

If your prostate cancer comes back

A guide to treatment and support



**PROSTATE
CANCER UK**

About this booklet

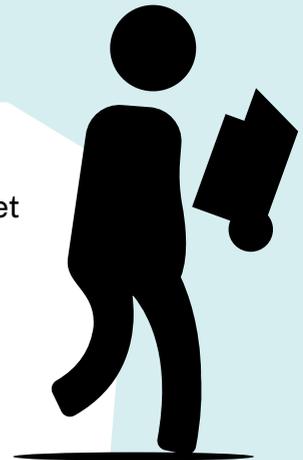
This booklet is for you if your prostate cancer has come back after treatment that aimed to get rid of it. This is called recurrent prostate cancer. Your partner, family or friends might also find this booklet helpful.

We explain what recurrent prostate cancer is, how it might make you feel and the impact it could have on your life. We discuss the different treatment options that may be available to you. We also describe ways to deal with recurrent prostate cancer and list other sources of information and support.

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 options and the support available to you. You can also speak to our Specialist Nurses, in confidence, on 0800 074 8383 or chat to them online.

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

-  Our Specialist Nurses
-  Our publications
-  Sections for you to fill in



Contents

About this booklet	2
What is recurrent prostate cancer?	4
Finding out your prostate cancer has come back	4
How do I know my prostate cancer has come back?	6
Why has my cancer come back?	8
Where will my prostate cancer come back?	8
Treatment for recurrent prostate cancer	10
Making a decision about treatment	10
What second-line treatments are there?	10
Which second-line treatments are available to me?	13
When will my treatment start?	17
What if I don't want further treatment?	20
How will my second-line treatment be monitored?	20
What happens if my cancer comes back again?	20
Dealing with recurrent prostate cancer	22
 Your health professional team	27
 Questions to ask your doctor or nurse	30
 Appointment diary	32
More information from us	35
Other useful organisations	36
About us	39

What is recurrent prostate cancer?

Some treatments aim to cure prostate cancer by getting rid of it, while others aim to control it instead. Recurrent prostate cancer is cancer that has come back after you've had a treatment that aimed to cure it, such as:

- surgery (radical prostatectomy)
- external beam radiotherapy
- brachytherapy
- high-intensity focused ultrasound (HIFU)
- cryotherapy.

All these treatments will have aimed to cure your prostate cancer. But sometimes not all of the cancer is successfully treated, or the cancer may have been more advanced than first thought. See page 8 for information about why prostate cancer might come back.

Finding out your prostate cancer has come back

It can be very difficult to learn that your prostate cancer has come back. All the thoughts and feelings you had when you were first diagnosed can come back again and they may be even stronger than before.

“Everyone’s experience of cancer is unique and I don’t think anyone can tell you how you should feel or behave.”

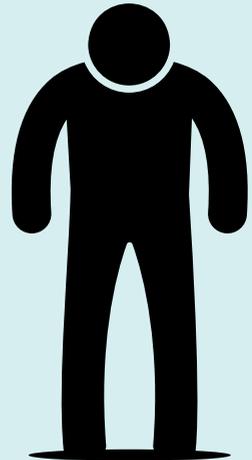
A personal experience

Common thoughts and feelings

Men respond in all types of ways when they find out their prostate cancer has come back.

- **Shock.** Knowing your cancer has come back may have come as a surprise. It's normal to feel shocked and it may take you a while to come to terms with it, but that's ok.
- **Anger.** A lot of men feel angry that their first treatment didn't work as well as they had hoped.
- **Denial.** You might find it difficult to accept that your prostate cancer has come back, especially if you feel well.
- **Frustration and disappointment.** You might feel frustrated and disappointed that your first treatment didn't get rid of all the cancer.
- **Worried or down.** You might worry about getting side effects from a new treatment and how they might impact your life. This can be more difficult if your first treatment has already caused side effects such as erection, urinary or bowel problems.
- **Anxiety.** Some men can feel worried, nervous or uneasy when things are uncertain and may find it hard to think about the future.

