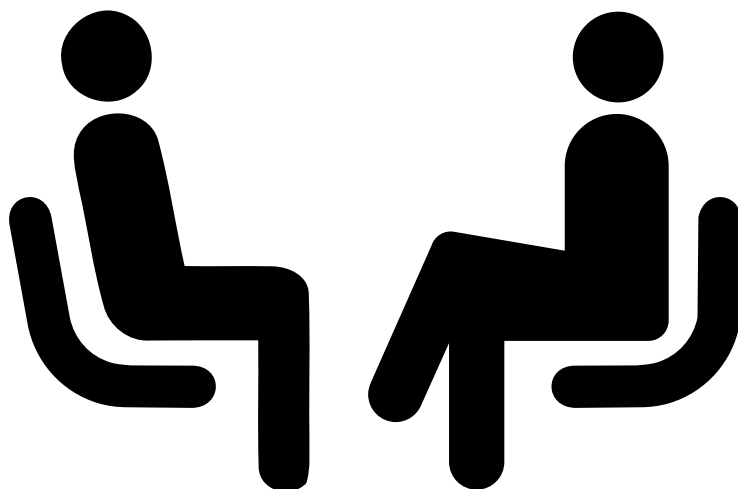


Follow-up after prostate cancer treatment

What happens next?



**PROSTATE
CANCER UK**

About this booklet

If you've had treatment aimed at getting rid of your prostate cancer, such as surgery (radical prostatectomy), radiotherapy or brachytherapy, you will have regular check-ups afterwards to check your progress. This is often called follow-up.

In this booklet, we describe the care and support you can expect after your treatment. There's also space to fill in details of your treatments, your follow-up plan, and a diary for your appointments. Your partner, family or friends might also find this booklet helpful.

Each hospital will do things slightly differently. Use this booklet as a general guide and ask your doctor or nurse for more details about your treatment and the support available to you. You can also speak to our Specialist Nurses, in confidence, on 0800 074 8383.

This booklet doesn't have information about treatments for advanced prostate cancer, such as life-long hormone therapy or chemotherapy. If you have advanced prostate cancer, you can find lots of information at prostatecanceruk.org/advanced

The following symbols appear throughout the booklet:



Our Specialist Nurses



Our publications



Sections for you to fill in

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Follow-up: an overview

After you've finished treatment for your prostate cancer, you will still have regular appointments to check your progress. These are known as follow-up appointments or check-ups. The aim is to:

- check how your cancer has responded to treatment
- check that your wounds have healed, if you've had an operation
- help you deal with any side effects of treatment
- give you a chance to raise any concerns or ask any questions.

Is my cancer cured?

Although you've had treatment aimed at getting rid of your prostate cancer, your doctor or nurse won't usually use the word 'cure'. Instead, they may say you're 'in remission'. This means there is no sign of cancer.

Unfortunately, your doctor or nurse can't say for certain whether or not your cancer will come back. Each cancer is different, and the success of your treatment will depend on many things. But they can tell you how you are doing and what is expected.

When and where will I have my appointments?

Your follow-up appointments will usually start two or three months after finishing treatment. You will then have appointments every three to six months. Around two years after your treatment, you may start to have appointments less often. Each hospital will do things slightly differently, so ask your doctor or nurse for more details about how often you will have follow-up appointments.

If your treatment was part of a clinical trial, how and when you have follow-up appointments will vary. The research nurse or doctor will give you more information about your follow-up plan.

Where you have your appointments will depend on the services in your area and on your own situation. Follow-up appointments could be:

- at the hospital where you had your treatment
- at another hospital closer to where you live
- at your GP surgery
- on the phone to your doctor or nurse, rather than going to the GP surgery or hospital.

The place where you have your follow-up appointments may change. For example, you might have your first few appointments at hospital and then be offered follow-up at your GP surgery.

Wherever you have your appointments, you should be given the details of someone to contact at any time if you have any concerns, such as new symptoms or side effects.

Remote follow-up

If your PSA level remains stable six months after treatment, you might be able to have your PSA levels checked remotely.

You'll still have PSA tests done at the hospital or your GP surgery, but you won't have to go back again to get your results. Instead, your hospital doctor, nurse or GP will telephone or write to you about the results, or just to let you know that they don't need to see you. Depending on where you live, you may be able to check your results on an online portal. Your doctor or nurse at the hospital will tell you what kind of follow-up you will have.

