Follow-up after prostate cancer treatment
What happens next?
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 it 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 for men on long-term treatment for prostate cancer, such as hormone therapy. Read about this in our booklet, Living with hormone therapy: A guide for men with prostate cancer.

The following symbols appear throughout the booklet:

- Our Specialist Nurses
- Our publications
- Sections for you to fill in
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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. And it can help you feel more confident speaking to your doctor or nurse. A treatment summary can also be useful if you see health professionals who don’t already have detailed information about your treatment.

If you don’t know these details, ask your doctor or nurse to help you fill them in.

Treatment summary

<table>
<thead>
<tr>
<th>Your PSA level when you were diagnosed</th>
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<tr>
<td>The PSA test is a blood test that measures the amount of a protein called prostate specific antigen (PSA) in your blood. After your treatment, a continuous rise in your PSA level can be a sign that the cancer has come back. Read more on page 24.</td>
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<table>
<thead>
<tr>
<th>Gleason score</th>
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<td>Your prostate cancer cells are given a Gleason score between 6 and 10. A higher score means that your cancer is likely to be more aggressive.</td>
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**T (tumour) stage**
This shows how far the cancer has spread in and around the prostate.

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<th><strong>N (nodes) stage</strong></th>
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| This shows whether the cancer has spread to the lymph nodes.

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<thead>
<tr>
<th><strong>M (metastases) stage</strong></th>
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</table>
| This shows whether the cancer has spread (metastasised) to other parts of the body.

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

<table>
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<tr>
<th>Treatment</th>
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<td>From</td>
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<table>
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<tr>
<th>Treatment</th>
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<td>From</td>
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**PSA levels after treatment**

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<thead>
<tr>
<th>Date</th>
<th>PSA level</th>
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<tr>
<td>Date</td>
<td>PSA level</td>
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<tr>
<td>Date</td>
<td>PSA level</td>
</tr>
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For more information about PSA, Gleason score and staging, read our fact sheet, **How prostate cancer is diagnosed**.
Follow-up: an overview

In this section:
• What is follow-up?
• When and where will I have my appointments?
• Who will I see?
• What happens at a follow-up appointment?
• What happens between appointments?
• How long will my follow-up last?

What is follow-up?

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
• 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 tell you whether 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 treatment. You will then have appointments every three to six months. Three 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 monitoring

If your PSA level remains stable two years 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 or GP will check your results and telephone you or send them to you in a letter.

Many men like getting their PSA test results this way, as it means they have fewer appointments.

If your PSA rises, you will be given an appointment at the hospital to talk about what this might mean. You can also ask to see your doctor or nurse at any time if you’re worried or have side effects from your treatment, such as urinary or sexual problems.

**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. The team may include:
- a specialist nurse
- a urologist (a doctor who is a surgeon and specialises in problems with the urinary and reproductive systems)
- an oncologist (a doctor who specialises in cancer treatments other than surgery, such as radiotherapy or chemotherapy)
- a radiographer (a health professional who specialises in planning and giving radiotherapy and providing information and support).

If you have your appointments at your GP surgery, you will see your GP or a 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.

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 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. 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 16 for more information about side effects.

**PSA test**

The PSA test is a blood test that 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.

If you are gay, bisexual or a man who has sex with men, being the receptive partner during anal sex might raise your PSA level for a while. 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. You can keep a record of your PSA levels in the appointment diary on page 38. And there’s more information about PSA levels after different treatments on page 24.

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

**Other tests**

If your doctor or nurse is concerned about your PSA level, they may recommend that you have some other tests, such as a prostate biopsy, CT scan, MRI scan, or bone scan. You might also be offered a PET (positron emission tomography) scan, which is another type of scan used to check if cancer has come back after treatment.

They may also recommend you have these tests if you have new symptoms that suggest your cancer might have come back (see page 25). Your doctor or nurse will explain these tests to you if you need them, or you can call our Specialist Nurses for more information.
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 appointment diary on page 38.