All these are very normal ways to feel, and how you feel might change from day to day. Things can get easier over time but some of these feelings may stay with you. Lots of men find it helpful to talk to someone about their feelings. This might be a friend or family member or someone who is trained to listen, like a counsellor or your doctor or nurse. Or you can talk to someone who's been there, through support groups or our one-to-one support service. Read more on page 25.



Remember, for many men, prostate cancer is slow-growing even when it comes back after treatment. Lots of men with recurrent prostate cancer continue to live long and active lives.

It can be a big shock to find out your cancer has come back. Read more about ways to deal with your feelings and the support that's available on page 22, or talk to our **Specialist Nurses**.



How do I know my prostate cancer has come back?

Everyone's prostate cancer journey is different, and it can take many months or even years before there is any sign that your prostate cancer has come back. This is why your doctors and nurses will have regularly monitored you after your first treatment so they can give you treatment as early as possible if it does come back.

Usually, the first sign that prostate cancer is starting to return is a continuous rise in the level of prostate specific antigen (PSA) in your blood, rather than any symptoms. The PSA test is a very effective way of checking how successful treatment has been. It can't show for certain if prostate cancer has come back, or where it might be. But it can be a useful first sign that the cancer may have come back. The exact change in PSA level that suggests your cancer has come back (PSA threshold) will depend on which treatment you had.

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. Advanced prostate cancer (cancer that has spread from the prostate to other parts of the body) can cause symptoms, such as extreme tiredness (fatigue), bone pain and problems urinating.

However, physical problems are often side effects of treatment rather than a sign that your cancer has come back. Your doctor or nurse can help find out what might be causing your symptoms and help you manage any side effects.

Your doctor may have done other tests to check if, and where, your cancer had come back. These may have included a CT (computerised tomography), MRI (magnetic resonance imaging), bone or a PET (positron emission tomography) scan. You may also need to have another biopsy, but this will depend on the type of treatment you had  first. Read more about this in our booklet, **Follow-up after prostate cancer treatment: What happens next?**



Why has my cancer come back?

It's not always completely clear why prostate cancer comes back, but there are two main possible reasons.

- **Not all the cancer cells in your prostate were destroyed during your first treatment.** Small groups of cells might have been left behind. Over time, these may have grown large enough to be picked up by tests or to cause symptoms.
- **The cancer was more advanced than originally thought.** Tests or scans you had when you were diagnosed might have missed small groups of cancer cells outside your prostate, for example in your lymph nodes or bones (see the diagram on page 9). Your first treatment would not have been aimed at these cells. Over time, the amount of these cells may have increased enough so they could be picked up by tests or cause symptoms.

When you were diagnosed your doctor would not have been able to tell you if your cancer would come back. But they may have said how likely it was. To work out your risk, your doctor will have looked at your PSA level, your Gleason score or grade group, and the stage of your cancer. If you don't know these details, ask your doctor or nurse.

You can read more about Gleason scores and the staging of prostate cancer in our fact sheet, [**How prostate cancer is diagnosed**](#).

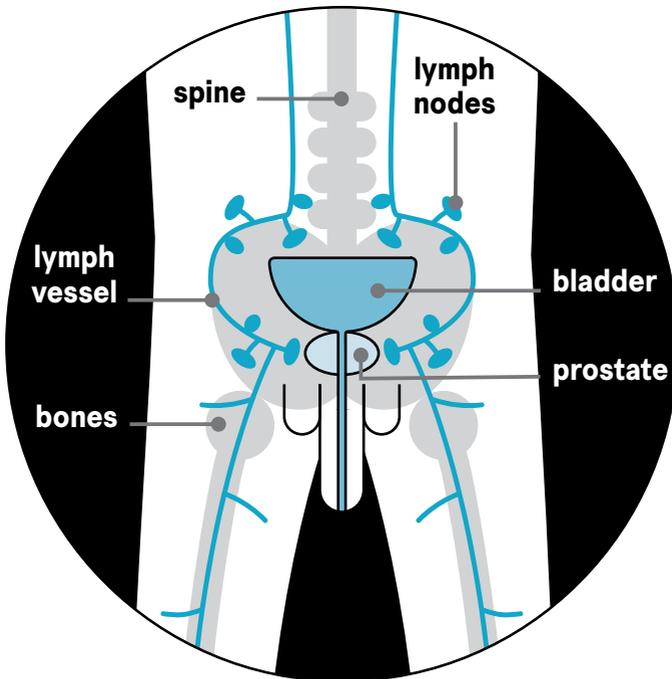
Where will my prostate cancer come back?

