish treatment. But some men have fatigue that lasts for many months, or sometimes years. And some men find that their fatigue doesn't start until after their treatment has finished. How long the fatigue lasts will also depend on the type of treatment you've had.

Let your doctor or nurse know if you have fatigue. They can help you understand what might be making your fatigue worse and help you find ways to manage it. They can also check for any other health problems that might be causing your fatigue or making it worse.

What can help?

Plan ahead and take things slowly

You might not have enough energy to do everything you used to do. But by planning ahead, you can try to do the things that are most important to you. Keeping a diary can help you plan your activities. Download our **Fatigue diary** from our website. Visit, **prostatecanceruk.org/fatigue-diary**

Eat and drink well

Eating a healthy diet can boost your energy levels. If you don't have the energy to prepare food for yourself, ask a friend or family member to help. Drinking plenty of fluids can keep you hydrated and improve your energy levels. Try to gradually increase how much fluid you drink to around 1.5 to 2 litres (3 to 4 pints) of water a day - or a little more in hot weather or if you're physically active. Read more about eating and drinking well on page 20.

Stay active

Physical activity can help to reduce your fatigue. Even light to moderate exercise can help. You could try walking to the shops, climbing stairs or swimming. If you do light to moderate exercise along with strength or resistance training, such as lifting light weights or using elastic resistance bands, this may be even more effective.

Try to plan physical activities at times when you usually have more energy. If you feel very tired, just do gentle exercise for a short time and take lots of breaks. Speak to your doctor before you make any changes to how you exercise.

Improve your sleep

Although fatigue doesn't always improve when you rest, sleeping well can often help. Your GP can suggest ways to help improve your sleep, such as relaxation techniques, going to bed and getting up at the same time every day, and making your bedroom as quiet and dark as possible. They may sometimes prescribe medication.

If you need the toilet a lot during the night, this can affect your sleep and make you feel more tired during the day. Talk to your doctor or nurse about ways to manage this.

Get help with your thoughts and feelings

Fatigue can sometimes be linked to feeling depressed, stressed or anxious. Feeling down can make you feel less energetic, and worrying all the time can affect your sleep and make your fatigue worse. If you're having any of these feelings, talking to someone or getting some support can help. Read our **Fatigue and prostate cancer** fact sheet for more information.

Our fatigue support

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. Speak to them on **0800 074 8383**, or visit **prostatecanceruk.org/fatigue**

Urinary problems

Many men get urinary problems after prostate cancer treatment, such as leaking urine, problems emptying their bladder or increased frequency of urinating, especially at night. Urinary problems usually last for a few weeks or months after treatment but some men may have them for several years or never fully recover, even if they have treatment to help.

Acute urine retention

This is when you suddenly and painfully can't urinate. It needs treating straight away. If it happens, go to your nearest accident and emergency (A&E) department and tell the doctor or nurse. They may need to drain your bladder using a catheter. This is a thin tube put into the bladder through either your penis or your abdomen (stomach area). Make sure the person treating you knows what prostate cancer treatment you've had.

What can help?

Tell your doctor or nurse about any urinary problems even if you're no longer having treatment for prostate cancer. They can suggest treatments and lifestyle changes to help manage them. They may refer you to a physiotherapist or a continence service run by specialists in urinary problems. You might also be offered tests to try to find out exactly what is causing your symptoms, and which treatments are most likely to help.

Depending on the type of problem you're having, ways to manage them can include lifestyle changes, pelvic floor muscle exercises, bladder retraining, medicines or surgery.

How can I help myself?

- Drink plenty of fluids – try to gradually increase how much fluid you drink to 1.5 to 2 litres (3 to 4 pints) a day – even if you're leaking urine, as it can help prevent bladder irritation and infection. Dark urine can be a sign that you need to drink more.
- Cut down on fizzy drinks, alcohol and drinks that contain caffeine (tea, green tea, coffee and cola), as these can irritate the bladder.
- Regular pelvic floor muscle exercises can help strengthen the muscles that control when you urinate, and help if you leak urine. Read more in our fact sheet, **Pelvic floor muscle exercises**.
- Try to stay a healthy weight. Being overweight can put pressure on your bladder and pelvic floor muscles.
- If you smoke, try to stop – as this will improve your overall health. Also, smoking can cause coughing, which puts pressure on your pelvic floor muscles. For more information about stopping smoking visit **www.nhs.uk/smokefree**
- Plan ahead when you go out. For example, find out where there are public toilets before leaving home.
- Pack a bag with extra pads, underwear and wet wipes. Some men also find it useful to carry a screw-top container in case they can't find a toilet.
- Get our **Urgent toilet card** to show to staff in public places. You can order a card on our website at **prostatecanceruk.org** or call our **Specialist Nurses**.
- Disability Rights UK runs a National Key Scheme for anyone who needs access to locked public toilets across the UK because of a disability or health problem.

Read more about managing urinary problems in our fact sheet, **Urinary problems after prostate cancer treatment**.

Bowel problems

Radiotherapy for prostate cancer can cause bowel problems because your bowel and back passage (rectum) are close to your prostate. Radiation can irritate the lining of the bowel and back passage (called proctitis). This may cause loose and watery bowel movements (diarrhoea) and pain in the stomach area or back passage. It can also cause bleeding and mucous from the back passage – this isn't usually something to be worried about, but let your doctor, nurse or radiographer know if it happens.

