Living with and after prostate cancer

A guide to physical, emotional and practical issues

PROSTATE CANCER UK
About this booklet

This booklet is for men living with prostate cancer – before, during and after treatment. It’s also for men 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 of living with prostate cancer 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.

The following symbols appear throughout the booklet:

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

The quotes with the photos are not the words of the people who appear.
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Living with and after prostate cancer
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. Some men find it hard to move on.

Support from health professionals

Health professionals can support you before, during and after your prostate cancer treatment. You’ll have 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.

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. 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 form 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.

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How can I help myself?

There’s a lot you can do to actively 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 and to talk to your doctor or nurse about them. There are tips on self-management throughout this booklet.

You might want to get some ideas from a health professional and learn some extra skills to make it easier to manage things yourself.

- Macmillan Cancer Support, Maggie’s Centres and Penny Brohn UK run free courses for people living with cancer.
- Ask your specialist nurse or local support group if they run training days or invite health professionals to give talks.
- Look out for events at your GP surgery, hospital, library, adult learning centre, or community centre.

Try our online ‘How to’ guides

Our interactive guides show you how to manage some of the side effects of treatment. You’ll find a huge variety of resources, ranging from expert ‘how-to’ films, to tips from other men, to journals and planners you can use to manage your health in the day-to-day.

We have guides on managing:
- sex and relationships
- fatigue
- urinary problems
- symptoms and side effects of advanced prostate cancer

Find them all at prostatecanceruk.org/guides
One great tip was to take a short rest each day when I got back home after my radiotherapy treatment.

A personal experience
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. These 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.

Treatment options for prostate cancer include monitoring (active surveillance and watchful waiting), surgery, external beam radiotherapy, brachytherapy and hormone therapy. High-intensity focused ultrasound (HIFU) and cryotherapy may also be offered to some men.

Read our Tool Kit fact sheets for more on each treatment. These are free and available to order or download online (see page 56). Or you can call 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 a range of feelings from tiredness to exhaustion, which makes it hard to carry out your daily activities. You may feel weak, lethargic or drained. It can affect your energy levels, motivation, ability to concentrate, emotions and sex drive. Fatigue isn’t always relieved by rest alone and many men find it difficult to cope with.
Fatigue is a common side effect of prostate cancer and some treatments for prostate cancer, such as hormone therapy and radiotherapy, can cause extreme tiredness. Men who have advanced prostate cancer are also more likely to have fatigue. It might also be a symptom of another condition, such as anxiety or depression.

Fatigue might improve after your treatment has finished but some men find it lasts longer. It’s hard to say how tired you’ll feel during and after treatment. Some men don’t feel tired at all. Other men get so tired it affects their everyday life.

Let your doctor or nurse know how you feel and if you’re getting very tired. They can check what’s causing your fatigue and help you find ways to manage it.

**What can help?**

**Plan your day**

It sounds simple, but looking at all the things you do each day could help you manage your fatigue.

For example, make a list of everything you do and see what’s most important. Then try to save energy for these things by holding back on other activities, and make time for rest. Your doctor or nurse might be able to refer you to an occupational therapist who specialises in helping people carry out their day-to-day activities.

Lots of men continue to work while they have treatment, but if tiredness becomes a problem you may need to take some time off work (see page 45).
**Eat well and stay active**
If you have a good appetite and are eating well, following a healthy and balanced diet should give you the energy you need. But if you are struggling to eat enough and are losing weight, this could add to your tiredness.

Light to moderate exercise, such as walking or swimming, can make you feel more awake. And adding gentle resistance exercises such as lifting a light weight while you walk or swim may have an even better effect.

Try to plan physical activities at times when you usually have more energy. If you feel particularly tired, just do gentle exercise for a short time and take lots of breaks. You can even exercise from your chair or bed. For example, use a resistance band to help you lift and stretch your arms and legs.

Speak to your doctor before you make any changes to how you exercise. Read more about how diet and physical activity can help on pages 23 to 27. You might also want to try our fatigue support service (see page 12).