Your prostate cancer can come back in one or more areas. It could be:

- in your prostate, if your prostate hasn't been removed by surgery
- in the area around where your prostate used to be (the prostate bed), if the prostate has been removed

- in the area just outside your prostate
- in other parts of your body.

Prostate cancer can spread to any part of the body, but it most commonly spreads to the bones and lymph nodes (part of your immune system). Your doctor or nurse will be able to give you more details about your own situation. Sometimes it's not clear where the cancer is. Some men may have a rise in their PSA level, but the cancer may not show up on other tests, at least at first. This is quite common and your doctor will discuss treatment options with you.



Treatment for recurrent prostate cancer

Treatments for recurrent prostate cancer are called second-line or salvage treatments. Many treatments used to treat prostate cancer when it's first diagnosed can also be used as second-line treatments.

Making a decision about treatment

Your doctor might offer you one treatment, or a choice of treatments for recurrent prostate cancer. You may also be able to have your cancer monitored rather than treated straight away (see page 12). Or you might decide you don't want any more treatment, other than treatment to help manage any symptoms you might get (see page 20).

All treatments have advantages, disadvantages and side effects. Everyone is different and some side effects might be a problem for one man but not for another. The following information aims to help you understand the different treatment options so you can think about what's right for you. It's important to discuss your options with your doctor before deciding on a treatment. There's a list of possible questions to ask your doctor or nurse on page 30. You could also talk through your options with your partner, family or friends, or speak to

 our **Specialist Nurses**.

What second-line treatments are there?

There are two main types of treatments – those that aim to get rid of the cancer (curative treatments) and those that aim to delay the cancer growing but won't get rid of it.

Treatments aiming to get rid of the cancer

- **External beam radiotherapy** uses high-energy X-ray beams to destroy cancer cells from outside the body. You might have it with or without hormone therapy.
- **Brachytherapy** is a type of internal radiotherapy. There are two types of brachytherapy – permanent seed brachytherapy and high dose-rate brachytherapy.
- **Surgery (radical prostatectomy)** removes your prostate and the cancer inside it.
- **High-intensity focused ultrasound (HIFU)** uses ultrasound energy to heat and destroy cancer cells in your prostate. HIFU is newer than some other treatments, so it isn't available everywhere and may only be available as part of a clinical trial.
- **Cryotherapy** uses extreme cold to freeze and destroy cancer cells. Cryotherapy is newer than some other treatments, so it isn't available everywhere and may only be available as part of a clinical trial.

Read more about these treatments on our website at

 prostatecanceruk.org/treatments, or get in touch with our

 **Specialist Nurses** and ask for a fact sheet.

Treatments aiming to control the cancer

- **Hormone therapy** works by either lowering the amount of testosterone in the body or by stopping it from reaching the cancer cells, wherever they are in the body. Prostate cancer cells usually need testosterone to grow.
- **Radiotherapy**, when combined with hormone therapy can also control prostate cancer that has spread to other parts of the body. This isn't suitable for all men. This may include a type of external beam radiotherapy such as Stereotactic Body Radiation Therapy (SBRT).



Read more about external radiotherapy in our factsheet,

External beam radiotherapy.

- **Chemotherapy** uses anti-cancer drugs to kill cancer cells, wherever they are in the body. You may be offered chemotherapy alongside hormone therapy. You need to be quite fit to have chemotherapy, because the side effects can be harder to deal with if you have other health problems.