If your PSA rises, you will be given an appointment to talk about what this might mean. This could be by telephone or at the hospital.

You may prefer this type of follow-up, as it means you can avoid going to hospital appointments when you're feeling well and don't have any concerns.

Your doctor or nurse will give you information about the possible side effects of your treatment and any symptoms to look out for. They will also give you details of who to call if you notice any changes. You, or your doctor or nurse, can arrange an appointment at any point if you have any questions or concerns.

Self-management

Some hospitals may give you fewer follow-up appointments. They will encourage you to take greater control of your own health and wellbeing. This is sometimes called self-management.

You may be able to see your results online. You might also be given a support worker who will be your main contact during your follow-up care. Some hospitals provide workshops to help you develop the knowledge, skills and confidence to take care of your health.

Who will I see?

If you have your follow-up appointments at a hospital, you will see a member of your multi-disciplinary team (MDT). This is the team of health professionals involved in your care. You might hear it called your specialist team. You might not see the same person each time, but they should have information about you.

The team usually includes:

- a specialist nurse
- a urologist (a surgeon who specialises in problems with the urinary and reproductive systems)
- an oncologist (a doctor who specialises in cancer treatments other than surgery, such as radiotherapy)
- a radiographer (a health professional who specialises in helping to plan and give radiotherapy).

If you have your appointments at your GP surgery, you will see your GP or a practice nurse. If there is any sign of your cancer coming back, they will refer you back to the hospital.

Your main contact (key worker)

After your treatment, there will usually be one person who is your main contact for your follow-up care. This might be your specialist nurse, hospital doctor, GP, radiographer, or another health professional. They are often called your key worker.

They help coordinate your care, answer your questions, and can help you get information and support. Make sure you know the name of your main contact and how to get in touch with them. In this booklet when we talk about your doctor or nurse, we are usually talking about this main contact. Remember you can also call our **Specialist Nurses** for information and support.



What happens at a follow-up appointment?

Discussion with your doctor or nurse

At each appointment, your doctor or nurse will ask how you've been since your last appointment.

Tell them about any symptoms or treatment side effects you've had, as well as any other problems or concerns. You can tell them how you're feeling emotionally as well as physically. You can also discuss any practical problems you might have, such as problems at work or with day-to-day activities. You may be given a questionnaire about your physical, social, emotional and practical needs. You might hear this called a holistic needs assessment (HNA) form.

Your GP or hospital doctor or nurse can help you deal with side effects or refer you to someone else who can. For example, if you have problems with leaking urine (incontinence), they might refer you to a continence service. Or if you have problems getting or keeping erections (erectile dysfunction), they can refer you to an erectile dysfunction (ED) service if this is available in your area. They can also help you get support for emotional problems, such as feeling anxious or depressed, and practical problems, such as managing your finances.

You might feel embarrassed talking about some of the side effects of treatments, such as erection problems. But remember – doctors and nurses see people with these problems every day, so be as open as you can. They are there to help. See page 12 for more information about side effects.

PSA blood test

This measures the amount of a protein called prostate specific antigen (PSA) in your blood. You will usually have one done a week or two before your appointment, so that the results are available at your check-up. You will be told when to make an appointment for the test. It might be done at your GP surgery or at the hospital, depending on the services in your area.

You may be asked to avoid any vigorous exercise and ejaculating in the 48 hours before a PSA test, as this could cause a temporary rise in your PSA level.

Receiving anal sex or having your prostate stimulated during sex might also raise your PSA level. It might be worth avoiding these activities for a week before a PSA test.

The PSA test is a good way to check whether your treatment was successful at getting rid of your prostate cancer. A continuous rise in your PSA level can be the first sign that the cancer has come back. Page 19 has more information about PSA levels after different treatments. You can keep a record of your PSA levels on page 33.

Speak to your doctor or nurse if you think you've missed a PSA test, or if you are concerned about your PSA level.

