

Living with and after prostate cancer





A guide to physical, emotional and practical issues

Introduction

This booklet is for men living with prostate cancer, before during and after treatment. It is also for men who may be having their prostate cancer monitored, rather than having treatment. It contains information about the physical and emotional effects of living with prostate cancer and treatment, and looks at ways to manage them. It also provides information about practical issues such as work and money. Partners, family and friends of men affected by prostate cancer may also find this booklet useful.

This booklet is a general guide and everyone's experience of living with prostate cancer will be different. If you would like more detailed information you can speak to your specialist team or GP. We have also listed a number of other sources of support and information at the end of this booklet, which you may find helpful.

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

-  The Prostate Cancer Charity Helpline
-  The Prostate Cancer Charity publications or other helpful organisations which we have listed at the back of this booklet.

If you would like to know more about anything you read in this booklet, you can call our confidential Helpline to speak to a

 Support and Information Specialist Nurse on 0800 074 8383.

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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 may still have side effects or you may find it hard to move on and might worry about your cancer coming back.

Support and follow-up

How often you see health professionals will depend on the stage and grade of your prostate cancer, what treatment you are having or have had in the past, how you respond to treatment and any side effects you may experience. Ask your doctor or nurse about your follow-up plan, how often you will have check-ups and who to contact if you need support.

There is also information throughout this booklet about how you can get support. The easiest way is to go and see your GP who can refer you to other services, even if it has been a while since you had treatment.

During and after treatment for prostate cancer you should let your GP or other health professional know if you have any symptoms or changes to your health. These may or may not be

signs of your cancer changing or coming back. They could be side effects of treatment, which you can read about further on in this booklet, or they may be caused by other health problems. It is still a good idea to get them checked out as there may be ways to manage them. The symptoms you should look out for will vary.

Ask your doctor or nurse to fill in specific symptoms or changes to your health to look out for and who you should contact about them here:

Problem or concern	Who to contact

A personal experience...


“Before my appointments I find it useful to write down any questions to ask the doctor, I take this in with me, so I don't forget.”

What is self-management?

Self-management means being actively involved in looking after your own health and wellbeing. Some examples include changing your diet, doing some exercise or learning other ways to look after yourself.

It is also important to be aware of any changes to your health and let your GP or specialist team know about them.

Many men with prostate cancer say that they want to be able to self-manage side effects or changes they might be experiencing. There are tips on self-management throughout this booklet. Getting advice from a health professional and learning some extra skills can make this easier. For example, you, your partner or family could go on a course or training day about living with and after cancer:

-  • Macmillan Cancer Support, The Expert Patients Programme and Penny Brohn Cancer Care run free courses for people living with cancer or long-term health problems.
- If you have a specialist nurse or belong to a support group, ask if they run training days or invite health professionals to give talks.
- Look out for courses at your GP surgery, local hospital, library, adult learning centre or local community or sports centres. Check their notice boards or websites.



Physical effects of prostate cancer

This section is about how prostate cancer and its treatment can affect your body and physical health. Many treatments for prostate cancer cause short-term or long-term side effects. In many cases these side effects can be treated, improved or managed. Discuss your concerns and experiences with your specialist team to make sure you get the help you need.

Tiredness (fatigue)

All treatments for prostate cancer can cause tiredness (fatigue). This can be during and after treatment. Your tiredness could improve after your treatment has finished. Some men find their tiredness is more long-lasting. Hormone therapy in particular can cause extreme tiredness. Men who have prostate cancer that has spread to other parts of the body (advanced prostate cancer) are also more likely to feel tired.

How tired you feel during and after treatment will vary. While some men do not feel tired at all, other men experience tiredness that affects their everyday life. Tiredness can affect your energy levels, your motivation, your ability to concentrate and your emotions. It can be difficult to cope with, especially if you are used to being very active.

It is important to let your specialist team or GP know how you feel and how tiredness is affecting you. They can check what is causing it and look for ways to help you. Tiredness may be due to your treatment but it can also have other causes such as the cancer itself or other conditions.

What can help?

Organising your day

Sorting out your daily routine can help manage your tiredness. Making lists, prioritising important tasks and making time for rest could help you make sure you are not doing too much and have time to yourself. Your GP or specialist team could also refer you to an occupational therapist who can help with this. Many men continue to work throughout their treatment but if tiredness becomes a problem you may need to take some time off work.

Physical activity and diet

As well as having time for some rest, doing light exercise can help. Gentle exercise such as walking or swimming can help to reduce tiredness. Speak to your doctor or nurse before starting any exercise programme.

If you have a good appetite and are eating well, following a healthy, balanced diet should be enough for you to get all the

A personal experience...

“One invaluable tip was to take a short rest each day when I got back home after having my radiotherapy treatment.”

energy you need. If you are struggling to eat enough and have lost weight, this may be adding to your tiredness. You can ask your GP or specialist team to refer you to a dietitian for advice about your diet. See page 25 for information about diet and physical activity.

Sorting out your sleep

Sleep problems can cause you to feel tired during the day or make any tiredness you already have worse. Lots of things can help you cope with sleep problems including relaxation techniques, dealing with any worries that are keeping you awake and, in some cases, taking medicines to help you sleep. Visit your GP to discuss any concerns you may have.

i If you are bothered by having to get up to go to the toilet a lot at night read our Tool Kit fact sheet, **Urinary problems and prostate cancer**, for information about what can help.