Clinical trials

Some men who have recurrent prostate cancer decide to take part in clinical trials of new treatments or new combinations of existing treatments. If you're interested in taking part in a clinical trial, ask your doctor if there are any that would be suitable for you.

For general information on clinical trials, visit our website at **prostatecanceruk.org/clinical-trials**

Monitoring your prostate cancer

You may be able to have your cancer monitored, instead of having second-line treatment straight away. For many men, prostate cancer is slow-growing and may not cause any problems or symptoms, even without treatment. The aim of monitoring is to avoid or delay treatment, and the side effects that treatment can cause.

If you decide not to have treatment straight away, your doctor and nurse will monitor you and your cancer closely for any changes. You will have regular PSA tests. You may also have other tests and scans.

If the tests show that your cancer is growing more quickly than expected, or if you have symptoms, your doctor will talk to you about starting second-line treatment.

“Once I'd found out about the different treatments available, and experienced the wonderful care of my medical team, things didn't look nearly so bad.”

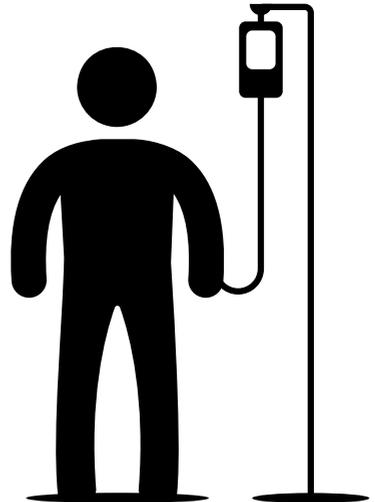
A personal experience

Which second-line treatments are available to me?

Several things affect which treatments are suitable, including:

- where your cancer is
- your general health
- your PSA level and other test results
- what treatment you've already had.

This means it's unlikely that all treatments will be available to you. Your doctor or nurse will talk to you about which ones are suitable.



Where your cancer is

Cancer that has returned in the prostate itself or in the prostate bed is called local recurrence. If you have local recurrence, you might be offered further treatment aiming to get rid of the cancer.

Cancer that has spread to the area just outside the prostate, but not to other parts of the body, is called locally advanced recurrence. Some men with locally advanced recurrence will also be offered treatment that aims to get rid of the cancer.

But if your cancer has spread to other parts of your body (advanced prostate cancer), then treatment can no longer cure it, but it could control the cancer for a long time. You will be offered hormone therapy and you might also be offered chemotherapy alongside it.

If your advanced prostate cancer has spread to other parts of your body but it is limited to just a few areas, this is called oligometastatic prostate cancer. If your cancer has spread to three sites or less, you might be offered a type of external beam radiotherapy called stereotactic ablative radiotherapy (SABR). This treatment can deliver high doses of radiation directly to the tumours which means it can be given in a shorter period. SABR aims to help control your cancer and delay the use of other treatments such as hormone therapy or chemotherapy.

Your general health

Your health and any other medical problems will also affect what treatments are available to you. For example, medications you are taking for other conditions or if you already have side effects from the first treatment you had. Having another treatment can cause side effects as well, so you'll need to be fit enough to cope with this.

Your PSA level and other test results

Your PSA level and how fast it is rising will affect what treatments you are offered. You might have the option of monitoring your PSA level for a while before you have further treatment, particularly if your PSA level is rising slowly. If your PSA level is rising quickly, this suggests your cancer is more likely to have spread further (see page 6).

What treatment you've already had

The table on the next page shows which second-line treatments might be options for you, based on your first treatment. But this will also depend on the other things described above.

Not all types of treatment are available at every hospital. For example, HIFU and cryotherapy aren't widely available. You may be offered them as part of a clinical trial or you might be able to ask for referral to another hospital, but this won't always be possible.

Surgery is rarely available as a second-line treatment because first treatments, such as radiotherapy, may damage the prostate and surrounding tissues. This makes it harder for a surgeon to remove the prostate and there is a higher risk of side effects, such as urinary problems.