- Bring someone with you. It can be hard to take everything in at your appointments. You might find it helpful to take someone with you, 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 38. Or you could ask to record the appointment, for example on your phone.

- 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. It will help you remember what was said at your appointment. If you don’t understand the letter, call 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 15.

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, 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.
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.

My follow-up appointments

<table>
<thead>
<tr>
<th>Question</th>
<th>Details</th>
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<tbody>
<tr>
<td>Where will my appointments be?</td>
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<tr>
<td>How often will I have appointments?</td>
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<tr>
<td>Who will I see at my appointments?</td>
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<tr>
<td>What will my appointments involve?</td>
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Use the appointment diary on page 38 to record the details of each appointment.
## Between appointments

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

<table>
<thead>
<tr>
<th>Name of medicine</th>
<th>Dose</th>
<th>How often</th>
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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
Side effects of treatment

In this section:
- Surgery (radical prostatectomy)
- External beam radiotherapy
- Brachytherapy
- Hormone therapy
- Other treatments

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

Side effects will affect each man 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 are treatments for them, as well as 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 and your partner, family or friends. Read more about this on page 27.
Surgery (radical prostatectomy)
The most common side effects of surgery are leaking urine (urinary incontinence) and problems getting or keeping an erection (erectile dysfunction). There are treatments and support to help with these, as well as things you can do yourself.

Many men leak urine for several months after their operation. This should improve with time and most men start to see an improvement one to six months after surgery. But a small number of men continue to leak urine for years after surgery. This can be hard to deal with, but there are things that can help.

You may get erection problems after surgery. These might improve but many men still have problems two or three years later. You may find that your erections aren’t as strong as they were before surgery. Some men will always need to use aids, such as tablets, a vacuum pump or injections, to get an erection.

Read more in our publications, Surgery: radical prostatectomy, Urinary problems after prostate cancer treatment, and Prostate cancer and your sex life.

The continence nurse was supportive and reassuring. She made me feel very comfortable and gave me helpful advice.

Personal experience
External beam radiotherapy

The side effects of external beam radiotherapy can include urinary problems, such as bladder irritation, needing to urinate urgently or more often and difficulty urinating. You might have problems getting or keeping an erection. And you may get extreme tiredness (fatigue).

Some men 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. 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 shortly after radiotherapy. For many men, side effects will settle down in the first year after treatment ends. But for some men, these side effects will continue. Some men start to get side effects months or even years after radiotherapy has ended.

There are treatments that can help, as well as things you can do yourself. Read more in our publications, External beam radiotherapy, Urinary problems after prostate cancer treatment, Prostate cancer and your sex life and Fatigue and prostate cancer.

Brachytherapy

You might have had permanent seed brachytherapy (low dose-rate brachytherapy) or high dose-rate brachytherapy. The most common side effects of brachytherapy are urinary problems, such as needing to urinate more often or a sudden urge to urinate, and problems getting or keeping an erection. Some men also get bowel problems, which tend to be mild. You may also get extreme tiredness (fatigue).
These problems tend to be worse in the first few weeks after treatment but usually start to improve after that. However, problems urinating can develop months after treatment.

You might have more side effects if you have high dose-rate brachytherapy and external beam radiotherapy together.

There are ways to manage these side effects. Read more in our publications, Permanent seed brachytherapy, High dose-rate brachytherapy, Urinary problems after prostate cancer treatment, Prostate cancer and your sex life and Fatigue and prostate cancer.

**Hormone therapy**

Side effects from hormone therapy can include hot flushes, sexual problems, extreme tiredness (fatigue), weight gain and mood changes.

For most men, 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 in our fact sheets, High-intensity focused ultrasound (HIFU) and 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.

<table>
<thead>
<tr>
<th>Side effect</th>
<th>Things I can do myself</th>
<th>Treatment I am having for it (if any)</th>
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**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 44). You can also call our Specialist Nurses.

