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

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

The photos in this booklet are of people personally affected by prostate cancer. The quotes with the photos are not the words of the people who appear.
Contents

About this booklet ................................................................................................................... 2

What is recurrent prostate cancer? ................................................................................. 4

Finding out your prostate cancer has come back ......................................................... 4
  How do I know if my prostate cancer has come back? ........................................... 6

Why has my cancer come back? ...................................................................................... 7
  Where will my prostate cancer come back? ............................................................. 7

Treatment for recurrent prostate cancer ........................................................................ 9
  Making a decision about treatment ........................................................................... 9
  What second-line treatments are there? .................................................................. 9
  Which second-line treatments are available to me? ............................................... 13
  When will my treatment start? .................................................................................. 16
  What if I don’t want further treatment? ................................................................. 19
  How will my second-line treatment be monitored? ............................................... 19
  What happens if my cancer comes back again? ..................................................... 19

Dealing with recurrent prostate cancer .......................................................................... 21

Your health professional team ......................................................................................... 27

Questions to ask your doctor or nurse ........................................................................... 30

Appointment diary ........................................................................................................... 32

More information from us .............................................................................................. 34

Other useful organisations ............................................................................................... 35

About us ............................................................................................................................ 38
What is recurrent prostate cancer?

Some treatments aim to cure prostate cancer and others aim to control it, without getting rid of it. 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 aim to get rid of 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 7 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.** It's normal to feel shocked and it may take you a while to make sense of how you’re feeling.

- **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, especially if your first treatment has already caused side effects such as erection, urinary or bowel problems.

- **Anxiety.** Some men feel anxious and find it hard to think about the future.

All these are very normal ways to feel. 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 our one-to-one support service. Read more on page 24.
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 21, or talk to our Specialist Nurses.

How do I know if my prostate cancer has come back?
Your doctors and nurses will monitor you after your first treatment to check for any signs that the cancer has come back.

Usually the first sign that your cancer is starting to return is a continuous rise in the level of prostate specific antigen (PSA) in your blood. The PSA test is a very effective way of checking how successful your treatment has been. The exact change in PSA level that suggests your cancer has come back depends on which treatment you had.

Your doctor may do other tests to check if, and where, your cancer has come back. These may include CT, MRI and bone scans. Read more about this in our booklet, Follow-up after prostate cancer treatment: What happens next?

I found that I went through good and not so good emotions.
A personal experience
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 of the cancer cells in your prostate were destroyed during your first treatment.** Small clusters 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 your doctor originally thought.** Tests or scans you had when you were diagnosed might have missed small clusters of cancer cells outside your prostate, for example in your lymph nodes or bones (see the diagram on the next page). Your first treatment would not have been aimed at these cells. Over time, the small clusters of cells may have grown large enough to be picked up by tests or to cause symptoms.

When you were diagnosed your doctor would not have been able to tell you whether or not 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 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 by surgery
• 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.

Ask your doctor or nurse for more details about where your cancer is or is likely to be.

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 of the 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 11). Or you might decide you don’t want any more treatment, other than treatment to help manage any symptoms you might get (see page 19).

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.

- **Permanent seed brachytherapy** involves implanting tiny radioactive seeds into your prostate.

- **Surgery (radical prostatectomy)** removes your prostate and the cancer inside it.

- **High-intensity focused ultrasound (HIFU)** uses ultrasound waves to heat and destroy cancer cells in your prostate. HIFU is newer than some other treatments, so it isn’t available everywhere.

- **Cryotherapy** uses freezing and thawing of your prostate to destroy cancer cells. Cryotherapy is newer than some other treatments, so it isn’t available everywhere.

Read more about these treatments on our website at [prostatecanceruk.org](http://prostatecanceruk.org), 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.

- **Chemotherapy** uses anti-cancer drugs to kill cancer cells, wherever they are in the body. You may be offered chemotherapy alongside hormone therapy. It can cause some serious side effects so you will need to be fit enough to cope with these.
**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 are 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, read our fact sheet, [A guide to prostate cancer 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 to have your prostate cancer monitored, 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, talk to your doctor 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 of the treatments will be available to you. Speak to your doctor or nurse about which ones are available to you.