Dealing with feeling depressed or anxious

During treatment for cancer, tiredness can sometimes be linked to feeling depressed or anxious. Feeling down can make you feel less energetic and worrying all the time can wear you out. If you are having any of these feelings, talking to someone or getting some support can help. See page 31 for more information.

A personal experience...

“I found exercise is the best thing to combat tiredness and it also motivates you in general and keeps your spirits up and stress levels down.”

Complementary (alternative) therapies

There is some research to show that some complementary therapies can help people with cancer manage tiredness. These types of therapies include: acupuncture, breathing control, muscle relaxation, massage, yoga and different types of meditation. Some people with cancer find that these therapies help them cope with their tiredness, but we still need more research into this. Some hospitals run complementary therapy services. Check with your specialist team or GP.

i The Complementary and Natural Healthcare Council is also a useful source of information.

What else can help?

- You can get help for other symptoms, such as pain, that can make tiredness worse.
- Ask your specialist team or GP to check if any medicines or combination of medicines you are taking are affecting your tiredness.
- You can get help for any other health problems you have. For example, if you have a heart problem as well as prostate cancer, this could be making your tiredness worse.

Urinary problems

After some treatments for prostate cancer you may have problems with controlling or passing urine. For example, leaking urine (incontinence) or problems emptying your bladder (urine retention). Treatments that can cause urinary problems include surgery, radiotherapy, brachytherapy, cryotherapy and high intensity focused ultrasound (HIFU).

Some men find that urinary problems last for a few weeks or months after treatment. Other men may have urinary problems for a number of years.

What can help?

You should speak to your specialist team or GP about any problems you are having passing urine, even if you are no longer having treatment for prostate cancer. They may refer you to a specialist continence nurse or physiotherapist or you may be able to refer yourself to your local continence service. You can find out if there are any continence services in your area by contacting the The Bladder and Bowel Foundation.

Depending on what problems you are having, possible treatments include pelvic floor exercises, bladder retraining, medicines or surgery.

If you have a sudden and painful inability to pass urine (acute urinary retention) you will need treatment straight away, for example at your local accident and emergency (A&E) department.

i Read our Tool Kit fact sheet, **Urinary problems and prostate cancer**, for more detailed information about managing urinary problems, such as information on bladder retraining and pelvic floor exercises.

Self-management of urinary problems

Making some changes to your lifestyle may help you to manage your urinary problems. These include:

- Maintaining a healthy weight and level of fitness.
- Stopping smoking as this can cause coughing, which can cause you to leak urine, if you already have problems with this.
- Avoiding constipation, for example by eating a healthy diet that is high in fibre.
- Drinking enough liquid (two litres or three to four pints per day), but avoiding or reducing the amount of liquid that may irritate the bladder such as fizzy drinks, caffeine-based drinks (tea, coffee and cola), and alcohol.

Bowel problems

Radiotherapy for prostate cancer (external beam radiotherapy and brachytherapy) can cause bowel problems for some men. Radiation can cause the lining of the bowel to become inflamed (proctitis) which then leads to symptoms such as loose and watery stools (diarrhoea), pain in the stomach area (abdomen) or back passage, or, more rarely, bleeding from the back passage. Some men find that changes to their bowel habits last for a short time or they can change permanently. Some men develop bowel problems months or years after treatment.

What can help?

You should let your specialist team or GP know about any changes in your bowel habits. There are medicines available that can help with symptoms and control diarrhoea.

If you have long-term bowel problems, you could ask to be referred to a bowel specialist (gastroenterologist). You may have a further test to check for any damage to the bowel.

Self-management of bowel problems

Try to follow a normal diet and drink plenty of fluids. Your specialist team might give you more detailed advice.

Although a diet high in fibre such as fruit and vegetables is generally healthy, some men find that too much fibre makes diarrhoea and wind worse. Eating a low fibre diet for a short time may help with these symptoms. Low fibre foods include rice, potatoes (without skins), pasta and meat.

Some men find that gentle exercise, such as regular walks, can help with bowel problems after radiotherapy.

- i** Macmillan Cancer Support and the Bladder and Bowel Foundation produce detailed information about coping with bowel problems.

Sexual problems

Prostate cancer and its treatment can have a number of symptoms and side effects that can affect your sex life.

Ejaculation

Treatment for prostate cancer can affect your ability to ejaculate and have an orgasm.

Penis size

Surgery for prostate cancer (radical prostatectomy) can cause your penis to become shorter. Radiotherapy and hormone therapy may also cause changes to your penis size.

Desire for sex (libido)

Hormone therapy for prostate cancer is likely to reduce, or cause you to lose, your desire for sex. This is because of the decrease in the hormone testosterone, which is responsible for giving

i you your 'sex drive'. You can read more in our booklet, **Living with hormone therapy: A guide for men with prostate cancer**.

In general, how you are feeling physically and emotionally may mean you do not feel like sex.

Problems getting an erection (erectile dysfunction)

Prostate cancer treatment can affect your ability to get an erection. Erectile dysfunction is also known as ED or impotence. It is more likely to occur as men get older. It can have many possible causes such as stress and anxiety, other medical conditions such as diabetes, heart disease, high blood pressure as well as treatment for prostate cancer.

For some men the loss of erections is not a problem and they choose not to have any kind of treatment. Others are less happy about losing what is a very important part of their lives and choose to have treatment.

Sexual problems can have an impact on your life if you are in a relationship or if you are single. You may be single and want an erection for masturbation or you may be thinking of starting a relationship in the future. There is no right or wrong time to consider getting help and treatment if you want to.

What can help?