**Sort out your sleep**
Sleep problems can make you feel tired during the day or make any tiredness you already have worse. Your GP can give you ideas to help improve your sleep, such as relaxation techniques, and may sometimes prescribe sleeping pills.

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 about ways to manage this.
Dealing with depression and anxiety

Tiredness can sometimes be linked to feeling depressed or anxious. Feeling down can make you feel less energetic, and worrying all the time can affect your sleep and wear you out. If you’re having any of these feelings, talking to someone or getting some support can help (see page 36).

What else can help?

• Get help for any other health problems or symptoms. For example, if you have a heart problem as well as prostate cancer, or you’re in pain, this could make you more tired.

• Ask your doctor or nurse to check if any drugs you’re taking might be making you tired.

• Some men like using complementary therapies. Acupuncture, massage, yoga or meditation may help you relax.

Read our Fatigue and prostate cancer fact sheet for more information or go through our online guide at prostatecanceruk.org/guides

Our fatigue support service

Our fatigue support service is a 10-week telephone service delivered by our Specialist Nurses. They will ask about how you’re feeling and try to help you find ways to manage your fatigue. Changes might be things like gradually becoming more active, getting back into hobbies, or changing your diet slightly. Visit our website at prostatecanceruk.org/get-support or call our Specialist Nurses to find out more.
**Urinary problems**

Many men get urinary problems after prostate cancer treatment such as leaking urine or problems emptying their bladder. Urinary problems usually last for a few weeks or months after treatment but some men may have them for several years.

**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 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 problems you’re having, ways to manage them can include lifestyle changes, pelvic floor muscle exercises, bladder retraining, medicines or surgery.

**Acute urine retention**

This is when you suddenly and painfully can’t urinate – it needs treating straight away. 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. This is a thin tube put into the bladder either through your penis or your abdomen (stomach area). Make sure they know what prostate cancer treatment you’ve had.
How can I help myself?

- Try to drink plenty of fluids, but cut down on fizzy drinks, alcohol, tea and coffee as these may irritate the bladder.

- Do pelvic floor muscle exercises to help strengthen the muscles that control when you urinate. 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. Smoking can cause coughing which puts pressure on your pelvic floor muscles. NHS Choices has more information about stopping smoking.

- 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 help make it easier to ask for urgent access to a toilet. You can get a card 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 condition.

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

Watch Paul’s story
Find out how he dealt with leaking urine after surgery.
Bowel problems

Radiotherapy for prostate cancer can cause bowel problems for some men. Radiation can irritate the lining of the bowel and back passage (rectum). This may cause loose and watery bowel movements (diarrhoea) and pain in the stomach area or back passage. More rarely, it can cause bleeding from the back passage.

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 are permanent. And some men develop bowel problems months or years after treatment.

What can help?
Tell your doctor or nurse 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).

Macmillan Cancer Support produce detailed information about coping with bowel problems.
How can I help myself?
There are things you can do to help manage your symptoms.

If you have diarrhoea, eating less fibre for a short time may help, although there is only a small amount of evidence for this. Low fibre foods include white rice, pasta and bread, potatoes (without the skins), cornmeal, eggs and lean white meat. Make sure you drink lots of water to replace the liquid your body is losing. Avoiding spicy food may also help.

If you’re passing more wind than usual, you may want to avoid beans and pulses, cruciferous vegetables such as cabbage, broccoli and cauliflower, fizzy drinks and beer. These foods and drinks may cause wind and bloating. Some people find that adding certain herbs or spices to their cooking, such as ginger, peppermint or dill, can help with wind.

You may find it helpful to plan ahead and find out where toilets are before you go out, and take with you some absorbent pads, underwear and wet wipes.

Sexual problems
Sex is an important part of life for many of us and prostate cancer and its treatment can affect your sex life.

Treatments for prostate cancer can affect:
• your ability to get an erection
• your desire for sex (libido)
• your ability to ejaculate and have an orgasm
• your ability to have children (fertility)
• how you feel about yourself sexually
• how your body looks
• your relationships.
But there are treatments and support that can provide some answers and ways for you to work through any problems.

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 an erection for masturbation or you might want to start a new relationship in the future.