Symptoms vary from man to man, and some will notice a slight change rather than a problem. Some men find that changes to their bowel habits last for a short time. For others, the changes last for a lot longer or are permanent. And some men develop bowel problems months or years after treatment.

What can help?

Tell your doctor, nurse or radiotherapist about any changes in your bowel habits. They can give advice and support to help manage them. There are also medicines available to help with symptoms and control diarrhoea.

Your local continence service can assess your bowel problems and give you information about treatments. Ask your GP to refer you. If you have long-term bowel problems, you could ask to be referred to a bowel specialist (gastroenterologist) or specialist dietitian. Also, Macmillan Cancer Support produces detailed information about coping with bowel problems.

How can I help myself?

There are things you can do to help manage your symptoms, such as eating or avoiding certain foods – although the evidence for doing this isn't very strong.

- If you have diarrhoea, changing your fibre intake may help. Talk to your doctor or dietitian about what would be right for you. Make sure you drink lots of water to replace the liquid your body is losing.
- If you find you're bloated or passing more wind than usual, there are certain foods you can try avoiding. These include beans, pulses, cruciferous vegetables (for example, cabbage, broccoli and cauliflower), onions, fizzy drinks and beer. Some people find that using certain herbs or spices in their cooking or drinking them as a tea, such as ginger or peppermint can help as well.
- Other ways to reduce wind and bloating include eating regularly, eating your meals slowly and trying to chew each bite well with your mouth closed. Also, try not to gulp drinks and sit a little while after eating to help digestion.
- You may find it helpful to plan ahead and find out where toilets are before you go out, and take some absorbent pads, underwear and wet wipes with you.



Sexual problems

Sex is an important part of life for many of us. Living with prostate cancer and the side effects of treatment can have an impact on your sex life.

Treatments for prostate cancer can affect:

- how you feel about yourself sexually and your desire for sex (libido)
- your ability to get an erection, ejaculate and have an orgasm
- your ability to have children (fertility)
- how your body looks
- your relationships.

But you are not alone, there are treatments and support that can provide some answers and ways that can help you through any problems affecting your sex life after prostate cancer.

There is no right or wrong time to consider getting help and treatment if you want to. Sexual problems can have an impact on your life whether you're in a relationship or single. You could be single and want to be able to masturbate, to have sex or you might want to start a new relationship.

Some worries about sex and prostate cancer explained.

- You can't pass on cancer through sexual activity.
- Having sex won't affect how well your treatment works.
- Having sex has no effect on your cancer or the chance of it coming back after treatment.
- It's safe to have an erection if you have a catheter in.

What can help?

You can get free treatment and support for erection problems or other sexual problems on the NHS. Speak to your GP, nurse, hospital doctor, or therapeutic radiographer to find out more. They can offer you treatment or refer you to a specialist service, such as an erectile dysfunction clinic.

Even though your sex life is unlikely to be the same as it was before, there are still ways of having pleasure, closeness or fun together. Being physically close can protect or even improve your relationship. Try to be realistic but flexible in your approach to sex. It doesn't have to be all about penetrative sex.

Feeling low or anxious can affect your erections and your desire to have sex. If you're finding it difficult to cope, you may find it helpful to speak to your nurse or GP, or to a counsellor or therapist. You can also talk to our **Specialist Nurses**, and there are other places you can get support (see pages 46 to 49).

Try to talk through any issues with your partner. See page 36 for more information about relationship issues.

How can I help myself?

Making some changes to your lifestyle might help you manage some of your sexual problems. Physical activity, staying a healthy weight, stopping smoking and doing pelvic floor exercises may help to improve your sex life and your erections.

Try not to put too much pressure on yourself – it takes time to come to terms with being diagnosed with prostate cancer and the side effects of treatment.

Read more in our booklet, **Prostate cancer and your sex life**.

Our sexual support service

This is a chance for you, or your partner, to talk to one of our **Specialist Nurses** trained 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.

Ability to have children

After prostate cancer treatment, you might not be able to have children naturally. If you have surgery (radical prostatectomy) you won't ejaculate any semen. And if you have radiotherapy or brachytherapy, the radiation might affect your ability to produce sperm, although this can be temporary. With radiotherapy you may produce less fluid when you ejaculate but you may still be fertile.

Changes to your sperm during radiotherapy, chemotherapy, and hormone therapy could affect any children you conceive during or after treatment. But the risk of this happening is very low and it hasn't been proven. If there is a chance of your partner becoming pregnant you should use a condom or other form of contraception during treatment and for a while afterwards to avoid fathering a child. This could be up to a year, but speak to your doctor, nurse or therapeutic radiographer about this.

If you and your partner are planning to have children, you can get information on fertility and possible treatments from your GP or specialist team, Macmillan Cancer Support or Fertility Network UK. You may want to think about storing your sperm before treatment, so that you can use it later for fertility treatment.