Men with prostate cancer can get treatment for erectile dysfunction (ED) free on the NHS. There is no age limit for receiving treatment. Your specialist team can prescribe treatments such as tablets (for example Viagra® or Cialis®), injections, pellets, vacuum pumps or in some cases surgical implants.

Exploring other ways of having an intimate relationship without having penetrative sex may be helpful. Hugging and kissing maintains intimacy, provides support and does not have to lead to intercourse. Some men find they become closer to their partner even though they have ED.

Try to talk through the issues with your partner. Further support such as counselling can help. If you or your partner are feeling depressed or anxious, then getting some help may improve your mood and in turn help your sex life. See page 37 for more information about relationship issues.

Self-management of sexual problems

Making some changes to your lifestyle may help you to manage some of your sexual problems.

- Maintaining a healthy weight and being physically active may benefit men with ED.
- Smoking can increase the risk of ED and make treatments for ED less effective.

Some early research shows that pelvic floor exercises may help to improve the quality of a man's erections. For more information about pelvic floor exercises read our Tool Kit fact sheet, **Urinary problems and prostate cancer**.

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Fertility

Treatment for prostate cancer can affect your ability to produce sperm or ejaculate and lead to infertility. It is possible for you to store some sperm before treatment so that they can be used later to fertilise an egg. Other infertility treatment options are also available. There is no age limit to storing your sperm for your own use. Sperm banking and fertility treatment are usually available on the NHS, although in some cases you need to pay.

For more information about sex, erectile dysfunction and fertility read our Tool Kit fact sheet, **Sex and prostate cancer**.

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Or contact the Sexual Advice Association, Relate or the College of Sexual and Relationship Therapists.

Side effects of hormone therapy

Hormone therapy for prostate cancer can cause a number of physical and emotional side effects. For many men these side effects can be difficult to adjust to. Side effects of hormone therapy might include:

- Loss of sex drive (libido)
- Tiredness (fatigue)
- Changes to your mood. For example feeling more irritable or emotional
- Risk of heart disease, diabetes and bone thinning
- Hot flushes
- Breast swelling and tenderness (gynaecomastia)
- Weight gain
- Strength and muscle loss
- Forgetfulness and problems with concentration

i You can read more about these and ways to help manage or reduce them, in our booklet, **Living with hormone therapy: A guide for men with prostate cancer.**

A personal experience...

“Our love making has improved in ways that are very fulfilling, despite lack of penetration.”

Pain

In the early stages of prostate cancer, pain should not be a significant issue. After surgery (radical prostatectomy) men may experience pain in the weeks they are recovering, but pain-relieving drugs such as paracetamol or codeine can help.

If you have prostate cancer that has spread outside of the prostate gland (advanced prostate cancer) you might experience some pain that needs controlling. This is normally because the cancer has spread to the bones. The growth of the cancer within the bone damages the bone structure and tissue and can cause pain.

You should not have to put up with pain, even if your prostate cancer is more advanced. Let your specialist team or GP know if you have any pain as soon as possible. They should investigate the cause of your pain and then offer you the most suitable treatment. It is important to get any pain you have checked out, as it may not be caused by cancer.

What can help?

Pain-relieving drugs

There are different kinds of pain-relieving drugs. Mild pain-relieving drugs such as paracetamol or non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen can work well. If you are in moderate to severe pain, drugs called opioids (codeine or morphine) can help.

Some men are worried about becoming addicted to stronger pain-relieving drugs like morphine. If you are taking morphine for the right reasons (pain) then addiction is unlikely. Remember, you might not have to start with the strongest type of pain-relieving drugs. Some men find that milder drugs such as paracetamol and ibuprofen are enough to control their pain.

Pain-relieving drugs, especially opioids, may cause side effects.

Other treatments

If your pain is caused by the prostate cancer spreading to your bones then treatments to shrink or control the cancer may help reduce pain. For example, hormone therapy or palliative radiotherapy. Medicines such as steroids and bisphosphonates may also help.

- i** Read our Tool Kit fact sheet, **Pain and advanced prostate cancer**, for more information about ways to manage pain and the possible side effects of pain-relieving drugs.

Risk of other health problems

Prostate cancer and its treatment can increase the risk of other health problems in some men. There are things you can do to help reduce these risks.

Bone thinning

Long term treatment with some types of hormone therapy (LHRH agonists or surgery to remove the testicles) can make your bones weaker. If this is severe it can lead to a condition called osteoporosis which can increase your risk of bone fractures. If you already have osteoporosis, have a family history of osteoporosis or have had fractures in the past, talk to your doctor before you start treatment with LHRH agonists or orchidectomy. You should also tell your doctor if you are taking any other medicines in case they increase your risk of osteoporosis.

Risk of heart disease and diabetes

Some studies have found that men receiving hormone therapy have an increased risk of heart disease and diabetes.

Self management

i You can help to reduce your risk of heart disease and diabetes by having a healthy diet and lifestyle. See page 25 for more information about diet and physical activity. Find out more about these health conditions by contacting the British Heart Foundation or Diabetes UK.

i Make sure you have enough vitamin D and calcium in your diet as this can help reduce the risk of osteoporosis. Your specialist team may discuss you taking vitamin D and calcium supplements to help with your bone health. More information about treatment for osteoporosis is available from the National Osteoporosis Society.

Metastatic spinal cord compression (MSCC)

Metastatic spinal cord compression (MSCC) happens when cancer cells grow in or near to the spine and press on the spinal cord. MSCC can happen in men with advanced (metastatic) prostate cancer that has spread outside of the prostate gland to the bones but it is rare. If you have advanced prostate cancer and want to know more about this read our fact sheet,

i **Metastatic spinal cord compression (MSCC).**



Diet and physical activity

By eating healthily and keeping active you can start to actively do something to improve your general health.