Tips to get the most out of your follow-up appointments

- **Write down any questions or concerns beforehand.** It's easy to forget what you want to say once you're at your appointment. There's space for you to write down questions in the My follow-up plan section on page 34.
- **Bring someone with you.** It can be hard to take everything in at your appointments. Some people find it helpful to take someone with them, to listen and discuss things with later. If your appointment is on the phone, you could ask a friend or family member to listen with you.
- **Make notes.** It can help to write things down during or after your appointment. There's space for this in the appointment diary on page 36.
- **Ask to record your appointment.** You could do this using your phone or another recording device. Talk to your doctor or nurse first to make sure they are happy with you recording the appointment, as not everyone is comfortable being recorded.
- **Don't be afraid to ask for help.** If anything is bothering you, let your doctor or nurse know.
- **If your appointment is with a hospital doctor or nurse, ask for a copy of the letter they send to your GP.** This will happen automatically at some hospitals. It will help you remember what was said at your appointment. If you don't understand the letter, call your main contact at the hospital or our **Specialist Nurses**.



What happens between appointments?

Contact your doctor or nurse if you have any concerns or get any new symptoms or side effects between your follow-up appointments. There's space to write down their contact details on page 38.

It's important to speak to them if you're concerned about anything – don't worry about them being too busy. You can get support or advice over the telephone, or they might bring forward the date of your next follow-up appointment.

How long will my follow-up last?

You will have follow-up appointments for some time after your treatment. Exactly how long will depend on your cancer, what treatment you had, any side effects of treatment, and the services in your area. You will usually have appointments for several years.

After your follow-up appointments finish, you may continue to have PSA tests. Speak to your GP if you have any problems or concerns – they can refer you back to the hospital. Make sure you remind them about your prostate cancer, especially if it's been a while since you had treatment or a PSA test.



Accompanying my husband to all his appointments allowed me to understand everything that he was going through and how best I could help him.

A personal experience

Side effects of treatment

Treatments for prostate cancer can cause side effects that might carry on after your treatment has finished. Some side effects can start several months or years after treatment finishes.

Side effects will affect everyone differently, and you may not get all the possible side effects from your treatment.

Side effects can affect your day-to-day life, but there may be treatments for them. And there might be things you can do yourself to manage them. It's important to speak to your doctor, nurse or GP about them.

Prostate cancer diagnosis and treatment can also have an emotional impact on you, your partner, family or friends. Read more about this on page 24.

Surgery (radical prostatectomy)

The most common side effects of surgery are leaking urine (urinary incontinence) and problems getting or keeping an erection (erectile dysfunction).

It's common to leak urine after prostate cancer surgery. This is because surgery can damage the muscles and nerves that control when you urinate.

Leaking urine usually improves with time. Most people start to see an improvement one to three months after surgery. But others continue to leak urine for a year or more. This can be hard to deal with, but there are things that can help such as staying a healthy

weight and doing regular pelvic floor muscle exercises. If these don't work, there are treatments available that might help, including medicines and surgery.

After surgery, including nerve-sparing surgery, many men find it difficult to get an erection strong enough for sex. It can take anything from a few months to a few years for erections to return, and they may not be as strong as before surgery. Some men will always need medical help to get erections, such as tablets, a vacuum pump or injections. Some men might not be able to get erections even with medical help.



There are treatments and support to help with these side effects, as well as things you can do yourself. Read more in our fact sheets, **Surgery: radical prostatectomy** and **Urinary problems after prostate cancer treatment**, and in our booklet, **Prostate cancer and your sex life**.



The continence nurse made me feel very comfortable and gave me helpful advice.

A personal experience.

External beam radiotherapy

Radiotherapy can irritate the lining of the bladder and the urethra, which is the tube men urinate (wee) and ejaculate through. This can cause urinary problems, such as needing to urinate urgently or more often, and difficulty urinating. You might have problems getting or keeping an erection. And you may also get extreme tiredness (fatigue).

Some people also find that their bowel habits change. You might have loose or watery bowel movements (diarrhoea), need the toilet more often or more urgently, or leak mucus from your back passage (rectum). You might also have pain in your stomach area (abdomen) or back passage, or have bleeding from your back passage.

These side effects usually start during or soon after radiotherapy. For many people, side effects will begin to improve several weeks after treatment. But for some, these side effects will continue. Some people start to get side effects months or even years after radiotherapy has ended. Speak to your doctor or nurse if you have any side effects, so that they can help you manage them.



There are treatments that can help, as well as things you can do yourself. Read more in our fact sheets, **External beam radiotherapy**, **Urinary problems after prostate cancer treatment**, **Diet and physical activity for men with prostate cancer** and **Fatigue and prostate cancer**, and in our booklet, **Prostate cancer and your sex life**.