Impact of hormone therapy

Hormone therapy for prostate cancer can cause a number of physical and emotional side effects. These side effects can be difficult to get used to. They might include:

- hot flushes
- changes to your sex life
- extreme tiredness (fatigue)
- weight gain
- strength and muscle loss
- breast swelling and tenderness
- loss of body hair
- bone thinning
- risk of type-2 diabetes, heart disease and stroke
- changes to your memory and concentration.

Read more in our booklet, **Living with hormone therapy: A guide for men with prostate cancer**.

Pain

Not everyone with prostate cancer has pain. Pain is more common in men whose cancer has spread to their bones. But even then, not all men will get pain. If cancer has spread to several places in your body, you might not get pain in all of these places.

Sometimes pain can be due to cancer treatments, for example after surgery to remove the prostate. Pain can also be caused by problems not linked to the cancer, such as an infection.

What can help?

There are different ways to treat pain. What's best for you depends on many things, including what's causing the pain, your general health, how you are feeling emotionally and what sort of things you do in your daily life.

You might need treatment for the pain itself, such as pain-relieving drugs, radiotherapy, medicines called bisphosphonates or surgery. Pain might be a sign that your prostate cancer treatment isn't working as well as it was. A different treatment for your cancer may help the pain, such as hormone therapy, steroids, chemotherapy or Radium-223.

There are other things that may also help with pain, including complementary therapies (see page 26) and emotional support.

Read more in our fact sheet, **Managing pain in advanced prostate cancer**.

Metastatic spinal cord compression (MSCC)

MSCC happens when cancer cells that have spread to your bones, 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. 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 and who to contact if you develop any symptoms 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 also get worse when you are sitting, standing or moving. It may wake you at night or stop you from sleeping.
- Tenderness or pain in your spine when touched.
- Muscle pain or cramping when you walk or exercise.
- A narrow band of pain around your abdomen (stomach area) or chest that can move towards your back, buttocks or legs.

- Pain that moves down your arms or legs.
- Weakness or loss of control 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

If you are diagnosed with MSCC, treatment should be started as soon as possible. MSCC could affect your ability to walk and move around if not treated quickly. Getting treatment early can reduce the risk of long-term problems.

Read more about MSCC and how it is treated in our fact sheet, **Metastatic spinal cord compression (MSCC)**.



Your lifestyle

A healthy lifestyle can give you more control over your health and help you to improve it.

Body weight

Staying a healthy weight is one of the best things you can do for your overall health. It can lower your risk of many health problems, including heart disease, type-2 diabetes and some cancers. It may also be important for men with prostate cancer, as there is strong evidence that being overweight raises the risk of aggressive or advanced prostate cancer.

Being a healthy weight may mean your prostate cancer is less likely to spread after surgery or radiotherapy. Hormone therapy might also be less effective if you're very overweight. And staying a healthy weight may help you manage or reduce some of the side effects of treatments, such as urinary problems after surgery.

Diet

A healthy diet is important for your overall health and can help you stay a healthy weight.

You may have heard of certain foods or diets that might be helpful for men with prostate cancer, and some that might be harmful. Unfortunately, different studies have had different results, so we don't know for sure whether specific foods can affect the growth of prostate cancer or the risk of it spreading. Until there's more evidence, it's best to have a balanced diet. For the latest information check our website at **prostatecanceruk.org/foods**

How can I eat more healthily?

A healthy diet doesn't need to be boring. In fact, it's good to eat a variety of different foods to make sure you get a range of nutrients. You could try some new foods to add more variety to your meals. For example, you could try a new fruit and vegetable each week. Most people should be able to get all the nutrients they need by eating a balanced diet, without taking supplements.

Nine steps to eating well

- **Try to aim for regular meals.** If you don't feel very hungry or you have difficulty eating, try to eat small amounts often instead. If you're struggling to eat because of nausea (feeling sick) try to avoid smelly foods. Cold foods tend to smell less, or it may help if someone cooks for you.
- **Eat at least five portions of fruit and vegetables every day.** Try to eat a variety of fruits and vegetables of different colours each day, as they contain different nutrients. They can be fresh, frozen, dried or tinned with no added sugar or salt.
- **Base your meals on starchy foods.** These include potatoes, bread, rice, pasta, plantain, sweet potato and yam. Choose wholegrain and other high-fibre options where possible. These give you energy and help you to feel full for longer, which is helpful if you're trying to lose weight.
- **Eat a variety of foods high in protein.** These include fish, meat, eggs, nuts and beans.
- **Eat some dairy foods or non-dairy sources of calcium.** Choose low-fat dairy foods, such as skimmed or semi-skimmed milk and reduced-fat cheese. Non-dairy sources of calcium include soya products with added calcium, green leafy vegetables, and fish where you eat the bones.

- **Choose unsaturated oils and spreads and eat these in small amounts.** These include olive oil, vegetable oils and rapeseed oil.
- **Eat less sugar and sugary foods.**
- **Cut down on salt.** Eat less than 6g of salt each day. Check the labels and look out for hidden salt in processed foods, such as bread, cereals, bacon and takeaways. Avoid adding salt when you cook – try using herbs and spices to add flavour instead, or use low-salt alternatives.
- **Drink lots of fluids**. Try to drink around 1.5 to 2 litres (3 to 4 pints) a day.