Diet

A healthy diet will benefit your overall health and reduce your risk of medical problems such as heart disease and diabetes. The research about prostate cancer and diet is limited and we are unsure how different foods affect the growth of prostate cancer. There is some evidence that certain foods such as tomatoes, pomegranate juice, vegetables from the cabbage family, soy, green tea and omega-3 fatty acids (found in nuts, oily fish and some vegetable oils) may slow down the growth of prostate cancer or reduce the risk of it returning after treatment. But we need more research to show clearly how diet can help men who have been diagnosed with prostate cancer. You can read more about diet and prostate cancer in our Tool Kit fact sheet, **Diet, exercise and prostate cancer**.

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How can I improve my diet?

Start by making small changes that you feel comfortable with, for example eating more fruit and vegetables. Set yourself realistic goals, make changes gradually and make sure you still

enjoy your food. Most people can get all the nutrients they need by eating a balanced diet rather than taking food supplements.

For a healthy diet:

- **Base your meals on starchy foods** like potatoes, bread, rice, pasta, plantain, sweet potato and yam. Try wholegrain options such as wholemeal bread, wholewheat pasta, brown rice and wholegrain breakfast cereals. These are high in fibre and also help you to feel full for longer.
- **Eat at least five portions of fruit and vegetables each day.**
- **Include some protein**, like fish, skinless chicken and pulses.
- **Eat less saturated fat.** There are different types of fat. Unsaturated fats (known as monounsaturated and polyunsaturated fats) are healthier, and are found in nuts, oily fish, vegetable oil and olive oil. Saturated fats are less healthy and are found in meat and meat products, dairy products such as butter and cheese, and processed foods such as cakes, biscuits and pastries. Eat foods that are low in saturated fat and higher in monounsaturated and polyunsaturated fats.
- **Cut down on sugar**, including sugar hidden in soft drinks and processed foods such as cakes and biscuits.
- **Cut down on salt.** Eat less than one and a quarter teaspoons each day and look out for hidden salt in processed foods. Try using pepper, herbs and spices instead of salt to add flavour when cooking.
- **Drink six to eight glasses of fluid each day** (two litres or three to four pints). This includes any soft drink, not just water. It does not include alcoholic drinks such as wine or spirits. Avoid sugary or fizzy drinks.

If you are having difficulty eating enough and you are losing weight, ask your GP to refer you to a dietitian who can give you further advice.

Ask your GP or specialist team to refer you to a dietitian if you are making big changes to your diet or if you have any other medical conditions that could be affected by your diet, such as diabetes.

Physical activity

Physical activity is important for general health. It can help you to stay a healthy weight by burning up extra energy which would otherwise be stored by the body as fat. It is not clear whether physical activity can help to slow down the growth of prostate cancer, but it can help with some of the side effects of treatment (see page 9). It can also help you cope with feelings of anxiety or depression.

How much physical activity should I do?

The amount of physical activity you are able to do will depend on the stage of your cancer and what treatment you are having, as well as your fitness levels. Even a small amount of exercise can be beneficial. Find an activity that you enjoy. Start gently, and gradually increase the amount that you do as you become fitter. Exercise at your level of fitness, take things at your own pace and rest when you feel you need to.

It is safe for men with prostate cancer and those having treatment to exercise. Speak to your GP or specialist team before you start any kind of exercise plan and get advice about keeping active safely.

What sort of physical activity should I do?

Try and work towards doing 150 minutes (two and a half hours) of moderate physical activity each week. One way you could approach this is by doing 30 minutes of physical activity five times a week. Moderate physical activity will raise your heart rate, make you feel warmer and breathe harder. But you should still be able to hold a conversation. Also try and include muscle strengthening and balance activities such as lifting weights, gardening or yoga, at least twice a week.

- Try walking, swimming, cycling or gardening.
- Get off the bus one stop earlier, or walk upstairs rather than using the lift.
- You can even exercise from your chair or bed. Try lifting and stretching your arms and legs, which can help improve your movement and muscle strength.
- If you are trying to lose weight, following an exercise programme such as walking 10,000 steps a day can be useful. This gives an indication of the amount of exercise you should aim to build up to. You can get more information about walking 10,000 steps a day from NHS Choices.
- If you are on hormone therapy, regular exercise may help to keep you strong and prevent falls which could lead to bone fractures. Gentle resistance exercise, which includes fast walking and exercising with small weights can be particularly helpful. High impact exercises such as running are not recommended if you are on hormone therapy.

You can get help with increasing your physical activity. Speak to your GP or specialist team, who will be able to give you

advice about what type of exercise is appropriate for you. You could also ask to be referred to an exercise programme or a physiotherapist where you can get further advice.

Exercise safely

- Be careful to avoid falls, especially if you are on hormone therapy which can increase your risk of bone thinning.
- Wear properly fitting clothing and trainers, and do not exercise on uneven surfaces.
- Make sure you drink enough water and do not get dehydrated.
- Do not exercise if you feel unwell, have any pain, sickness or any other unusual symptoms. Stop if you experience any of these while exercising.
- If you are having radiotherapy and have any skin irritation, avoid swimming pools as the chlorine can make this worse.

A personal experience...