Your doctor might also suggest monitoring your prostate cancer (see page 20) instead of having treatment straight away.

What was your first treatment for prostate cancer?	Second-line treatments that may be suitable
Surgery (radical prostatectomy)	<ul style="list-style-type: none"> • Radiotherapy to the prostate bed • Hormone therapy • Both
External beam radiotherapy	<ul style="list-style-type: none"> • Hormone therapy • HIFU * • Cryotherapy * • Brachytherapy • Surgery, but this isn't common
Permanent seed brachytherapy or high dose-rate (HDR) brachytherapy	<ul style="list-style-type: none"> • Hormone therapy • External beam radiotherapy • More brachytherapy • Surgery, but this isn't common • Cryotherapy * • HIFU *
High-intensity focused ultrasound (HIFU)	<ul style="list-style-type: none"> • More HIFU * • External beam radiotherapy • Brachytherapy • Cryotherapy • Hormone therapy • Surgery, but this is rare
Cryotherapy	<ul style="list-style-type: none"> • More cryotherapy * • HIFU * • External beam radiotherapy • Brachytherapy • Hormone therapy • Surgery, but this is rare

* These treatments are not available everywhere in the UK and may only be offered as part of a clinical trial. You can talk to your doctor if you would like to know if they are a suitable option for you.

When will my treatment start?

This varies from man to man. For example, your doctor might want to delay it if you're still recovering from the side effects of your first treatment. Ask your doctor for more information about when your treatment will start.

If you have treatment that aims to get rid of the cancer

If you're having treatment that aims to get rid of the cancer, your treatment could start straight away. But for some men, there might be an option to delay treatment until tests show that the cancer is growing more quickly.

If you have treatment that aims to control your cancer

If you're having hormone therapy to control your cancer, when you start treatment will depend on several things, including:

- whether your prostate cancer has spread to other parts of your body
- whether you have any symptoms from your cancer
- how quickly your PSA level is rising
- how you feel about starting treatment.

You might start hormone therapy straight away or you might be monitored for a while before you start. Monitoring involves regular check-ups and PSA tests. If your PSA reaches a level that suggests your cancer is growing more quickly, you will then be offered hormone therapy.

Some men feel uneasy knowing that their cancer is back and isn't being treated, but there can be good reasons to delay hormone therapy.

These include:

- if you still have side effects from your first treatment
- delaying side effects of hormone therapy, such as sexual problems, hot flushes and fatigue.

If you are on life-long hormone therapy and having problems with side effects, you might be able to have intermittent hormone therapy. This involves stopping treatment when your PSA level is low and stable, and starting treatment again when your PSA level starts to rise or you notice a change in your symptoms. Some of the side effects may improve while you're not having treatment, but it can take several months for the side effects to wear off.

Read more about the side effects of hormone therapy in our booklet,

 **Living with hormone therapy: A guide for men with prostate cancer.**

If you are concerned about delaying the start of treatment, discuss this with your doctor or nurse.



Side effects of second-line treatment

All treatments have side effects. The risk of side effects is usually higher when a treatment is used as a second-line treatment than when it's used as a first treatment. This is because your first treatment may have already caused some damage to the tissue surrounding the prostate.

Side effects may also be more severe with a second-line treatment. And you might still be getting side effects from your first treatment.

Ask your doctor or nurse for more information about the possible side effects from the second-line treatments they offer you. Our other fact sheets also provide information about the most common side effects of each treatment. Finding out about possible side effects might help you to choose between different treatment options, or decide whether you want to have any treatment.

There are also things you can do to manage side effects. For example, eating healthily and being physically active may help. The following fact sheets and booklets have more information on managing side effects of treatment.



- [**Diet and physical activity for men with prostate cancer**](#)
- [**Urinary problems after prostate cancer treatment**](#)
- [**Prostate cancer and your sex life**](#)
- [**Fatigue and prostate cancer**](#)
- [**Living with hormone therapy: A guide for men with prostate cancer**](#)
- [**Living with and after prostate cancer: A guide to physical, emotional and practical issues**](#)

For details of how to order publications see page 35.