If you want help to improve your diet, ask your doctor to refer you to a dietitian. They can help if you want to make big changes to your diet, or if you have any other health problems that could be affected changes in your diet, such as diabetes.

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

Physical activity

Physical activity is any type of movement that uses energy. It doesn't have to be a sport or going to the gym – it could be walking, swimming or gardening.

We don't know for sure if physical activity can help slow the growth of prostate cancer, but we do know that it's important for your overall health and wellbeing. It helps to prevent many health problems, such as heart disease and type-2 diabetes, and can help you stay a healthy weight. Being a healthy weight may help to lower your risk of advanced prostate cancer.

Being active can also help with some of the side effects of treatment. And exercise may lift your mood and make you feel happier in your day-to-day life, as well as helping you cope with feelings of anxiety or depression.

It's usually safe for men with prostate cancer and those having treatment to be physically active. But it's still a good idea to speak to your GP, nurse, physiotherapist or hospital doctor before you start any kind of exercise plan. This is very important if you have cancer that has spread to other areas of the body (advanced prostate cancer), such as the bones or lungs. Or you have other health problems, such as heart disease or problems with your joints or muscles. Your doctor or nurse can talk to you about exercising safely and may refer you to an exercise programme run by a cancer specialist personal trainer, or a physiotherapist who can help you plan your exercise.

What type of physical activity should I do?

The type of physical activity you do isn't really important – the main thing is to get active. If you find an activity you enjoy that fits into your life, you're more likely to keep doing it. The following tips may help.

- Walking, swimming, cycling and gardening are all good exercise.
- You can do simple things, such as getting off the bus one stop earlier or using stairs rather than a lift.
- You can even exercise from your chair or bed. Lifting and stretching your arms and legs can help improve your movement and muscle strength. Visit **www.nhs.uk/live-well** for exercises to do while sitting down.
- Gentle resistance exercise, such as lifting light weights or using elastic resistance bands, is particularly good if you're on hormone therapy and are at risk of bone thinning.

- If you're trying to be more active, an exercise programme such as walking 10,000 steps a day can be useful. You might not manage this at first – just do what you can, and try to walk a little further each day. Visit **www.nhs.uk/live-well** to find out more.
- Try a variety of activities or sports so that you don't get bored, and set some goals to aim for. You may prefer to exercise with a friend or in a group.

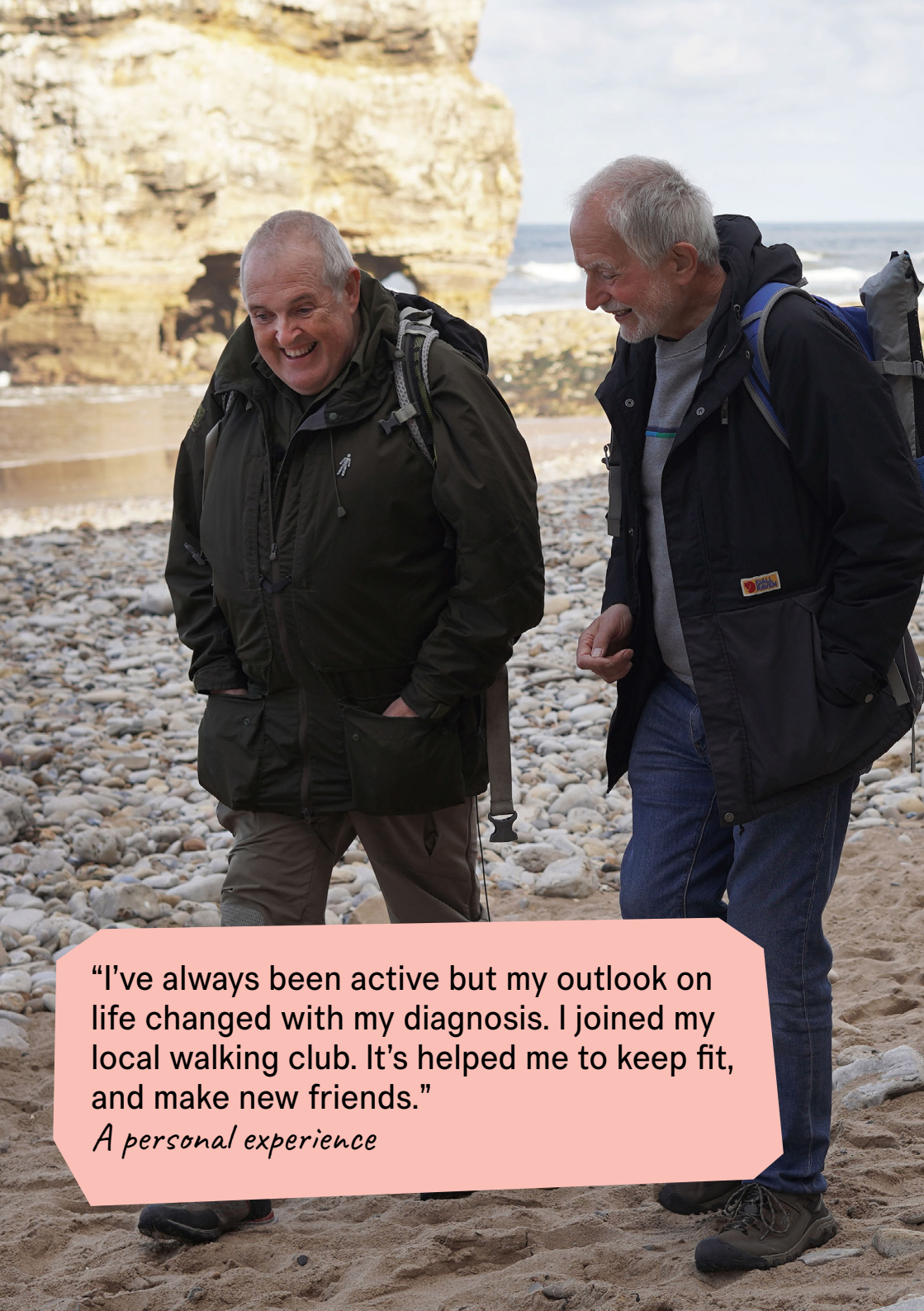
How much physical activity should I do?