“Although I’d always been active, my outlook on life changed with my cancer diagnosis. I joined my local walking club. Not only has this taken me on some wonderful walks in the hills and introduced me to some lovely parts of the country that I didn’t know existed, it’s helped me to keep fit and I’ve made loads of new friends. The walks are graded and I worked my way up the grades as I got fitter.

It’s been six years since my initial cancer treatment and I think my active lifestyle and healthy diet helped me to remain so well for so long. I’ve had to lower my expectations recently, but I still go for walks and cycle rides when I can.”



Prostate cancer and your feelings

This section is about the impact that living with prostate cancer can have on your feelings. Even if your treatment has finished you may need to get some emotional support. Partners and family members and friends also need support. There is no right or wrong way to feel and each person's response to living with prostate cancer will be different.

If you have prostate cancer it is not unusual to feel worried or low. But if you have had treatment for prostate cancer you are at an increased risk of depression and anxiety. If you are feeling very down or worried and are finding it difficult to cope, speak to your GP or specialist team. There are treatments and support available. If you need to speak to someone immediately you could ring the Samaritans on 08457 90 90 90.



Common feelings

Getting the diagnosis

Men respond in all kinds of ways to being diagnosed with prostate cancer. Some men feel shocked, frightened or angry. If you feel well you may not believe that you have prostate cancer. It can also be difficult to decide what treatment to have and you might feel stressed. All of these emotions are normal

reactions to a diagnosis of cancer. These feelings may stay with you, but some men find their feelings gradually change.

Changes

Finding out that you have prostate cancer may have changed the way you thought about yourself, your life and your plans. It can also change the plans of those close to you, for example if you have a partner. These changes can be frustrating and disappointing. You could also be coping with changes to your everyday routine, for example, taking time off work or travelling to and from treatments. If you have finished treatment for prostate cancer you could feel isolated, especially if you are no longer seeing your specialist team.

Coping with side effects of treatment

If you have side effects like erection, urinary and bowel problems, coping with these can make you feel down or worried.

If you are on hormone therapy, then reduced testosterone levels can contribute to a low mood. Hormone therapy can also cause physical changes to your body, such as putting on weight, or changes to your sex life. This may make you feel very different

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.”

about your body and cause a sense of loss. Sometimes men describe feeling less masculine because of their diagnosis and treatment.

Living with uncertainty

Men who are not having treatment but who are having their cancer monitored may find it difficult living with prostate cancer and worry that it may change or spread. Men having treatment may also feel worried. Even after treatment has finished men may feel anxious and find it difficult to move on and think about the future.

What can help?

There is no right or wrong way to deal with your feelings. Try to go easy on yourself, and do not expect to have all the answers. Take some time to think about what is bothering you, find out about the options available and pick one that suits you.


Some men find their own way to cope and might not want any outside help. Other men try to cope on their own because they are too embarrassed or afraid of worrying loved ones. Sometimes talking about any troubling feelings can help you to cope with them. One study found that men who talked about their emotions experienced a greater sense of wellbeing.

A personal experience...

“I’m always worried when my appointment is due. You never know if it’s going to come back.”

Health professionals


You could talk to your nurse, doctor or any other health professionals you see about how you are feeling. You can also

 call our confidential Helpline and speak to a specialist nurse.

Family and friends

You may already have your own support network. Talking to your partner, family and friends can help take some of the pressure off you.

A common worry for men with prostate cancer is how to tell their family or friends that they have cancer. A good way to overcome the worry is by talking, but this is not always easy. It can be

 difficult to know where to start. Macmillan Cancer Support produce information that can help.

Support groups

You might like to get in touch with your local prostate cancer support group. Support groups can be a good way for you to meet people with similar experiences. They can also help you feel more positive, in control and in some men help relieve feelings of depression and anxiety. These groups are often set up by local health professionals, or by people who have experience of prostate cancer. Meetings are usually informal and offer an opportunity to find out about other people's experiences as well as discussing your own thoughts and concerns. Many support groups also welcome partners, friends and relatives.

If you have access to the internet, you may also like to sign up to The Prostate Cancer Charity online community, where you can share your views and experiences with others affected by prostate cancer.

Visit our website at www.prostate-cancer.org.uk to sign up to the online community and to find a list of some support groups in the UK. Or call our confidential Helpline for more information.

One-to-one telephone peer support

Not everyone feels comfortable going to a support group. If you prefer speaking to someone one-to-one then you could try our telephone peer support service. Call our confidential Helpline and a specialist nurse will match you, where possible, with one of our volunteers who may have had similar experiences or treatments. Our volunteers include both men and women whose lives have been affected by prostate cancer either as a patient, partner or other family member.

Counselling

It can sometimes be difficult to speak to those close to you because you do not want to upset them, or because you are finding it hard to show your emotions. Some people find it easier to talk to someone they do not know. Counsellors are trained to listen and can help you to understand your feelings and find your own answers. Your GP may be able to refer you to a counsellor or you can see a private counsellor. To find out more contact the British Association for Counselling and Psychotherapy or the UK Council for Psychotherapy.

Medicine

Sometimes anti-depressant medicine can be helpful for people who have cancer and are depressed. Before you start taking anti-depressants, it is important that your GP or specialist team know about any other medicines or natural remedies you are taking.

Self-management of anxiety and depression

- Learning ways to relax such as yoga or meditation could help your mood.
- Exercise may help ease feelings of anxiety or depression.
- Try keeping up with your usual hobbies and social activities or try some new ones. Some men say that this helps them stay happy and relaxed.
- Look for courses to learn ways to manage side effects, feelings and relationships. Macmillian Cancer Support, The Expert Patients Programme and Penny Brohn Cancer Care offer free courses.