Brachytherapy

You might have had permanent seed brachytherapy (low dose-rate brachytherapy) or high dose-rate brachytherapy (HDR). The most common side effects of brachytherapy are urinary problems, such as difficulty urinating, needing to urinate more often or a sudden urge to urinate, and problems getting or keeping an erection. Some people also get bowel problems, which tend to be mild. You may also get extreme tiredness (fatigue), especially if you are having external beam radiotherapy or hormone therapy as well. These problems are generally at their worst a few weeks or months after treatment but usually start to improve after that. You may

develop urinary problems a few months after treatment, but these usually get better over time. You might have more side effects if you have brachytherapy and external beam radiotherapy together.



There are ways to manage these side effects. Read more in our fact sheets, **Urinary problems after prostate cancer treatment** and in our booklet, **Prostate cancer and your sex life**.

Hormone therapy

You may have had hormone therapy alongside your main treatment for prostate cancer. Side effects from hormone therapy can include hot flushes, extreme tiredness (fatigue), weight gain, breast swelling and tenderness, strength and muscle loss, mood changes, and changes to your sex life, such as loss of desire for sex.

For most people, side effects gradually improve after they stop hormone therapy. But it can take several months for them to wear off.



There are ways to manage these side effects. Read more in our booklet, **Living with hormone therapy: A guide for men with prostate cancer**.

Other treatments

High-intensity focused ultrasound (HIFU) and cryotherapy are less common treatments for prostate cancer. They can both cause erection problems and urinary problems.

Read more on our website, **prostatecanceruk.org/hifu** and **prostatecanceruk.org/cryotherapy**

Managing side effects from my treatment

You might have a meeting with your doctor or nurse to work out what support you need. This information may be included in your care plan, if you have one. Or you might find it helpful to record your side effects and ways to manage them below. Your doctor or nurse can help you fill this in.



Side effect	Things I can do myself	Treatment I am having for it (if any)

Further support with side effects

Read more about the side effects of treatment, including ways to manage them, in our other fact sheets and booklets (see page 39).



You can also call our **Specialist Nurses** on **0800 074 8383**.

If you're having problems with a side effect, your doctor or nurse might refer you to someone who can give you more advice and support. You can write down their details here.



Why?	Who?	Contact details
Emotional effects	Counsellor or psychologist	
Urinary problems	Urologist, continence service or physiotherapist	
Sexual problems	Erectile dysfunction (ED) clinic or sex therapist	
Bowel problems	Gastroenterologist	

Will my cancer come back?

For many men with localised or locally advanced prostate cancer, treatment is successful and gets rid of the cancer. But sometimes not all the cancer is successfully treated, or the cancer may have been more advanced than first thought. If this happens, your cancer may come back – this is known as recurrent prostate cancer. One of the aims of your follow-up appointments is to check for any signs that your cancer has come back. If your cancer does come back, there are treatments available that aim to control or get rid of the cancer.

The risk of your cancer coming back

Your doctor can't say for certain whether your cancer will come back. They can only tell you how likely this is.

When your prostate cancer was first diagnosed, your doctor may have talked about the risk of your cancer coming back after treatment. To work out your risk, your doctor will have looked at your PSA level, your Gleason score or grade group, the stage of your cancer and your Cambridge Prognostic Group (CPG). If your prostate was removed, it will have been sent to a laboratory for further tests. This can give a better idea of how aggressive the cancer was and whether it is likely to spread. If you don't know these details, ask your doctor or nurse. There is space to record all this information in the Summary of my treatment section on page 32.



Read more about Gleason scores, grade groups, the staging of prostate cancer and CPG in our fact sheet, **How prostate cancer is diagnosed**.

How will I know if my cancer has come back?

A continuous rise in your PSA level over several tests is likely to be the first sign that your cancer has come back. This should be picked up by your regular PSA tests.

The exact change in PSA level that suggests your cancer has come back will depend on the treatment you had. Speak to your doctor or nurse about your own situation.

If you have follow-up appointments with your GP, talk to them about what change in your PSA level should lead to a referral to the hospital for further tests. Your doctor may talk to you about your PSA doubling time. This is the time it takes for your PSA level to double. The change in PSA that would lead to a referral will vary from person to person, so it may help to show this information to your GP.