This will depend on many things, including the stage of your cancer, any treatments you are having, and your fitness levels. Even if you can't do a lot of physical activity, a small amount can still help. Take things at your own pace and don't do too much. Make sure you rest when you feel you need to.

Aim to be physically active at least two to three times a week. If you're not usually active, start gently for short periods of time, such as 10 to 15 minutes, and gradually exercise for longer as you become fitter. If you can, work up to 30 minutes of moderate exercise three to five days a week. Moderate exercise means your heart should beat faster but you should still be able to talk – about the level of a brisk walk.

Thirty minutes may seem like a lot, but remember you can reach this amount by being active for 10 minutes, three times a day. Some people find it helpful to use an app on their phone or a fitness tracker that can be worn. These can monitor your activity levels and remind you to be active.

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



"I've always been active but my outlook on life changed with my diagnosis. I joined my local walking club. It's helped me to keep fit, and make new friends."

A personal experience

Smoking

Some research suggests that smoking makes prostate cancer more likely to grow and spread to other parts of the body (advanced prostate cancer). And the more you smoke, the greater the risk.

Smoking may also make prostate cancer more likely to come back after surgery or radiotherapy, and heavy smoking may mean you're more likely to die from prostate cancer. However, if you stop smoking, your risk should start to drop – and after 10 years it could be as low as for men who have never smoked.

Stopping smoking can also help with the side effects of prostate cancer treatment. For example, you may be less likely to get certain urinary problems after radiotherapy if you don't smoke.

There's lots of support available to help you stop smoking. Talk to your doctor or nurse, or visit **www.nhs.uk/smokefree**

Complementary therapies

Complementary therapies include acupuncture, massage, yoga, meditation, reflexology and hypnotherapy. Many men find complementary therapies help them deal with their symptoms and the day-to-day impact of their cancer, helping them feel more in control. Some men find they feel more relaxed and better about themselves and their treatment.

Complementary therapies are usually used alongside or after medical treatments, rather than instead of them.

It is important to tell your doctor or nurse about any complementary therapies you're using or thinking of trying. Some complementary therapies can have side effects and some may interfere with your cancer treatment. You should also tell your complementary therapist about your cancer and any treatments you're having, as this can affect what therapies are safe and suitable for you.

Some GPs, hospitals, cancer clinics and hospices offer complementary therapies. But if you want to find a therapist yourself, the Complementary and Natural Healthcare Council has advice about finding a therapist. Make sure they are properly qualified and belong to a professional body.

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

Herbal remedies

Some men like to take herbal medicines to help manage their prostate cancer or the side effects of treatment. But there is very little evidence that herbal remedies can help to treat prostate cancer or reduce side effects. Some herbal remedies or supplements may interfere with your treatment, so let your doctor know if you're taking any.

Not all herbal remedies in the UK are licensed, and the quality varies a lot. Be very careful when buying herbal remedies over the internet. Many are made outside the UK and may not be high-quality. Many companies make claims that are not based on proper research. There may be no real evidence that their products work, and some may even be harmful. Remember that even if a product is 'natural', this doesn't mean it is safe. For more information about using herbal remedies safely, visit **www.mhra.gov.uk**

Your wellbeing

Prostate cancer and your feelings

Living with prostate cancer can be hard to deal with emotionally as well as physically, and can affect how you feel. There is no right way to think and feel, and everyone reacts in their own way.

Lots of men find it useful to get some support or find ways to look after themselves – even if their treatment has finished. Your partner, family and friends can also find this a difficult time and may also need support. There are lots of services available that can help – ask your doctor or nurse about what's available in your area.

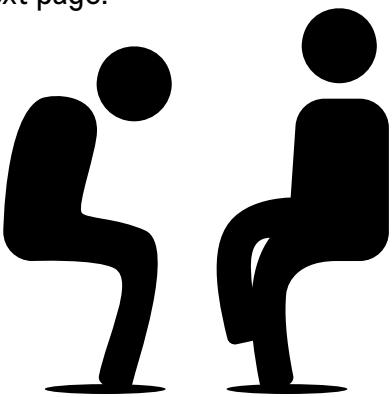
Common thoughts and feelings

People respond in all kinds of ways to being diagnosed and living with prostate cancer. You may feel a wide range of emotions and they might change very quickly.