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 then 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 recurrence) then treatment can no longer cure it. You will be offered hormone therapy to control the cancer, rather than getting rid of it. You might also be offered chemotherapy alongside hormone therapy.

Your general health
Your health and any other medical problems will also affect what treatments are available to you. For example, you may 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 for a while before you have further treatment, particularly if your PSA is rising slowly. If your PSA is rising quickly, this suggests your cancer is more likely to have spread further.

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, cryotherapy and HIFU are not 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.
<table>
<thead>
<tr>
<th><strong>What was your first treatment for prostate cancer?</strong></th>
<th><strong>Second-line treatments that may be suitable</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Surgery (radical prostatectomy)</td>
<td>• Radiotherapy to the prostate bed (with or without hormone therapy)</td>
</tr>
<tr>
<td></td>
<td>• Hormone therapy alone</td>
</tr>
<tr>
<td>External beam radiotherapy</td>
<td>• HIFU (high-intensity focused ultrasound)</td>
</tr>
<tr>
<td></td>
<td>• Cryotherapy</td>
</tr>
<tr>
<td></td>
<td>• Hormone therapy</td>
</tr>
<tr>
<td></td>
<td>• Brachytherapy</td>
</tr>
<tr>
<td></td>
<td>• Surgery</td>
</tr>
<tr>
<td>Permanent seed brachytherapy or high dose-rate (HDR) brachytherapy</td>
<td>• Cryotherapy</td>
</tr>
<tr>
<td></td>
<td>• Hormone therapy</td>
</tr>
<tr>
<td></td>
<td>• HIFU</td>
</tr>
<tr>
<td></td>
<td>• Surgery</td>
</tr>
<tr>
<td>High-intensity focused ultrasound (HIFU)</td>
<td>• More HIFU</td>
</tr>
<tr>
<td></td>
<td>• External beam radiotherapy</td>
</tr>
<tr>
<td></td>
<td>• Cryotherapy</td>
</tr>
<tr>
<td></td>
<td>• Hormone therapy</td>
</tr>
<tr>
<td></td>
<td>• Surgery</td>
</tr>
<tr>
<td>Cryotherapy</td>
<td>• More cryotherapy</td>
</tr>
<tr>
<td></td>
<td>• External beam radiotherapy</td>
</tr>
<tr>
<td></td>
<td>• Hormone therapy</td>
</tr>
<tr>
<td></td>
<td>• Surgery</td>
</tr>
</tbody>
</table>
If you had brachytherapy as a first treatment, you probably won’t be offered HIFU as a second-line treatment. This is because both treatments can damage the lining of the back passage (rectum). This increases the risk of developing a rectal fistula, which is a hole between the back passage and the urethra (the tube you urinate through).

Your doctor might also suggest monitoring your prostate cancer (see page 19) instead of having treatment.

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
- to delay having 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 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
- 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 34.
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 it 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 20).

How will my second-line treatment be monitored?

You will have regular follow-up 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 in our fact sheet, A guide to prostate cancer 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. Hormone therapy treats prostate cancer wherever it is in the body.

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. These include other types of hormone therapy as well as chemotherapy. 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. If you have symptoms between your check-ups, tell your doctor or nurse as soon as possible. New symptoms can be side effects of treatment or signs that your cancer is growing. If they are signs of the cancer coming back your doctor will talk to you about treatment options.

Your doctor or nurse can also give you advice and treatment to help manage your symptoms. For example, if your cancer has spread to the bones and is causing pain, there are treatments to help, such as pain-relieving drugs, drugs called bisphosphonates and pain-relieving radiotherapy. 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. If you are dealing with recurrent prostate cancer 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. But there’s no right way that you’re supposed to feel and everyone reacts in their own way. Finding out that your prostate cancer has come back can be a particularly challenging time.