You can record your PSA level in the appointment diary on page 37. Or you can order one of our PSA record cards from **prostatecanceruk.org/publications**

The amount of PSA in your blood is measured in nanograms (a billionth of a gram) per millilitre of blood (ng/ml).

PSA level after surgery (radical prostatectomy)

At four to eight weeks after surgery your PSA level should drop so low that it's not possible to detect it (less than 0.1 ng/ml). This is because the prostate, which produces PSA, has been removed. A rise in your PSA level may suggest that you still have some prostate cancer cells.

PSA level after radiotherapy or brachytherapy

After radiotherapy or brachytherapy, your PSA should drop to its lowest level (nadir) within 18 months to three years. If you are having hormone therapy at the same time as your radiotherapy, your PSA may reach its lowest level very quickly. Your PSA level won't fall to zero as your healthy prostate cells will continue to produce some PSA.

Your PSA level may actually rise after radiotherapy or brachytherapy treatment, and then fall again. This is called 'PSA bounce'. It could happen up to three years after treatment. This is more common in younger men and men with a large prostate. It is normal, and doesn't mean that the cancer has come back.

Your cancer may have come back if:

- your PSA level rises by 2 ng/ml or more above its lowest level, **or**
- your PSA level rises for three PSA tests in a row within six months.

Your doctor will continue to check your PSA level and will talk to you about further tests and treatment options.

PSA level after high-intensity focused ultrasound (HIFU) or cryotherapy

Because these treatments are relatively new, we don't know so much about what PSA level can be a sign that your cancer has come back. But your PSA level should fall and then stay low after your treatment. If your PSA level rises, this may mean your cancer has come back. Speak to your doctor or nurse about your own situation.

What symptoms should I look out for?

If your cancer does come back, the first sign is likely to be a rise in your PSA level, rather than any symptoms. Any problems will often be side effects of treatment rather than a sign that your cancer has come back.

However, it's important to let your doctor or nurse know if you do get any new symptoms or side effects, or are worried that your cancer might have come back. If your cancer has come back and has spread from the prostate to other parts of the body, it can cause symptoms such as extreme tiredness (fatigue), pain in the back, hips or pelvis, and problems urinating.

Your doctor or nurse can help find out what might be causing your symptoms, and help you manage any side effects. They can also look at your PSA level and do other tests to see whether or not your cancer might have come back.

What other tests might I have?

If your doctor or nurse is concerned about your PSA level, or if you have new symptoms that suggest your cancer might have come back, they may recommend that you have some other tests. These may include a prostate biopsy, MRI scan, CT scan, bone scan or PET scan.



Your doctor or nurse will explain these tests to you if you need them, or you can call our **Specialist Nurses** for more information. You can also find out more about scans on our website at **prostatecanceruk.org/scans**

MRI scan

An MRI (magnetic resonance imaging) scan uses magnets to create a detailed picture of the inside of your body. This will show whether the cancer has come back in or around the prostate and, if so, where it has spread to.

You will lie very still on a table that will move slowly into the scanner. The radiographer might give you an injection of a dye during the scan. An MRI scan usually takes 30 to 45 minutes.

CT scan

A CT (computerised tomography) scan can show whether the cancer has come back and spread outside the prostate, for example to the lymph nodes or bones. Lymph nodes are part of your immune system and are found throughout your body. The lymph nodes near the prostate are a common place for prostate cancer to spread to. The scan results will help your doctor to work out if you need further treatment.

At your scan appointment, you'll be given a special dye to help the doctor see your organs more clearly on the scan. This will be given to you as an injection or a drink. You will lie on a table that moves slowly through the middle of the scanner. The scan will take up to 20 minutes.

Bone scan

A bone scan can show whether any cancer cells have spread to your bones, which is a common place for prostate cancer to spread to.

A small amount of dye is injected into a vein in your arm and travels around your body. If there is any cancer in the bones, the dye will collect in these areas and show up on the scan. It takes up to four

hours for the dye to travel around your body and collect in your bones, so you'll need to wait a while before you have the scan. You will lie on a table while the scanner moves very slowly down your body taking pictures. This takes around 30 minutes.

The doctor will look at the scan images to see if there is any cancer in your bones. Areas where dye has collected may be cancer – these are sometimes called 'hot spots'. You may need to have X-rays of any 'hot spots' to check if they are cancer. If it's still not clear, you may need an MRI scan or a bone biopsy.