- **Shock, fear, anger or confusion.** You could feel any or all of these things when you're told you have prostate cancer.
- **Denial.** If you feel well, you may find it difficult to accept that you have prostate cancer.
- **Frustration and disappointment.** The way you think about yourself, your life and your plans might have changed.
- **Stress.** It can be difficult to decide what treatment to have and you might feel stressed.
- **Worries about side effects.** If you have side effects like erection, urinary and bowel problems, then coping with these could also make you feel down or worried.

- **Sense of loss.** Hormone therapy can cause physical changes to your body, such as putting on weight, reduced physical strength, or changes to your sex life. This might make you feel very different about your body and cause a sense of loss.
- **Changing identity.** Sometimes men say they feel less of a man because of their diagnosis and treatment. Some men feel that their role in the family has changed – for example, because they've had to stop working.
- **Mood swings.** Hormone therapy can make you feel emotional and down. It can also cause mood swings, such as getting tearful and then angry.
- **Anxiety.** Some men worry about getting their prostate specific antigen (PSA) test results. The PSA test is used to monitor your cancer if you're not having treatment straight away, or to check how successful treatment has been. Even after treatment has finished some men feel anxious and find it hard to move on and think about the future.
- **Feeling alone.** You might feel isolated, especially if your treatment has finished and you're no longer seeing your doctor or nurse.

All these are very normal ways to feel. These feelings may stay with you, but some men find they gradually change with time. Read about things that can help on the next page.



Depression – seeing the signs

When you have prostate cancer, you may feel sad or down at times. This could be when you're diagnosed, during or treatment or after your treatment.

Depression can cause a variety of symptoms from feelings of unhappiness and hopelessness, to losing interest in the things you usually enjoy and feeling very tearful. Many people with depression also feel anxious or worried. These feelings can impact on your life and mean that you feel constantly tired, sleep badly and have no appetite. You may feel more angry and irritable than before.

If you notice these changes in yourself for most of the day and they don't go away after a couple of weeks, speak to your GP, hospital doctor or nurse – there are things that can help. Regular physical activity may also help you deal with feelings of anxiety and depression. Learning ways to relax, such as yoga or meditation, might also help.

You can also talk things through with our **Specialist Nurses**. If you need to speak to someone immediately, ring the Samaritans or NHS 111.

What can help?

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.

Some men want to find their own way to cope and don't want help from anyone else. Other men try to cope on their own because they are uncomfortable talking about how they feel or are afraid of worrying loved ones. But there is support available if you need it.

You may find some of the following suggestions helpful.

Talk with a loved one or a health professional

A lot of men find that talking about how they feel can help. You can get support from talking to your 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 else.

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

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.

> "It helps me to talk about it. It makes me feel that I'm hitting back at the cancer."
> *A personal experience*

Talk to someone who's been there

It can sometimes help to talk to other men living with prostate cancer. All the services below are free of charge.

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

- Our online community is a place to talk about whatever's on your mind – your questions, your ups and downs. Anyone can ask a question or share an experience.
- At support groups, people affected by prostate cancer get together to share their experiences of living with it. Some support 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. To find your local or an online support group, please visit **www.tackleprostate.org/supportgroups**

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

Trained counsellors

Counsellors and psychotherapists can help you to talk about your feelings, think about your choices or behaviour and make positive changes in your life. This could include things like learning to accept that you have cancer and to take each day as it comes. 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 refer you to a counsellor or therapist. You can also refer yourself for counselling on the NHS website, or you see a private counsellor or therapist. To find out more, visit **www.nhs.uk/counselling** or contact the British Association for Counselling & Psychotherapy.

Medicines

If you are feeling anxious or depressed, anti-depressants might help. Speak to your doctor about this. It is important that you tell them about any other medicines or complementary therapies you are taking.

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



How can I help myself?

- Find out about prostate cancer and its treatments. Understanding more about your cancer might reduce your risk of anxiety or depression.
- Find out about any side effects of treatment, so you know what to expect, and how you can try to manage them.
- Visit our online wellbeing hub to find out about the mental and emotional impact of prostate cancer and its treatments. You can also read real life experiences of men with prostate cancer. Find out more at **prostatecanceruk.org/wellbeing**
- Be as active as you can. Physical activity can lift your mood. Read more about staying active on page 22.
- Think about what you eat and drink. Some men find they manage better by aiming for a healthy, balanced diet. Read more about healthy eating on page 20.
- Take time out to look after yourself. When you feel up to it, learn some ways to manage stress and to relax – like breathing exercises or listening to music.
- Set yourself goals and plan things to look forward to. Keep up with your usual hobbies and social activities or try some new ones. Doing something you enjoy can make you feel more positive.

Get more ideas about how to look after yourself from Macmillan Cancer Support, Maggie's and Penny Brohn UK, as well as local cancer support centres.

Relationships and family life

Prostate cancer can change the normal pattern of your life and affect relationships, friendships and roles within the family. It can bring challenges, but can also bring some couples and families closer together. You might find that your plans get interrupted or your priorities change after a prostate cancer diagnosis. If you have side effects, like tiredness, your normal family role might change.