There are things you can do to help yourself and people who can help. Families can also find this difficult and they may need support too. This section might also be helpful for them.

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.

Look into your treatment options
Find out about the different treatments that are available to you. Bring a list of questions to your doctor or nurse. And ask about any side effects so you know what to expect and how to manage them. This will help you decide what’s right for you.

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. Your GP, nurse or other health professionals involved in your care should be able to answer any questions or concerns you might have.
Set yourself some goals
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.

Eat a healthy, balanced diet
Eating well is good for your general health and lowers your risk of other health problems. There is also evidence that staying a healthy weight may slow down the growth of prostate cancer. 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. Some research suggests that physical activity may help to slow down the growth of prostate cancer. Physical activity can also help with some side effects of treatment, such as anxiety, depression and extreme tiredness (fatigue). Even if you can’t do a lot of physical activity, a small amount can still help. Take things at your own pace. For more information, read our fact sheet, Diet and physical activity for men with prostate cancer.

Quit smoking
Smoking increases the risk of health problems such as heart disease, stroke and some other cancers. It may also be harmful for men with prostate cancer. Some studies suggest that smoking may increase the chance that prostate cancer will 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 men who have never smoked.

Stopping smoking can also help to reduce 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 www.nhs.uk

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

Who else can help?

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

Our Specialist Nurses
Our Specialist Nurses can answer your questions and explain your diagnosis and treatment options. They’ve got time to listen, in confidence, to any concerns you or those close to you have.
**Trained counsellors**
Counsellors are trained to listen and can help you to 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. Your GP may also 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 & Psychotherapy.

**Our one-to-one support service**
Our one-to-one support service is a chance to speak to someone who’s been there and understands what you’re going through. They can share their experiences and listen to yours. You can discuss whatever’s important to you. Our Specialist Nurses will try to match you with someone with similar experiences.

**Our online community**
Our free online community is a place to talk about whatever’s on your mind – your questions, your ups and your downs. Anyone can ask a question or share an experience.

**Local support groups**
At local support groups, men get together to share their experiences of living with prostate cancer. You can ask questions, share worries and know that someone understands what you’re going through. Some groups have been set up by local health professionals, others by men themselves. Many also welcome partners, friends and relatives.
Our fatigue support service
Our fatigue support service is a 10-week telephone service delivered by our Specialist Nurses. It can help if you have problems with extreme tiredness (fatigue), which is a common symptom of prostate cancer. Fatigue can also be a side effect of some treatments for prostate cancer. The fatigue support service can help you make positive changes to your behaviour and lifestyle, which can improve your fatigue over time.

Hospices
You may be able to get support from your local hospice or community palliative care team. They provide a range of services including treatment to manage symptoms such as pain. Hospices don’t just provide care for people at the end of their life. Some people go into a hospice for a short time to get their symptoms under control then go home again. 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. It’s important to get spiritual support if you need it. This could be from your friends or family, or from your religious leader or faith community.

To find out more about any of the above, visit prostatecanceruk.org/get-support or call our Specialist Nurses on 0800 074 8383.
If your prostate cancer comes back

A guide to treatment and support

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 to 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.

<table>
<thead>
<tr>
<th>Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>Telephone number</td>
</tr>
<tr>
<td>Out of hours contact details</td>
</tr>
<tr>
<td>Notes</td>
</tr>
</tbody>
</table>
**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.

<table>
<thead>
<tr>
<th>Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>Telephone number</td>
</tr>
<tr>
<td>Out of hours contact details</td>
</tr>
<tr>
<td>Notes</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>Telephone number</td>
</tr>
<tr>
<td>Out of hours contact details</td>
</tr>
<tr>
<td>Notes</td>
</tr>
</tbody>
</table>

**Consultant urologist**
This is a doctor who specialises in problems with the urinary system. Urologists are also surgeons.