**Some common questions answered**

- You can’t pass on cancer through sexual activity.
- Having sex won’t affect your cancer or the success of your treatment.
- Having sex won’t affect the chances of your cancer coming back.
- Erections are still safe if you have a catheter in.

**What can help?**

You can get free medical treatment and support for erection problems or other 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 such as an erectile dysfunction clinic.

Even though your sex life might not be the same as it was before cancer, you don’t have to give up on having pleasure, closeness or fun together. It’s often helpful to explore other ways of having an intimate relationship, without having penetrative sex. Some men find they become closer to their partner even though they have some sexual problems.
Try to talk through the issues with your partner. Some couples find it useful to see a relationship counsellor. The charity Relate provides relationship counselling and a range of other relationship support services.

If you or your partner is feeling depressed or anxious, getting help for this could improve your mood and may in turn help your sex life. See page 41 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.

- Regular physical activity may help to increase your desire for sex, improve your self esteem and give you more energy for sex.
- Keeping a healthy weight, stopping smoking and doing pelvic floor exercises may help with erection problems.
- Try not to put too much pressure on yourself – it can take 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* or visit our interactive online guide at prostatecanceruk.org/guides

**Ability to have children**
Prostate cancer treatment can affect your ability to have children. For example, you won’t ejaculate any semen after surgery (radical prostatectomy). If you have radiotherapy or brachytherapy, the radiation might affect your ability to produce sperm, although this is very unlikely.
Changes to your sperm during radiotherapy, brachytherapy and chemotherapy could affect any children you may conceive during or after treatment but the risk of this happening is very low. You may wish to use a condom or other type of contraception to avoid fathering a child during treatment and for up to two and a half years afterwards.

If you and your partner are planning to have children speak to your GP or specialist team. You may want to think about storing your sperm before treatment, so that you can use it later for fertility treatment (IVF). Macmillan Cancer Support have more information on fertility and treatment options.

**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 including loss of desire for sex
- extreme tiredness
- weight gain
- strength and muscle loss
- breast swelling and tenderness
- loss of body hair
- bone thinning
- risk of 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 all men with prostate cancer have pain. The most common cause of pain from prostate cancer is when it has spread to the bones. But even then more than a quarter of men (25 per cent) don’t have any pain. And if cancer has spread to several places in the body, men often only have pain in a few of these.

Sometimes pain can be due to cancer treatments. For example, radiotherapy can sometimes irritate your skin, or chemotherapy can cause numbness or tingling in your hands and feet. Some men may have pain for a few weeks after surgery.

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 a number of 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.

Treatments to control pain include:
• treatment for the cancer itself, such as hormone therapy, chemotherapy or steroids
• treatment for the pain, such as pain-relieving drugs, radiotherapy, or drugs called bisphosphonates which treat bone pain
• complementary therapies (see page 29).

Read more in our fact sheet, Managing pain in advanced prostate cancer.
**Metastatic spinal cord compression (MSCC)**

MSCC happens when cancer cells grow in or near to the spine and press on the spinal cord. Cancer cells pressing on the spinal cord can cause problems with how the nerves in the spinal cord carry messages to the rest of the body. This can cause a range of symptoms which can get worse if left untreated. Symptoms can include:

- pain in your back or neck that is severe or different from usual pain
- a narrow band of pain around your 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
- numbness or tingling in your legs, arms, fingers, toes, buttocks, stomach area or chest, that doesn’t go away
- problems controlling your bladder or bowel.

Only men with advanced prostate cancer are at risk of having MSCC. It is not common but if it happens, it’s very important you get treatment straight away. At its worst, MSCC can cause paralysis. Getting treatment straight away can lower the risk of having permanent problems.

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

A healthy lifestyle can give you more control over your health and help you to improve it. It can also help you manage the effects of prostate cancer and its treatment.

Staying a healthy weight and having a healthy diet can reduce your risk of many health problems, including heart disease, diabetes and some cancers. There is also strong evidence that being overweight or obese increases the risk of aggressive or advanced prostate cancer. So it may be particularly important for men with prostate cancer to eat a healthy diet and stay a healthy weight.