PET scan

You may be offered a PET (positron emission tomography) scan to show if the cancer has come back. This is often combined with a CT scan (PET-CT) to give even more detail about any prostate cancer inside the body. The scan can detect small areas of cancer.

A small amount of radioactive dye is injected into your arm or hand. There are two main types of dye that can be used – choline and PSMA (prostate specific membrane antigen). You'll need to sit for an hour while the dye travels around your body and is absorbed. You will then lie on a bed that will move into the scanner. The scan usually takes 30 to 60 minutes. The scanner works by detecting the radiation given off by the dye, which collects in areas that may be cancer.



If your cancer does come back, there are treatments available that aim to control or get rid of the cancer. Speak to your doctor or nurse about your options. Read more in our booklet, **If your prostate cancer comes back: A guide to treatment and support**. You can also call our **Specialist Nurses**.

Life after prostate cancer treatment

Having treatment for prostate cancer can change how you feel about life. If you or your loved one has been dealing with prostate cancer you may feel scared, stressed or even angry. There is no right way to feel and everyone reacts differently. There are things you can do to help yourself and people who can help.

Common thoughts and feelings

You may feel all sorts of things after you finish treatment. Some people are relieved and feel ready to put the cancer behind them and get back to normal life. But others find it difficult to move on. Adjusting to life after cancer can take time.

The emotional impact of what you have been through may only hit you after you've finished treatment. You might feel angry – for example, angry at what you have been through, or about the side effects from treatment. Or you might feel sad or worried about the future.

Follow-up appointments can also cause different emotions. You might find it reassuring to see the doctor or nurse, or you may find it stressful, particularly a few days before your appointments.

Worries about your cancer coming back

It's normal to worry about your cancer coming back, and it will often improve with time. There are things you can do to help manage your concerns, such as finding ways to reduce stress. Breathing exercises and listening to music can help you relax and manage stress. Some people find that it helps to share what they're thinking with somebody else, like a friend. If you are still

struggling, you can get help for stress or anxiety on the NHS – you can refer yourself directly to a psychological therapies service or ask your GP.

There's more information about the chance of your cancer returning and how you'll know if it's come back on page 19. If you're worried about your PSA level or have any new symptoms, speak to your doctor or nurse. If the cancer does come back, you'll be offered further treatment. Read more in our booklet,



If your prostate cancer comes back: A guide to treatment and support.

Feeling isolated

During follow-up, you won't see your doctor or nurse as often as you did during your treatment. You might miss their regular support and reassurance. Some people find this quite difficult and say they feel isolated and abandoned when they finish their treatment. Speak to your GP if you have any concerns, or find out who else can help on page 30.

Dealing with side effects of treatments

Some men with long-term side effects only notice the emotional impact of these once their cancer treatment has finished. Getting support to manage your side effects can help. You can find out more about the side effects of treatments, and how to manage them in our booklet, **Living with and after prostate cancer:**



A guide to physical, emotional and practical issues.

Depression and anxiety

If you have prostate cancer, you may get depressed before or after treatment.

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

If you notice these changes in yourself and they don't go away after a few weeks, speak to your GP, hospital doctor or nurse – there are things that can help.

Regular physical activity can 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.



I think treatment and side effects affect men psychologically more than we realise. We don't like to talk about it but everyone's thinking about it.

A personal experience

How can I help myself?

Everyone has their own way of dealing with prostate cancer, but you may find some of the following suggestions helpful.

- **Talk to someone.** Share what you're thinking – find someone you can talk to. It could be someone close or someone trained to listen, like a counsellor or your doctor or nurse.
- **Set yourself goals and things to look forward to.** Even if they're just for the next few weeks or months.
- **Look after yourself.** Take time out to look after yourself. When you feel up to it, learn some techniques to manage stress and to relax – like breathing exercises or listening to music. If you're having difficulty sleeping, talk to your doctor or nurse.
- **Eat healthily.** It's good for your general health and can help you stay a healthy weight, which may be important for men with prostate cancer. Certain changes to your diet may also help with some side effects of treatment. Read our fact sheet, **Diet and physical activity for men with prostate cancer**.
- **Be as active as you can.** Keeping active can improve your physical strength and fitness, and can lift your mood. It can also help with some side effects of treatment. Take things at your own pace and don't overdo it. Read more in our fact sheet, **Diet and physical activity for men with prostate cancer**.