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.

<table>
<thead>
<tr>
<th>Who?</th>
<th>Why?</th>
<th>Contact details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Counsellor or psychologist</td>
<td>To help deal with the emotional effects of having prostate cancer.</td>
<td></td>
</tr>
<tr>
<td>Urologist, continence service or physiotherapist</td>
<td>For advice and support with urinary problems.</td>
<td></td>
</tr>
<tr>
<td>Erectile dysfunction (ED) clinic or sex therapist</td>
<td>For advice and support with sexual problems.</td>
<td></td>
</tr>
<tr>
<td>Gastroenterologist</td>
<td>For advice and support with bowel problems following radiotherapy.</td>
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</tbody>
</table>
**Our fatigue support service**
Our Specialist Nurses provide a fatigue support service for men. They can give you information and ongoing support over the telephone. They will encourage you to take practical steps to manage your fatigue. You can speak to them, in confidence, on 0800 074 8383.

The side effects can be managed and there is a lot of expert help out there to get you through it. Ask your doctor about what services are available.

**Personal experience**

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

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

Find them all at prostatecanceruk.org/guides
Will my cancer come back?

In this section:
• The risk of your cancer coming back
• How will I know if my cancer has 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 and the stage of your cancer. If your prostate has been 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.

Read more about Gleason scores and the staging of prostate cancer 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 can 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 which treatment you had. Speak to your doctor or nurse about your own situation.

You can record your PSA level in the appointment diary on page 38. Or you can order one of our PSA record cards.

PSA level after surgery (radical prostatectomy)

Your PSA level should drop so low that it’s not possible to detect it (less than 0.1 ng/ml) at six to eight weeks after surgery. 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) after 18 months to two years. 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 treatment, and then fall again. This is called ‘PSA bounce’. It could happen up to three years after treatment. It is normal, and doesn’t mean that the cancer has come back.
If your PSA level rises by 2 ng/ml or more above its lowest level, or if it rises for three or four PSA tests in a row, this could be a sign that your cancer has come back. 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. 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. And 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. 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.

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 to see whether or not your cancer might have come back.
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.

In this section:
- Common thoughts and feelings
- How can I help myself?
- Who can help?

**Common thoughts and feelings**

You may feel all sorts of things after you finish treatment. Some men 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.

For some men, the emotional impact of what they have been through only hits them after they have finished treatment. You might feel angry – for example, angry at what you have been through, or 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 in the few days before your appointments.
Worries about your cancer coming back
You may worry about your cancer coming back. This is natural, and will often improve with time. There are things you can do to help manage your concerns, such as finding ways to reduce stress.

There’s more information about the chance of your cancer returning and how you’ll know if it’s come back on page 23. 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 might find it difficult seeing your doctor or nurse less often than when you were having treatment. You might miss their regular support and reassurance. Some men 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 33.

I was told I didn’t need to see the doctor anymore. I felt so abandoned, it was like ‘Okay, you can go now, you’re on your own again’.
Personal experience

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.
Depression and anxiety

Some men with prostate cancer feel anxious and may become depressed, even after treatment has finished. If you’re depressed you may feel low, feel bad about yourself, or not want to do things. Some men who are depressed find they get angry more easily, start drinking more alcohol, and stop taking care of themselves.

If you often feel uneasy, have difficulty sleeping or can’t concentrate, this could be a sign that you are feeling anxious.

If you have these kinds of feelings, there are things you can do to help yourself and people who can help (see below). Speak to your GP or doctor or nurse. If you need to speak to someone immediately, you could call 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.”

Personal experience

How can I help myself?

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.
Some people find it helpful to talk to people with personal experience of prostate cancer. Read more about this on page 33.