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Relationships

Prostate cancer can change the normal pattern of your life and have an impact on your relationships, particularly with your partner. It can bring challenges, but can also bring some couples closer together.

You and your partner may experience some of the following issues:

- Changing priorities
- Interrupted plans
- An uncertain future together
- Side effects, like tiredness, changing the normal roles of your relationship
- Intimacy issues and changes to your sex life

Some couples find that they can deal with these issues, learn to live with them or overcome them. Some general things that might help include:

- A good wider support network so you are not only relying on each other. This might be other family, friends or health professionals.
- If you have practical pressures to do with work, money or household tasks, make sure you get some advice or help.

A personal experience...

“Before we set up these massive goals. Now my partner isn't as well as he was and things are different.”

- Getting support for any relationship or communication difficulties.
- Making sure that any other side effects you are experiencing, such as tiredness, are well-managed.

Talking about it

If you have a partner, or are starting a new relationship, try and talk to them about how you are feeling. Talking could help you and your partner 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, emotional and practical changes you are going through.

Sometimes talking more is easier said than done, especially during stressful times. In particular, talking about sex can be difficult, even for a couple who have known each other for a long time. Some couples find that they need some further support. Relationship therapy can help. Some hospitals can offer specialist counselling. Contact your specialist team or GP if you would like to see a counsellor.

i You might like to read our Tool Kit fact sheet, **Sex and prostate cancer**, for more information or contact the Sexual Advice Association, Relate or College of Sexual and Relationship Therapists.

A personal experience...

“One of the biggest difficulties I think he had was the fact that we could talk about lots of issues relating to it, but he couldn’t really talk about the sexuality issues.”

i You may also find it useful to watch our DVD **Couples: Facing prostate cancer together**. It explores some of the issues facing men with prostate cancer and their partners, families and friends. The script is taken directly from interviews with people affected by prostate cancer.

You can order it from www.prostate-cancer.org.uk or by calling our confidential Helpline.

A personal experience...

“I work full time, and when I come home, if he is really worn out, then it’s difficult sometimes for me to accommodate that. Where is our time?”



Support for partners, family and friends

This section is for anyone who is close to a man with prostate cancer, such as partners, families or friends. The diagnosis of a loved one can have a big impact on your life and you may need support and information.

You may have had to take on more responsibilities, for example making sure your partner, relative or friend has information about treatments, keeping track of appointments, asking health professionals questions and taking on more tasks at home.



You may also be giving emotional support and in some cases providing medical and personal care. At the same time as all of this, you could be dealing with your own feelings, such as shock, worry, and loneliness. You could still be living with these feelings even if your partner, relative or friend no longer has prostate cancer.

A personal experience...

“I have always seen Dad as a big, strong, nothing-can-affect-him sort of character, and when I see that something actually has affected him and upset him... it is hard, it is really hard.”

What can help?

If you are feeling unwell, tired or down make sure that you see your own GP and get checked out. You may be able to get support through your friends and family, or you could:

- Meet other partners, family members and friends of men with prostate cancer at support groups. Or you can be put in touch with someone experiencing similar issues through our one-to-one peer support service.
- See a counsellor on your own to talk things through, especially if you have different needs and concerns from your partner, family member or friend. See page 35 for details of counselling.
- Read pages 48 to 51 of this booklet to find out more about practical help you could get with money and help in the home.
- Learn new skills that will help you look after yourself. Contact  The Expert Patient Programme or Carers UK who run courses for people who live with or care for someone with a health condition or disability.
-  Macmillan Cancer Support has a number of booklets for people who are close to someone with cancer.

A personal experience...

“I think it was a very shared illness. I went to every meeting with the oncologist and joined the support group as well.”

Getting information


Some partners and family members of men affected by prostate cancer find that learning more about prostate cancer is helpful.

Knowing more about prostate cancer diagnosis and treatment can help partners:

- Feel more confident about talking to health professionals
- Gain a better understanding of what to expect and things to look out for, such as side effects of treatment

Some partners and family members find that supporting someone with prostate cancer in making changes to his lifestyle, such as eating a healthier diet and being more physically active gives them a sense that they are doing something to help. Bear in mind that not all men will want or be able to make these changes.

All the fact sheets and booklets that we produce and our Helpline are also there for you if you are a partner or family member or friend of a man with prostate cancer. See

 page 52 for more information about our confidential Helpline and our publications.

A personal experience...

“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.”



Daily life and prostate cancer

This section is about work, money issues and other practical issues like getting around and help at home.

Work

How can prostate cancer affect my working life?

You may need to take time off work for treatments. This includes time for travelling to hospital and in some cases time to recover. If you have surgery (radical prostatectomy) you may need to take two to eight weeks off work. You will need to avoid climbing too many stairs, lifting heavy objects or doing manual work for eight weeks after the operation. Ask your specialist team for advice on how much time you will need to take off.

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

Can I continue working?

People living with and after cancer may feel that continuing to work or returning to work helps their recovery and return to

normal life. Not everyone is able to continue working, and some men decide to work part-time, or take early retirement.

If you are a man with prostate cancer the Equality Act 2010 covers you. The Equality Act is a law that protects anyone who has, or has had, a disability. If you have cancer you are classed as disabled under the Equality Act. Even if you no longer have cancer, you will continue to be protected against discrimination at work.

Under the Equality Act your employer has a duty to make reasonable adjustments to workplaces and working practices to make sure that you get the same chances as the people you work with.