<table>
<thead>
<tr>
<th>Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>Telephone number</td>
</tr>
<tr>
<td>Out of hours contact details</td>
</tr>
<tr>
<td>Notes</td>
</tr>
</tbody>
</table>
**Other health professionals**

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

<table>
<thead>
<tr>
<th>Name</th>
<th>Telephone number</th>
<th>Out of hours contact details</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Name</th>
<th>Telephone number</th>
<th>Out of hours contact details</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Name</th>
<th>Telephone number</th>
<th>Out of hours contact details</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Name</th>
<th>Telephone number</th>
<th>Out of hours contact details</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Questions to ask your doctor or nurse

Which second-line treatments are available to me?

Are there any clinical trials I could 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

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
- [ ] sexual problems
- [ ] bowel problems
- [ ] fatigue problems
- [ ] emotional or mood problems
- [ ] diet
- [ ] physical activity
- [ ] 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.
<table>
<thead>
<tr>
<th><strong>Fill in during or after your appointment</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>My questions or concerns</td>
</tr>
<tr>
<td>Answers to my questions or concerns</td>
</tr>
<tr>
<td>Advice from my doctor or nurse</td>
</tr>
<tr>
<td>PSA level</td>
</tr>
<tr>
<td>Date and time of next appointment</td>
</tr>
</tbody>
</table>
More information from us

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.bladderandboweluk.co.uk
Telephone: 0161 607 8219
Impartial information and advice about bladder and bowel problems.

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

Cancer Research UK
www.cancerresearchuk.org
Telephone: 0808 800 4040
Information about prostate cancer and clinical trials.

College of Sexual and Relationship Therapists (COSRT)
www.cosrt.org.uk
Telephone: 020 8543 2707
Information about sexual and relationship therapy, and details of accredited therapists.

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
A network of drop-in centres for cancer information and support. Includes an online support group.

Marie Curie
www.mariecurie.org.uk
Telephone: 0800 716 146
Runs hospices throughout the UK and a nursing service for people in their own home free of charge.

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

NHS Direct Wales
www.nhsdirect.wales.nhs.uk
Telephone: 0845 46 47
Provides health advice 24 hours a day, and lists local health services in Wales, including GPs and dentists.
**NHS Inform**  
www.nhsinform.co.uk  
Telephone: 0800 22 44 88  
Health information and details of NHS and other support services in Scotland.

**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  
Runs courses and offers physical, emotional and spiritual support for people with cancer and those close to them.

**Samaritans**  
www.samaritans.org  
Telephone: 116 123  
Confidential, judgement-free emotional support, 24 hours a day, by telephone, email, letter or face-to-face.

**Sexual Advice Association**  
www.sda.uk.net  
Information about treatment for sexual problems, including erection difficulties.
About us

Prostate Cancer UK has a simple ambition: to stop men dying from prostate cancer – by driving improvements in prevention, diagnosis, treatment and support.

At Prostate Cancer UK, we take great care to provide up-to-date, unbiased and accurate facts about prostate diseases. We hope these will add to the medical advice you have had and help you to make decisions. Our services are not intended to replace advice from your doctor.

References to sources of information used in the production of this booklet are available at prostatecanceruk.org

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

It was reviewed by:
• Kate Bullen, Professor of Psychology and Head of The School of Applied Social Science, University of Brighton
• Ben Challacombe, Consultant Urological Surgeon and Honorary Senior Lecturer, Guy’s and St Thomas’ NHS Foundation Trust, London and King’s College London
• Louisa Fleure, Prostate Cancer Specialist Nurse, Guy’s and St Thomas’ NHS Foundation Trust, London
• Chris Parker, Consultant Clinical Oncologist, Royal Marsden Hospital, Sutton
• Our Specialist Nurses
• Our Volunteers.
Donate today – help others like you

Did you find this information useful? Would you like to help others in your situation access the facts they need? Every year, 40,000 men face a prostate cancer diagnosis and millions more face other prostate diseases. 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.

To make a donation of any amount, please call us on 0800 082 1616, visit prostatecanceruk.org 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