Being a healthy weight may mean your prostate cancer is less likely to spread after surgery or radiotherapy. Hormone therapy may also be less effective if you are very overweight. Staying a healthy weight might also 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 general health. It can help you stay a healthy weight.

How can I eat more healthily?
A healthy diet doesn’t need to be boring. It’s good to eat lots of different foods to make sure you get a range of nutrients. Start by making small changes that you feel comfortable with, such as eating 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

- **Eat three regular meals a day.** If you have loss of appetite or difficulty eating, try to eat small amounts regularly instead.

- **Eat at least five servings of fruit and vegetables each day.**

- **Eat starchy foods at each meal.** 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 if you are trying to lose weight.

- **Include some protein-rich foods.** 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 soy products with added calcium, green leafy vegetables, and fish where you eat the bones.

- **Choose foods that are low in saturated fat.** These include olive oil, vegetable oils, avocados, nuts and seeds, and oily fish.

- **Eat less sugar.**

- **Cut down on salt.** Eat less than 6g of salt each day. Look out for hidden salt in processed foods and takeaways. Avoid adding salt when you cook – try using herbs and spices to add flavour instead.

- **Drink lots of water.** Try to drink around 1.5 to 2 litres (3 to 4 pints) a day.

If you’re having difficulty eating enough and you’re losing weight ask your doctor to refer you to a dietitian. They can help if you’re making big changes to your diet, or if you have any other health
problems that could be affected by your diet, such as diabetes. There are some specific foods that may be helpful for men with prostate cancer, either by reducing the chance of cancer spreading or by helping to reduce side effects of treatment.

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

**Physical activity**

Physical activity is important for general health and wellbeing. It can help you to stay a healthy weight by using spare energy that the body would otherwise store as fat. Being a healthy weight may help to lower your risk of advanced prostate cancer.

Physical activity can also help with some of the side effects of treatment and help you cope with feelings of anxiety or depression. Some research suggests that physical activity may help slow down the growth of prostate cancer, although other studies haven’t found this.

**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, and that fits into your life, you’ll be 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. Try lifting and stretching your arms and legs – this can help improve your movement and muscle strength.
• 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. For more information about walking 10,000 steps a day, visit the NHS Choices website.

• 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. Rest when you feel you need to.

Aim to be physically active at least two to three times a week. Start gently for short periods of time, such as 10 to 15 minutes, and gradually increase the amount as you become fitter. If you can, build up to include 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. 30 minutes may seem like a lot, but remember you can reach this amount by being active for 10 minutes, three times a day.

It’s safe for men with prostate cancer and those having treatment to be physically active. But it might be a good idea to speak to your GP, nurse or hospital doctor before you start any kind of exercise plan. This is particularly important if 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. You could also ask to be referred to an exercise programme or a physiotherapist for further advice.

**Exercise safely**
- Be careful to avoid falls, especially if you’re on hormone therapy or your cancer has spread to the bones – both of these can increase your risk of breaking bones.
- Wear clothing and trainers that fit properly, and don’t exercise on uneven surfaces.
- Make sure you drink enough water.
- Don’t exercise if you feel unwell, or have any pain, sickness or other unusual symptoms. Stop if you get any of these while exercising.

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, make new friends and it’s introduced me to parts of the country that I didn’t know existed.

A personal experience
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.

How to use complementary therapies

Complementary therapies are usually used alongside medical treatments, rather than instead of them. Some therapies can have side effects and some may interfere with your cancer treatment. So tell your doctor or nurse about any complementary therapies you’re using or thinking of trying. You should also tell your 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, make sure they are properly qualified and belong to a professional body. The Complementary and Natural Healthcare Council has advice about finding a therapist.

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.
I have acupuncture and reflexology every week and they are the most effective pain relievers for me. If I have pain in a specific area, they remove the pain quickly.

A personal experience

**Herbal remedies**

Some men like to take herbal medicines to help manage their prostate cancer or the side effects of treatment. For example, some men drink sage tea to help with hot flushes, which are a common side effect of hormone therapy. But there is very little evidence that herbal remedies can help to treat prostate cancer or reduce side effects.

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
I found it very important to remain positive, and made changes to my life such as improving my diet and taking up new interests.