What if I don't want further treatment?

Some men think about the advantages and disadvantages and decide they don't want to have second-line treatment for their cancer. Speak to your doctor or nurse if you're thinking about not having further treatment. They may suggest monitoring your prostate cancer with regular tests. If the cancer starts to cause symptoms, then you're likely to be offered hormone therapy to control the cancer and help relieve symptoms. There are also other treatments to help manage symptoms (see page 21).

How will my second-line treatment be monitored?

You will have regular appointments to monitor how well your treatment is working. These will include regular PSA tests. The aim of these appointments is to:

- check how your cancer has responded to treatment
- deal with any side effects of treatment
- give you a chance to raise concerns and ask questions.

What happens if my cancer comes back again?

If your cancer comes back again after second-line treatment, you will be offered hormone therapy to control your cancer, though you may not need to start it straight away. Read about the different types of

 hormone therapy in our fact sheet, **Hormone therapy**. For information  about side effects and how to manage them, read our booklet, **Living with hormone therapy: A guide for men with prostate cancer**.

You might also be offered chemotherapy, alongside hormone therapy.

 Read more about chemotherapy in our fact sheet, **Chemotherapy**.

Some men decide they want to take part in a clinical trial of a new treatment or a new combination of existing treatments. Read more about this on our website at prostatecanceruk.org/clinical-trials

How long will hormone therapy control my cancer?

Hormone therapy can keep your cancer under control for many months or years before you need to think about other treatments.

But over time, the behaviour of your cancer cells may change and your cancer may start to grow again. You may continue having your original hormone therapy, but there are also other treatments available. Further treatment options may include other types of hormone therapy, chemotherapy, and radium-223 (Xofigo[®]). Read more about

📖 these treatments in our fact sheet, [Treatment options after your first hormone therapy](#).

What if I develop symptoms?

Tell your doctor or nurse about any symptoms you have (see page 6). If you notice any new symptoms between check-ups, tell your doctor or nurse as soon as possible. The changes you notice may be side effects of treatment, or they may be a sign that your cancer is growing. If tests show your cancer is growing, your doctor will talk to you about treatment options.

Your doctor or nurse can also tell you about treatments and other ways to help manage your symptoms. For example, if your cancer has spread to the bones and is causing pain, there are treatments that may help, such as pain-relieving drugs, pain-relieving radiotherapy, and drugs called bisphosphonates. Read more about these in our fact sheet,

📖 [Managing pain in advanced prostate cancer](#).

Dealing with recurrent prostate cancer

Some men say having prostate cancer changes the way they think and feel about life. Finding out that your prostate cancer has come back can be a particularly challenging time. You might feel scared, worried, stressed, helpless or even angry. At times, lots of men with prostate cancer get these kinds of thoughts and feelings. There's no right way to feel and everyone reacts in their own way.

Finding out about things you can do to help yourself can help you feel more in control. Those close to you can also find this a difficult time and they may need support and information too. They may want to read our  booklet, **When you're close to someone with prostate cancer: A guide for partners and family.**

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.

Your medical team

Ask your nurse or doctor about any side effects so you know what to expect and how to manage them.

Talk to someone

Share what you're thinking – find someone you can talk to. It could be someone close to you, someone who's been through prostate cancer themselves or someone trained to listen, like a counsellor or your doctor or nurse.

Set yourself some goals

Set yourself some 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. We don't know for sure if physical activity can help slow the growth of prostate cancer. But it can help you stay a healthy weight, which may help to lower your risk of advanced prostate cancer.

Physical activity can also help with some side effects of treatment.

Even a small amount can help. 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**](#).

Quit smoking

Some studies suggest that smoking makes prostate cancer more likely to grow and spread to other parts of the body (advanced prostate cancer). The more you smoke, the greater the risk. And heavy smoking may mean you're more likely to die from prostate cancer. But if you stop

smoking, your risk should start to drop – and after 10 years it could be as low as for men who have never smoked.