Some examples of reasonable adjustments include:

- Allowing you time off to attend medical appointments
- Allowing extra breaks
- Temporarily allowing you to have lighter duties
- Providing adequate toilet facilities

You can find out more about the Equality Act and working during and after cancer treatment from Macmillan Cancer Support.

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Most employers will be helpful and support you if you take time off work and if you return. Where problems come up it might be due to misunderstandings. Some men say that even though they have prostate cancer, they still 'look okay' so their boss does not understand that they are feeling unwell.


Self-management

If your employer learns more about prostate cancer and its treatment they may be more understanding. If you do not feel like talking about it then perhaps you could give them some of our publications to read.

Take a look at your company policies and employee handbook if you have one. 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, changing your job role or duties for a while.

Know your legal rights. Find out more about the Equality Act and make sure your boss or company is aware of it. You could also contact your union if you are part of one.

 If you are self-employed or if you are looking for work you can get more specific information from Macmillan Cancer Support or the charity RADAR.

A personal experience...

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

Money

If you are struggling with the financial costs of cancer, or your income has changed, you should be able to get some help.

Sick pay

If you have had time off work, find out if statutory sick pay and occupational or company sick pay are relevant to you. Check your employment contract or contact the Benefit Enquiry Line on

i 0800 882 200 or DirectGov online.

Benefits

The benefits you are entitled to will vary depending on whether you are working, how old you are and other factors.

You could also be entitled to help with housing costs such as mortgage interest payments, services charges or ground rent.

i To get more information about benefits and how to apply for them:

- Call the Benefits Enquiry Line on 0800 882 200 or visit DirectGov online.
- Visit your local Citizen's Advice Bureau, who offer free, independent, confidential and impartial advice.
- Call Macmillan Cancer Support to find out if you have a local Macmillan Cancer Support Benefits service.

Other costs

Financial help may also be available to cover travelling to and from hospital and other medical costs. You may also be entitled to free prescriptions.

- i** Contact Macmillan Cancer Support for more information.

Travel insurance

Some men have told us that they find it hard to get travel insurance because of their prostate cancer diagnosis. Our Tool

- i** Kit fact sheet, **Travel and prostate cancer**, gives tips on buying travel insurance.

Grants

Grants from other charities or organisations are available.

- i** Contact Turn2us for advice about grants that may be available.

Self-management

- i** Try to maximise your money coming in, reduce money going out and manage any debts. The charity RADAR produce information that may help and tells you where to get further advice.

An independent financial adviser can let you know which companies offer the best life assurance, mortgages, pensions and other financial services for your situation.

Driving and public transport

The Blue Badge Scheme gives parking benefits to people with a disability who find it very hard to walk. If you use public transport, in some cases you can get discounts and free travel. Contact your local council for more details. To find your local council's

i contact details visit DirectGov online or look in the phone book.

The Motability Scheme can help you with leasing or buying a car if you are receiving certain benefits. Even if you do not drive yourself, you can apply for a car as a passenger and propose two other people as your drivers. You could also be eligible to get help to adapt the car you already have to make it more

i suitable. Contact DirectGov for more information.

In the home

Some men with prostate cancer have told us that they have difficulty carrying out their usual activities. This may be because of side effects like pain, or because they are not as mobile as they used to be.

If you think you could do with some extra help in the home, get in touch with your local authority's social services department or your GP to see if they can give you some advice or support. You can find the telephone number of your social services department from the town hall, or in the phone book under the name of your local authority.

You can ask social services for an assessment. This is to see whether you or your carer, if you have one, need any services. This includes:

- Equipment or adaptations to your home
- Help at home, for example with getting dressed, cooking or tasks like housework or shopping
- Breaks away from home for you or anyone who is caring for you

Your local social services department can refer you to an occupational therapist (OT). They can help you overcome any practical problems that you might have and help you live as independently as possible. They can assess whether you need help at home or work and give advice about equipment or adaptations to the home. A social worker can give you advice about practical issues such as money, work and things to make day-to-day living easier. Your specialist team or GP could also arrange for you to meet an occupational therapist or social worker.

Community health services


Community, district and Macmillan nurses can offer medical care at home and give you or your partner or family advice on ways to look after yourself. You may also be able to arrange to have other care staff visit you at home. You can arrange this through your GP or other health professionals.

The Prostate Cancer Charity

The Prostate Cancer Charity is the UK's leading charity working with people affected by prostate cancer. We fund research, provide support and information, and we campaign to improve the lives of men with prostate cancer. Our vision is a world where lives are no longer limited by prostate cancer.

Confidential Helpline

If you have any questions about prostate cancer or other prostate problems call our confidential Helpline to speak to a specialist nurse.



Confidential Helpline
0800 074 8383*
Mon - Fri 10am - 4pm, Wed 7pm - 9pm

You can also send your questions to our specialist nurses by using our Helpline email contact form.

Visit www.prostate-cancer.org.uk

Leaflets and booklets

Other leaflets and booklets about living with prostate cancer can be ordered free of charge from The Prostate Cancer Charity.



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

Tool Kit

The Tool Kit information pack contains fact sheets that explain how prostate cancer is diagnosed, how it is treated and how it may affect your lifestyle. Each treatment fact sheet also includes a list of suggested questions to ask your doctor.

-  To order these publications call our **Helpline on 0800 074 8383** or email us at **literature@prostate-cancer.org.uk**. You can also download all of our publications from our website at **www.prostate-cancer.org.uk**.

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More information

The following organisations may be able to offer you, your partner or your family further support and information.