People find that they go through stages of adjusting and develop new ways of thinking about life and relationships. You might find some of these ideas can help:

- learning more about prostate cancer together
- talking about things
- getting all the support you need as a family
- getting help with practical matters, such as work, money or household tasks
- developing a wider support network including other family, friends or health professionals
- finding ways to manage or treat your side effects.

Try to make time for family activities, such as holidays and enjoying time together. You may not feel up to some activities that you have done together in the past, but it could be an opportunity to try something new.

Couples

Prostate cancer and its treatments can affect your relationship and sex life. You and your partner might need particular support for relationship and sexual issues.

Talking about it

If you have a partner, or are starting a new relationship, talking about sex and your thoughts and feelings will help you both deal with any changes. You may worry about the effect that changes to your sex life could have on your partner. Try not to guess how they feel about things. And encourage them to get support too.

It's not always easy to talk about sex and relationships, even if you've been together for a long time. If talking face to face feels difficult or uncomfortable, it may help to write a letter to your partner or see a relationship counsellor.

Your nurse or GP can put you in touch with a counsellor. You could also try contacting organisations such as Relate or the College of Sexual and Relationship Therapists.

Read more about dealing with the impact on sexual relationships in our booklet, **Prostate cancer and your sex life**.

Talking to children

Talking to children about cancer can be difficult and upsetting. It usually helps to be honest. Keeping things from them might only make them worry more. Children can often sense that something is wrong, even if they don't fully understand. They may also notice that things at home have changed, such as their daily routine. This can be confusing, especially for younger children. Charities such as Macmillan

Cancer Support have information about talking to children when a family member has cancer. You could also ask your GP for advice, or call our **Specialist Nurses**.

Are you supporting someone with prostate cancer?

If someone close to you has prostate cancer, you might be able to offer them a great deal of support, but it is likely that you will need help and support as well. You may find some of the information on pages 30 to 34 helpful.

Make sure you make time for yourself, such as keeping up hobbies and seeing friends. It's important to look after your own health as well. If you're feeling unwell, tired or down make sure you see your GP. You might also find that seeing a counsellor can help you work through any concerns.

Don't be afraid to ask for help if you need it. Friends or family might be able to help out, and support is also available from social services and voluntary organisations. Read more about how you can support someone with prostate cancer in our booklet, **When you're close to someone with prostate cancer: A guide for partners and family** or visit **prostatecanceruk.org/family**

"When my dad was diagnosed I knew very little and I wanted to learn more so I could support him, as he wasn't looking for information for himself."

A personal experience

Your daily life

Prostate cancer and the side effects of treatment can have an impact on your daily life. You might need to make decisions about work and money. This section looks at managing these and other practical issues, like getting around and help at home.

Work

How can prostate cancer affect your working life?

You may need to take time off work for treatments. This may include time for travelling to and from hospital and to recover after.

If you have surgery (radical prostatectomy), avoid climbing lots of stairs, lifting heavy objects or doing manual work for eight weeks after the operation. Talk to your doctor about when it's safe to return to your usual activities and go back to work. The amount of time you take off work varies from man to man and will depend on how quickly you recover, other medical conditions you may have, how much physical effort your work involves, and whether you feel ready to go back to work.

If you have radiotherapy, talk to your doctor or radiographer about working. Many men continue to work while having external beam radiotherapy but others find that they need time to rest during treatment. You may need to go to hospital five days a week for several weeks during the course of radiotherapy – and each visit could take at least an hour.

Some of the side effects of treatments could affect your working day. For example, having urinary or bowel problems, hot flushes or tiredness could mean you need to take extra breaks. Some men have to deal with these side effects for months or years after they have finished treatment.

Can I keep working?

Some men feel that work helps their recovery and return to normal life. But not everyone is able to continue working, and some may decide to work part-time or take early retirement.

If you live in England, Scotland or Wales, the Equality Act protects your rights in different areas of life, including at work. The Equality Act is a law that protects anyone who has, or has had, a disability – and cancer is classed as a disability under this law. Even if you no longer have cancer, you are still protected against discrimination.

If you live in Northern Ireland, you have protection under the Disability Discrimination Act.

Under the Equality Act and Disability Discrimination Act your employer has a duty to make 'reasonable adjustments' to where and how you work, to make sure you get the same chances as the people you work with.

For example, a reasonable adjustment could be time off for medical appointments, extra breaks, changing your job description to remove tasks that cause problems or providing suitable toilet facilities.

Most employers will be helpful and support you if you take time off work and then return. However, not all employers are as supportive as they should be. Some men say that even though they have prostate cancer, they still 'look okay' so their boss doesn't understand that they are feeling unwell.

You can find out more about your rights at work during and after cancer treatment from Macmillan Cancer Support.

What can help at work?

If your employer learns more about prostate cancer and its treatment, they might be more understanding. If you don't feel like talking about it, perhaps you could give them some of our publications to read.

Take a look at your company policies and employee handbook. Talk to your occupational health service for advice.

Go to your employer with suggestions about what would help you. For example, taking extra breaks, working from home, flexible hours, or changing your job role or duties for a while.