Stopping smoking can also help with the side effects of treatment for prostate cancer. For example, you may be less likely to get certain urinary problems after radiotherapy if you don't smoke. Smoking also increases your risk of bone thinning. If you're having hormone therapy for your prostate cancer you're already at risk of bone thinning, but stopping smoking will help reduce your overall risk.

For information about stopping smoking, talk to your doctor or visit the NHS website.

Get more ideas about how to look after yourself from Macmillan Cancer Support, Maggie's Centres, Penny Brohn UK, or your nearest cancer support centre. You can also find more ideas in our booklet, **Living with and after prostate cancer: A guide to physical, emotional and practical issues.**

Check out our online 'Wellbeing hub'

Visit our online wellbeing hub to find information on the mental and emotional impact of prostate cancer diagnosis and its treatments. You'll find information on how to manage stress and anxiety and where to get support. Find out more at prostatecanceruk.org/wellbeing

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 your treatment and side effects, 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 at the hospital if this is available. You can also refer yourself for counselling on the NHS, or you could see a private counsellor.

To find out more, visit www.nhs.uk/counselling or contact the British Association for Counselling & Psychotherapy.

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

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 questions or worries in confidence
- **our one-to-one support service**, where you can speak to someone who understands what you're going through
- **our online community**, a place to ask questions or share experiences
- **our sexual support service**, speak to one of our trained Specialist Nurses about sexual problems after treatment for prostate cancer
- **our fatigue support**, speak to our Specialist Nurses about ways to help manage your fatigue.

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



Hospices

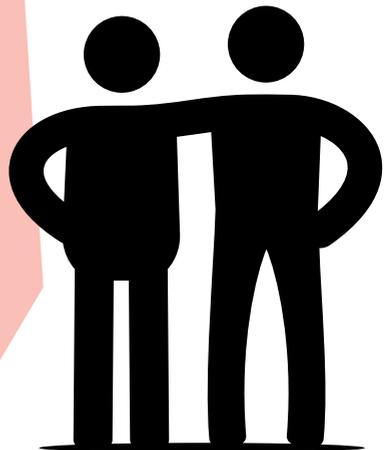
You may be able to get support from your local hospice or community palliative care team. Hospices don't just provide care for people at the end of their life – you may be able to use their services while still living at home. They provide a range of services, including treatment to manage pain. They can also offer emotional and spiritual support, practical and financial advice, and support for families. Your GP, doctor or nurse can refer you to a hospice service, and will work closely with these teams to support you.

Spiritual support

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

“I was grateful to have counselling. Later, I joined a stress management class and my local support group. The support and friendship we give each other means so much to me.”

A personal experience



Your health professional team

When you were first diagnosed with prostate cancer you may have seen a number of health professionals who were involved in your care.

When you have treatment for recurrent prostate cancer you might meet some of the same health professionals. But there might be some new people involved in your care as well.

Use this space to record names and contact details of the health professionals involved in your care. They will discuss your cancer and suitable treatment options.

We have listed the health professionals you are most likely to see, but you may not meet all of these.

Your main contact (key worker)

Your key worker is your main point of contact. They help coordinate your care and can help you get information and support. Your key worker is often your specialist nurse, but may also be your hospital doctor, GP, radiographer or another health professional.



Name:

Telephone number:

Out of hours contact details:

Notes:

Specialist nurse

You may have a urology, uro-oncology or prostate cancer specialist nurse as part of your health professional team. They can answer any questions you may have about your cancer and your care.



Name:

Telephone number:

Out of hours contact details:

Notes:

Consultant oncologist

This is a doctor who specialises in cancer treatments other than surgery, such as radiotherapy or chemotherapy.



Name:

Telephone number:

Out of hours contact details:

Notes:

Consultant urologist

This is a surgeon who specialises in problems with the urinary system.