AGE UK

www.ageuk.org.uk

Telephone: 0800 169 6565 (8am-7pm)

Information or advice for older people on anything from health to housing.

Benefit Enquiry Line

www.direct.gov.uk/disability-money

Freephone: 0800 882 200

Advice and information about benefits for disabled people and carers.

The Bladder and Bowel Foundation

www.bladderandbowelfoundation.org

Nurse helpline: 0845 345 0165 (24 hour answer phone service).

Information about bladder and bowel related problems.

Confidential advice and support from helpline nurses. Details of local NHS services.

British Association for Counselling and Psychotherapy

www.bacp.co.uk

Telephone: 01455 883316

BACP will help you find counsellors.

British Dietetic Association

www.bda.uk.com

Telephone: 0121 200 8080

Information on finding a registered dietitian and following a healthy diet.

British Heart Foundation

www.bhf.org.uk

Heart Helpline: 0300 330 3311 (9am-5pm, Mon-Fri)

Information about heart disease and eating for a healthy heart.

Carers UK

www.carersuk.org

Carers line: 0808 808 7777 (10-12am and 2-4pm, Wed & Thurs)

Information and advice for carers including signposting to support groups.

Citizen's Advice

www.citizensadvice.org.uk

Helps people resolve legal, money and other problems by providing free information and advice. Find the contact details for your local Citizen's Advice Bureau on their website or in the phone book.

College of Sexual and Relationship Therapists (COSRT)

www.cosrt.org.uk

Telephone: 020 8543 2707

Information on sexual and relationship therapy, including a list of therapists.

The Complementary and Natural Healthcare Council (CNHC)

Telephone: 020 3178 2199

83 Victoria Street, London SW1H 0HW

Provides details of complementary therapy practitioners who meet national standards of competence and practice.

Diabetes UK

www.diabetes.org.uk

Careline: 08451202960 (9am-5pm, Mon-Fri)

For information about diabetes

DirectGov

www.direct.gov.uk

Information and practical advice about public services such as money, benefits, work and help at home.

Expert Patients Programme

www.expertpatients.co.uk

Freephone: 0800 988 5550

Offer free self-management courses to help you to take control of your health and manage your condition better on a daily basis.

Macmillan Cancer Support

www.macmillan.org.uk

Freephone Cancerline: 0808 808 2020 (9am-9pm, Mon-Fri)

For support and information about cancer, including financial advice.

Maggie's Centres

www.maggiescentres.org

Telephone: 0131 537 2456

A network of drop-in centres across the UK for people affected by cancer.

Marie Curie Cancer Care

www.mariecurie.org.uk

Freephone 0800 716 146 (9am-5.30pm, Mon-Fri)

Marie Curie run hospice centres throughout the UK and provide a nursing service for patients in their own home day and night, free of charge.

NHS Choices

www.nhs.uk

Includes an A-Z of treatments and conditions and information on NHS health services in your local area.

National Osteoporosis Society

www.nos.org.uk

Helpline: 0845 450 0230 (9am-4.30pm, Mon-Thurs)

Provides a nurse-led helpline about osteoporosis.

Penny Brohn Cancer Care

www.pennybrohncancercare.org

Helpline: 0845 123 23 10 (9.30am-5pm, Mon-Fri)

Complementary care for people with cancer and their families.

RADAR

www.radar.org.uk

Telephone: 020 7250 3222

Provides practical information for people affected by disability.

Relate

www.relate.org.uk

Telephone: 0300 100 1234

Relationship counselling, sex therapy and other support services.

Sexual Advice Association

www.sda.uk.net

Helpline: 0207 486 7262 (9am-5pm Mon, Wed and Fri)

Detailed information on treatments for erectile dysfunction.

Samaritans

www.samaritans.org

Helpline: 0845 790 9090 (Open 24 hours a day)

Offers confidential emotional support to anyone in the UK.

Turn2US

www.turn2us.org.uk

Free and confidential helpline: 0808 802 2000

(8am-8pm, Mon-Fri)

Helps people access the money available to them through welfare benefits, grants and other help.

UK Council for Psychotherapy

www.psychotherapy.org.uk

Telephone: 020 7014 9955

A national register of psychotherapists and counsellors and gives information to help you choose a therapist.

References to sources of information used in the production of this booklet are available at www.prostate-cancer.org.uk

The Prostate Cancer Charity makes every effort to provide up-to-date, unbiased and accurate facts about prostate cancer. We hope that these will add to any medical advice you have had. Please continue to talk to your doctor if you are worried about any medical issues.

The Prostate Cancer Charity is the UK's leading charity working with people affected by prostate cancer. We fund research, provide support and information, and campaign to improve the lives of men with prostate cancer. If you would like to make a donation to support our work, please call 020 8222 7666 or visit www.prostate-cancer.org.uk/donations

Tell us what you think

We hope you have found this information useful. If you have any comments or suggestions about any of our publications, you can email literature@prostate-cancer.org.uk or write to The Information team at The Prostate Cancer Charity, 100 Cambridge Grove, London W6 0LE



The Prostate Cancer Charity

London

Cambridge House
100 Cambridge Grove
London W6 0LE
Email: info@prostate-cancer.org.uk
Telephone: 020 8222 7622

Glasgow

Unit F22-24 Festival Business Centre
150 Brand Street
Glasgow G51 1DH
Email: scotland@prostate-cancer.org.uk
Telephone: 0141 314 0050



Confidential Helpline

0800 074 8383*

Mon - Fri 10am - 4pm, Wed 7pm - 9pm

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