Know your legal rights. Find out more about the law and make sure your boss or company is aware of it. Contact your union if you are part of one. Your local Citizens Advice can also help.

If you are self-employed or you're looking for work, you can get more specific information from Macmillan Cancer Support or Disability Rights UK.

Money

If you're struggling with the financial costs of cancer, or your income has changed, you should be able to get some help. Macmillan Cancer Support has information on managing your finances. You might also be able to get help with the cost of travel to and from hospital, and some other medical costs.

Sick pay

If you've had or are looking to have time off work, find out if you can get statutory sick pay, occupational or company sick pay. Check your employment contract or contact your local Citizens Advice. You can also get information from the official government website, **www.gov.uk**

Benefits

The benefits you are entitled to vary depending on whether you are working, how old you are and other factors. Find out more about benefits and how to apply for them by visiting **www.gov.uk** or contacting your local Citizen's Advice or Macmillan Cancer Support to get advice on benefits.

Free prescriptions

If you live in England and are having cancer treatment, including treatments for symptoms or side effects, you are entitled to free prescriptions. You'll need to apply for a medical exemption certificate by asking your doctor for an FP92A form. Once the form has been filled in and signed by your doctor, you will be sent the certificate. You'll need to take the certificate with you whenever you collect a prescription. You can find out more about free prescriptions on the NHS website. If you live in Scotland, Wales or Northern Ireland, all prescriptions are free.

Travel insurance

Some men find it harder to get travel insurance because of their prostate cancer. Our fact sheet, **Travel and prostate cancer** gives tips on buying travel insurance.

How can I manage financially?

Citizens Advice can give you free advice on how to manage your finances. Or you can speak to an independent financial adviser, who can let you know which companies offer the best life insurance, mortgages, pensions and other financial services for your situation. Disability Rights UK and Macmillan Cancer Support has helpful information, including where to get further advice.

Driving and public transport

There are various schemes available to help with transport. These include the Blue Badge Scheme for parking, and cheap or free travel on public transport. Contact your local council for details. You could also apply for the Motability scheme, which helps with leasing a car. Find out more details about eligibility for the scheme at **www.motability.co.uk**

In the home

When living with prostate cancer, you may find everyday tasks more difficult. This could be because of side effects, pain, or because you find it harder to move about.

If you need extra help in the home, speak to your GP or ask your local council. The council's social services department may be able to provide 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 adaptions 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 will be able to 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 your partner, family 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 in for a few days.

Thinking about the future

It's natural to find it difficult and upsetting to think about the future – particularly if you have advanced prostate cancer. Many men with advanced cancer will have treatment that will control their cancer for many months or years but they may find it a worrying time.

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.

You can read more about planning ahead and the support available in our booklet, **Advanced prostate cancer: Managing symptoms and getting 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**

Chat to one of our Specialist Nurses

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



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

* Calls are recorded for training purposes only. Confidentiality is maintained between callers and Prostate Cancer UK.

Other useful organisations

Bladder and Bowel UK

www.bbuk.org.uk
Telephone: 0161 214 4591
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 Heart Foundation

www.bhf.org.uk
Telephone: 0808 802 1234
Information about heart disease and eating for a healthy heart.

Cancer Research UK

www.cancerresearchuk.org
Telephone: 0808 800 4040
Patient information from Cancer Research UK.

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.

Citizens Advice Scotland

www.cas.org.uk

Telephone: 0800 028 1456

Free, confidential and independent advice and support for NHS patients in Scotland.

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.

Complementary and Natural Healthcare Council

www.cnhc.org.uk

Telephone: 020 3327 2720

Details of complementary therapists who meet national standards.

Disability Rights UK

www.disabilityrightsuk.org

Telephone: 0330 995 0400

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

GOV.UK

www.gov.uk

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

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.

Medicines and Healthcare products Regulatory Agency (MHRA)

www.mhra.gov.uk
Telephone: 020 3080 6000
Advice about how to use medicines and herbal remedies safely and runs the Yellow Card Scheme, a system for reporting unusual side effects.

Mind

www.mind.org.uk
Telephone: 0300 123 3393 (Infoline); 0300 102 1234 (Support line)
Information and support for mental health issues such as depression or anxiety.

NHS websites

England: www.nhs.uk
Scotland: www.nhsinform.scot
Wales: 111.wales.nhs.uk

nidirect

www.nidirect.gov.uk

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 (England) 0300 003 2340 (Wales)
Information, advice and relationship counselling and sex therapy.

Relationships Scotland

www.relationships-scotland.org.uk
Telephone: 0345 119 2020
Information, 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.



About us

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

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

References used in this booklet are available at **prostatecanceruk.org**

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

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- Our Specialist Nurses
- Our volunteers.

Tell us what you think

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

Donate today – help others like you

Every year over 64,000 men get the life-changing news that they have prostate cancer. But thanks to our generous supporters, we're there to help men when they need us most. You can help more men get free, unbiased, confidential support by donating to us today:

- £10 could fund a call with one of our Specialist Nurses.
- £20 could give 40 men vital information through our handy **Know your prostate: a quick guide**.

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

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

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

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Call our Specialist Nurses from Monday to Friday 9am – 5pm, Wednesday 10am – 5pm
* Calls are recorded for training purposes only.
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