Name:

Telephone number:

Out of hours contact details:

Notes:

Other health professionals

You can record details of other health professionals below. These might include a radiographer, pharmacist, dietitian, sex therapist, continence nurse, community nurse, practice nurse or GP.



Name:

Telephone number:

Out of hours contact details:

Notes:



Name:

Telephone number:

Out of hours contact details:

Notes:

Questions to ask your doctor or nurse



Which second-line treatments are available to me?

Are there any clinical trials I can take part in?

How long do I have to decide on my treatment?

Does the treatment aim to get rid of the cancer or to control it?



What are the side effects of the treatment?

What are the chances of treatment being successful?

What happens if the cancer comes back again?

What check-ups will I have after treatment?

Who can I contact if I have questions or concerns?

Appointment diary

You can fill in this diary before and after your appointments, to help you get the most out of them. You might want to photocopy one of the pages or download another copy from prostatecanceruk.org/publications so you have enough copies to last 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:

- | | |
|---|---|
| <input type="checkbox"/> urinary problems | <input type="checkbox"/> emotional or mood problems |
| <input type="checkbox"/> sexual problems | <input type="checkbox"/> diet |
| <input type="checkbox"/> bowel problems | <input type="checkbox"/> physical activity |
| <input type="checkbox"/> fatigue problems | <input type="checkbox"/> 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:



More information from us

The Tool Kit

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

Leaflets and booklets

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

To order publications:

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

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

Chat to one of our Specialist Nurses

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



**Chat to one of our
Specialist Nurses**

0800 074 8383*

prostatecanceruk.org

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

Other useful organisations

Bladder and Bowel UK

www.bbuk.org.uk

Telephone: 0161 214 4591

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.

Hospice UK

www.hospiceuk.org

Telephone: 020 7520 8200

Information about hospice care, including a database of hospice and palliative care providers.

Macmillan Cancer Support

www.macmillan.org.uk

Telephone: 0808 808 0000

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

Maggie's Centres

www.maggiescentres.org

Telephone: 0300 123 1801

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

Marie Curie

www.mariecurie.org.uk

Telephone: 0800 090 2309

Runs hospices throughout the UK and a free nursing service for people in their own home.

NHS Direct Wales

www.111.wales.nhs.uk

Telephone: 0845 46 47

Provides health advice 24 hours a day and lists local health services in Wales.

NHS Inform

www.nhsinform.scot

Telephone: 0800 22 44 88

Health information and details of NHS and other support services in Scotland.

NHS website

www.nhs.uk

Telephone: 020 7520 8200

Information about conditions, treatments and lifestyle. Support for carers and a directory of health services in England.

nidirect

www.nidirect.gov.uk

Information about government services in Northern Ireland, including health services.

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

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

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

References used in this booklet are available at prostatecanceruk.org

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

It was reviewed by:

- Ann Henry, Professor in Clinical Oncology, University of Leeds
- Karen Wilkinson, Uro-Oncology Clinical Nurse Specialist, University College London Hospital
- Samantha McBeigh, Uro-oncology Clinical Nurse Specialist, Belfast City Hospital
- Richard Gledhill, Prostate Cancer Nurse Specialist, University Hospitals Birmingham
- Our Specialist Nurses
- Our volunteers.

Tell us what you think

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

Donate today – help others like you

Every year over 52,000 men get the life-changing news that they have prostate cancer. But thanks to our generous supporters, we're there to help men when they need us most. You can help more men get free, unbiased, confidential support by donating to us today:

- £10 could fund a call with one of our Specialist Nurses.
- £20 could give 40 men vital information through our handy

 **Know your prostate: a quick guide.**

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

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



Registered with
**FUNDRAISING
REGULATOR**



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

**Trusted
Information
Creator**

Patient Information Forum

 **@Prostate Cancer UK**  **@ProstateUK**  **@ProstateCancerUK**

© Prostate Cancer UK May 2025 | To be reviewed May 2028

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.

Prostate Cancer UK is a registered charity in England and Wales (1005541) and in Scotland (SC039332). Registered company number 02653887.

7773

REC/APR25