A personal experience

I have a different richness in my life. Having cancer made me think about what it is I’m actually doing instead of just being on autopilot.

A personal experience
My treatments and side effects lasted for a while, and I found that I went through good and not so good emotions.

A personal experience
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.

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 may also need support. There is no right way to think and feel, and everyone reacts in their own way.

Common thoughts and feelings

Men 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 or anger**. 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.
**Depression – seeing the signs**
Many men with prostate cancer feel anxious and worried at times. If you’re feeling very down, your sleep pattern or appetite has changed a lot, or you get angry more easily, this could be a sign of depression. If you notice these changes in yourself, speak to your GP, hospital doctor or nurse. There are things that can help.

Regular physical activity can often 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.

**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 it could be a worrying time.

You might find that making plans helps you feel more prepared for what the future may hold, and reassured 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*.

**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.

**Talking about it with a loved one or a health professional**

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 else.

It could be useful to speak to your nurse, doctor, GP or someone else in your medical team. They can help you understand your treatment and side effects, listen to your concerns, 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 to any concerns you or those close to you have about living with prostate cancer. Everything is confidential.

"It helps me to talk about it. It makes me feel that I’m hitting back at the cancer."

A personal experience
Talking to someone who’s been there
It can sometimes help to talk to other men living with prostate cancer.

- 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 could talk about treatments, dealing with side effects, or telling people about your cancer – whatever’s important to you.

- Our online community is a place to talk about whatever’s on your mind. Anyone can ask a question or share an experience. It’s a place to deal with prostate cancer together.

- 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. Many also welcome partners, friends and relatives.

To find out more about any of our services visit our website at prostatecanceruk.org/get-support or call our Specialist Nurses.
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.

- Be as active as you can. Physical activity can lift your mood. Read more about staying active on page 25.

- 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 23.

- Share what you’re thinking – find someone you can talk to. It could be someone close, or someone trained to listen, like a counsellor or your medical team.

- 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 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 Centres and Penny Brohn UK, as well as local cancer support centres.
Counselling
Some men find talking to a professional counsellor helpful. 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 if this is available.

Your GP can also refer you or you can see a private counsellor. To find out more contact the British Association for Counselling & Psychotherapy.

Drugs
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’s helpful and relaxing to chat with other men. A shared experience lets you know that you’re not on your own.”
A personal experience
Living with and after prostate cancer
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 diagnosis of prostate cancer. 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 sure that you 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 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, try to talk to them about how you’re feeling. Talking could help you both feel better and reduce any worries you have about what each other is thinking. Talking may also help your partner understand more about any physical and emotional changes you’re going through.

Sometimes it’s not easy to talk, especially during stressful times. In particular, talking about sex can be difficult, even for a couple who have been together for a long time. Relationship therapy can sometimes help. Your GP, nurse or hospital doctor 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. It comes with a DVD of men talking about their own experiences. The information and films are also available on our website.

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
Are you supporting someone with prostate cancer?
If someone close to you has prostate cancer you might be able to offer him 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 36 to 38 helpful.

Make sure you make time for yourself. Try to keep up with 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 a man with prostate cancer: A guide for partners and family.
Daily life and prostate cancer

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 includes time for travelling to hospital and, for some men, time to recover.

If you have surgery (radical prostatectomy) you may need to take up to eight weeks or even longer off work. You’ll need to avoid climbing too many stairs, lifting heavy objects or doing manual work for eight weeks after the operation. Ask your doctor or nurse for advice on how much time to take off.

Many men continue to work while having external beam radiotherapy but some men find that they need time to rest during treatment. You will 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 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 have prostate cancer, 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 these laws 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:
• giving you time off to go to medical appointments
• allowing extra breaks if you feel tired
• changing your job description to remove tasks that cause problems
• providing suitable toilet facilities.

You can find out more about your rights at work when you have cancer from Macmillan Cancer Support.

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.
**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 Bureau 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.

**“**

My work often involved travelling. I would have found it very difficult to keep this up during and after treatment. However, returning to the normal work environment, even if it wasn’t full-time, has really helped me to feel better in myself.