Visit prostatecanceruk.org/living for more ideas, or read our booklet, **Living with and after prostate cancer: A guide to physical, emotional and practical issues**. You could also contact Macmillan Cancer Support, Maggie's, Penny Brohn UK or your nearest cancer support centre.

Information about things I can do to help myself

You might find it helpful to record things you can do yourself below. Your doctor or nurse can help you fill this in.



Fill in things you can do yourself

Diet

Physical activity

Extreme tiredness (fatigue)

Relationships and sex



Fill in things you can do yourself

Stress and anxiety

Complementary therapies – some men find these help with side effects or general wellbeing

Work and finances

Practical issues, such as holidays and insurance

Details of events or courses about life after cancer treatment

Who else can help?

Your medical team

You might find it useful to speak to your nurse, doctor, GP or someone else in your medical team. They can explain any side effects you have, listen to your concerns, and put you in touch with other people who can help.

Trained counsellors

Counsellors are trained to listen and can help you find your own ways to deal with things. Many hospitals have counsellors or psychologists who specialise in helping people with cancer – ask your doctor or nurse if this is available. You can also refer yourself for counselling on the NHS website, or you could see a private counsellor. To find out more, visit **www.nhs.uk/counselling** or contact the British Association for Counselling & Psychotherapy.

Local information centres

Many hospitals have cancer information centres. They offer free, confidential information and support. They may also run courses to support you following cancer treatment. Ask your doctor or nurse for information about what's available in your area.

Support groups

People affected by prostate cancer get together to share their experiences of living with it. Some groups also hold meetings online. You can ask questions, share worries and know that someone understands what you're going through. Some groups have been set up by health professionals, others by men themselves. Many also welcome partners, friends and relatives. To find your local support group, please visit

www.tackleprostate.org/supportgroups

Spiritual support

You might begin to think more about spiritual beliefs as a result of having prostate cancer. You could get spiritual support from your friends, family, religious leader or faith group.

Prostate Cancer UK services

We have a range of services to help you deal with problems caused by prostate cancer or its treatments, including:

- **our Specialist Nurses**, who can help with any questions or worries in confidence
- **our one-to-one peer support service**, where we'll match you with a trained volunteer who understands your anxieties and uncertainties because they've been there themselves
- **our online community**, a place to ask questions or share experiences
- **our sexual support service**, speak to one of our trained Specialist Nurses about sexual problems after treatment for prostate cancer.

To find out more about any of the above, visit prostatecanceruk.org/get-support or call our



Specialist Nurses on 0800 074 8383.

Summary of my treatment

You might find it helpful to have a summary of your diagnosis and your treatments. Knowing about your own cancer and treatment can help you get the support that’s right for you. It can also help you feel more confident speaking to your doctor or nurse. A treatment summary can also be useful if you see other health professionals who may not have detailed information about your treatment. If you don’t know these details, ask your doctor or nurse to help you fill them in.



Information about my cancer

Your PSA level when you were diagnosed	
Gleason score	
Grade group	
T (tumour) stage	
N (nodes) stage	
Cambridge Prognostic Group (CPG)	



For more information about PSA levels, Gleason score, staging and CPG, read our fact sheet, **How prostate cancer is diagnosed**.



Summary of my treatment

You may be given a summary of your treatment by your doctor or nurse.

Treatment:

From:

To:

Treatment:

From:

To:

Treatment:

From:

To:



PSA levels after treatment

Date:

PSA level:

Date:

PSA level:

Date:

PSA level:

Date:

PSA level:

Date:

PSA level:

My follow-up plan

Your doctor or nurse should discuss your follow-up plan with you. They should tell you where and when you will have your appointments, what they will involve, and how long follow-up might go on for. You may be offered a written care plan at the end of your treatment that will have this information. Or you can ask your doctor or nurse to help you write down the details in this section. If there is anything you are unsure or concerned about, speak to your doctor or nurse. They may be able to help or refer you to someone who can.



Information about my follow-up

Where will my appointments be?

How often will I have appointments?

Who will I see at my appointments?

What will my appointments involve?



Information about my follow-up

How will I receive my results?

Are there any side effects I might develop at a later stage

Is there anything I can do myself to manage side effects?

What is the risk of my cancer coming back?



I found it important to remain positive and made changes to my life such as improving my diet and taking up new interests. I joined a support group and found speaking to other men with the same experiences to be both invaluable and rewarding.