A personal experience
Money
If you’re struggling with the financial costs of cancer, or your income has changed, you should be able to get some help.

Sick pay
If you’ve had time off work, find out if you can get statutory sick pay, or occupational or company sick pay. Check your employment contract or contact your local Citizens Advice Bureau. 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.

- Visit the www.gov.uk
- Contact your local Citizens Advice Bureau – they offer free advice.
- Call Macmillan Cancer Support to get advice on benefits.

Other costs
You might also be able to get help with the costs of travel to and from hospital, and some other medical costs.

If you live in England and are having treatment for cancer, including treatments for symptoms or side effects, you are entitled to free prescriptions. You’ll need to apply for a medical exemption certificate. Ask your doctor for a FP92A form. Once you have filled out the form, your doctor will need to sign it, and you will be sent the certificate.
You can find out more about free prescriptions at NHS Choices. 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 produces 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, 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.

**In the home**
Some men with prostate cancer may find everyday tasks more difficult. This could be because of side effects, pain, or because they find it harder to move about.

If you need extra help in the home, speak to your GP or ask your local council for advice. The council’s social services department may be able to provide a range of support services.
Services vary from place to place, but can include practical and financial advice and access to emotional support.

Social services can assess your needs – and the needs 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 can help make living at home easier. 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 your cancer means you need ongoing care from your partner or a family member, respite care allows them to have a break. A professional will take over your care for a short time.

Not all local areas provide or pay for the same services. Speak to your GP, nurse or local social services about what practical support or respite care is available for you.
Other useful organisations

British Association for Counselling & Psychotherapy
www.itsgoodtotalk.org.uk
Telephone: 01455 883 300
Information about counselling and details of therapists in your area.

British Heart Foundation
www.bhf.org.uk
Telephone: 0300 330 3311
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
Advice on a wide 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 accredited therapists.
Complementary and Natural Healthcare Council
www.cnhc.org.uk
Telephone: 020 3668 0406
Details of therapists who meet national standards.

Disability Rights UK
www.disabilityrightsuk.org
Telephone: 020 7250 8181
Practical information guides 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.

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 00 00
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. Includes an online support group.

Marie Curie
www.mariecurie.org.uk
Telephone: 0800 090 2309
Runs hospices throughout the UK and a nursing service for people in their own home free of charge.

Medicines and Healthcare products Regulatory Agency
www.mhra.gov.uk
Telephone: 020 3080 6000
Provides advice about how to use herbal remedies safely. Also runs the Yellow Card Scheme, a system for reporting unusual side effects from any treatment, including herbal remedies.

Mind
www.mind.org.uk
Telephone: 0300 123 3393
Information and support for mental health issues such as depression or anxiety.

National Osteoporosis Society
www.nos.org.uk
Telephone: 0808 800 0035
Information and support for people with weak bones.
NHS 24
www.nhs24.com
Telephone: 111
Health information and self care advice for people in Scotland. Lists local NHS services including GPs.

NHS Choices
www.nhs.uk
Information and advice, including information about how to eat healthily and exercise. Support for carers and a directory of health services in England.

Penny Brohn UK
www.pennybrohn.org.uk
Telephone: 0303 300 0118
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.

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: 08457 116 123  
Confidential, non-judgemental emotional support, 24 hours a day, by telephone, email, letter or face to face.

**Turn2us**

www.turn2us.org.uk  
Telephone: 0808 802 2000  
Help to access money that’s available through benefits, grants and other help.
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 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 or text NURSE to 70004. You can also 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.
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:
• Vanessa Basketter, Advanced Prostate Cancer Nurse Specialist, University Hospital Southampton, Southampton
• Kate Bullen, Head of The School of Applied Social Science, University of Brighton, Brighton
• Jonathan Rees, GP with special interest in Urology and Men’s Health, Backwell and Nailsea Medical Group, North Somerset
• Nona Toothill, Urology Clinical Nurse Specialist, Airedale NHS Foundation Trust, Keighley
• Cathryn Woodward, Consultant Oncologist, West Suffolk Foundation Trust, Suffolk
• 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, 40,000 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