A personal experience

My appointment diary

You can fill in this diary before and after your follow-up appointments, to help you get the most out of them. You might want to photocopy a blank diary or download pages of this booklet from prostatecanceruk.org/publications so you have enough to last you for a while.



Date of appointment

Fill in before your appointment

How I've been feeling – you can include physical things (for example, side effects of treatment) as well as emotional things.

Things I want to talk about at my appointment:

- | | |
|---|---|
| ☐ urinary problems | ☐ emotional or mood problems |
| ☐ sexual problems | ☐ diet |
| ☐ bowel problems | ☐ physical activity |
| ☐ fatigue | ☐ work and finances |

Your doctor or nurse may not have time to talk about all of these things, so think about what is most important to you. You can also call our **Specialist Nurses** in confidence.





Fill in during or after your appointment

My questions or concerns

Answers to my questions or concerns

Advice from my doctor or nurse

PSA level

Date and time of next appointment



Between appointments

Details of any medicines I am taking for prostate cancer or for the side effects of treatment.

Name of medicine	Dose	How often

Who should I contact if I have any concerns, or develop any new symptoms or side effects between appointments?

Name:

Phone:

Contact details for my GP (if different to above).

Name:

Phone:



Prostate Cancer UK Specialist Nurses: 0800 074 8383

Who should I contact if I have any other problems, such as cold or flu-like symptoms or another health problem? This will usually be your GP.

Name:

Phone:

More information from us

The Tool Kit

The Tool Kit information pack contains fact sheets that explain how prostate cancer is diagnosed, how it's treated and how it may affect your lifestyle. Each treatment fact sheet also includes a list of suggested questions to ask your doctor. Call our Specialist Nurses for a personally tailored copy.

Leaflets and booklets

We have a range of other leaflets and booklets about prostate cancer and other prostate problems.

To order publications:

All our publications are free and available to order or download online. To order them:

- call us on **0800 074 8383**
- visit our website at **prostatecanceruk.org/publications**

Call our Specialist Nurses

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



**Speak to our
Specialist Nurses**

0800 074 8383*

prostatecanceruk.org

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

Other useful organisations

Bladder and Bowel UK

www.bbuk.org.uk

Telephone: 0161 214 4591

Information and advice about bladder and bowel problems.

British Association for Counselling & Psychotherapy

www.bacp.co.uk

Telephone: 01455 883 300

Information about counselling and details of therapists in your area.

Cancer Research UK

www.cancerresearchuk.org

Telephone: 0808 800 4040

Information about prostate cancer and clinical trials.

College of Sexual and Relationship Therapists

www.cosrt.org.uk

Telephone: 020 8106 9635

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

Macmillan Cancer Support

www.macmillan.org.uk

Telephone: 0808 808 0000

Practical, financial and emotional support for people with cancer, their family and friends.

Maggie's

www.maggies.org

Telephone: 0300 123 1801

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

NHS websites

England: www.nhs.uk

Scotland: www.nhsinform.scot

Wales: www.111.wales.nhs.uk

nidirect (Northern Ireland)

www.nidirect.gov.uk

Penny Brohn UK

www.pennybrohn.org.uk

Telephone: 0303 3000 118

Courses and physical, emotional and spiritual support for people with cancer and their loved ones.

Samaritans

www.samaritans.org

Telephone: 116 123

Confidential, judgement-free emotional support, 24 hours a day, by telephone, email, letter or face to face.

About us

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.

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- Joe Kearney, Macmillan Uro Oncology Clinical Nurse Specialist, Buckinghamshire Healthcare NHS Trust
- Sean Ralph, Consultant Therapeutic Radiographer in Prostate Cancer, Leeds Teaching Hospitals NHS Trust
- our Specialist Nurses
- our volunteers.

Donate today – help others like you

Did you find this information useful? Would you like to help others in your situation access the facts they need? Every year, over 64,000 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



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



**Speak to our
Specialist Nurses**

0800 074 8383*

prostatecanceruk.org

**Trusted
Information
Creator**



Patient Information Forum

f Like us on Facebook: Prostate Cancer UK

t Follow us on Twitter: @ProstateUK

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**Call our Specialist Nurses from Monday to Friday 9am - 5pm,
Wednesday 10am - 5pm**

* Calls are recorded for training purposes only.

Confidentiality is maintained between callers and Prostate Cancer UK.

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