**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 some evidence that certain foods may help slow down the growth of prostate cancer or reduce the chance of it coming back. Eating a healthy diet can help with some side effects of treatment, such as bowel problems and urinary problems. For more information, 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 studies suggest that physical activity may help slow down the growth of prostate cancer, although other studies haven’t found this. It can also 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, 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*.

You can find more ideas in our booklet, *Living with and after prostate cancer: A guide to physical, emotional and practical issues*. 

Information about things I can do myself

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

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<th>Fill in things you can do yourself</th>
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<tr>
<td>Diet</td>
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<td>Physical activity</td>
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<tr>
<td>Extreme tiredness (fatigue)</td>
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<td>Relationships and sex</td>
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## Fill in things you can do yourself

<table>
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<th>Section</th>
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<tr>
<td>Stress and anxiety</td>
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<tr>
<td>Complementary therapies – some men find these help with side effects</td>
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<tr>
<td>Work and finances</td>
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<td>Practical issues, such as holidays and insurance</td>
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<tr>
<td>Details of events or courses about life after cancer treatment</td>
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Who can help?
There are lots of people who can help. For more information about any of our services mentioned below, contact our Specialist Nurses on 0800 074 8383 or visit prostatecanceruk.org/get-support

Your medical team
It could be 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 others who can help.

Some hospitals run courses to provide information for men who have finished prostate cancer treatment. Macmillan Cancer Support and Maggie’s Centres also run courses. Ask your doctor or nurse for information about what’s available in your area.

Our Specialist Nurses
Our Specialist Nurses can answer your questions and explain how to manage any side effects you have. They’ve got time to listen in confidence to any concerns you or those close to you have.

Trained counsellors
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. If you don’t have appointments at the hospital any more, your GP may be able to refer you to a counsellor, or you can see a private counsellor. To find out more, contact the British Association for Counselling & Psychotherapy.

Our one-to-one support service
Speak to someone who’s had personal experience of prostate cancer 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 to someone with similar experiences.

**Our online community**
Our free online community is a place to talk about whatever’s on your mind. Anyone can ask a question or share an experience. It’s a place to deal with prostate cancer and side effects from treatment together.

“I wish I had known about the online community sooner. Until you start using it, you don’t appreciate its worth.”
*Personal experience*

**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.

**Local support groups**
At support groups, men share their experiences of living with and after prostate cancer – you can ask questions, share concerns 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 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.

Spiritual support
You might begin to think more about spiritual beliefs as a result of having had prostate cancer. It’s important that you get spiritual support if you need it. This could be from your friends or family, or from your religious leader or faith community.

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.

Personal experience
Questions to ask my doctor or nurse

How often will I have follow-up appointments and where will they be?

What will happen at my appointments?

Who will I see at my appointments?

Who do I contact with questions or concerns between my appointments?

Who will help manage my side effects?
Are there any side effects I might develop at a later date?

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

What is the risk of my cancer coming back?

Is there any sign that my cancer might be coming back?

What rise in my PSA level might suggest my cancer has come back?
My appointment diary

You can fill in this diary before and after follow-up 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 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 problems
- [ ] 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
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.

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- bowel problems
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- diet
- physical activity
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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 or text NURSE to 70004. You can also email or chat online with our nurses on our website. Visit prostatecanceruk.org/get-support

Speak to our Specialist Nurses
0800 074 8383*
prostatecanceruk.org

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

**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.

**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.

**NHS Choices**  
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  
Provides 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.sexualadviceassociation.co.uk
Information about sexual problems and their treatments, including erection problems.
About us

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

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

References to sources of information used in the production of this booklet are available at prostatecanceruk.org
This publication was written and edited by:
our Health Information team.

It was reviewed by:
• Vanessa Basketter, Advanced Prostate Cancer Nurse Specialist, University Hospital Southampton NHS Foundation Trust
• Ben Challacombe, Consultant Urological Surgeon and Honorary Senior Lecturer, Guy’s and St Thomas’ Hospitals NHS Foundation Trust and King’s College London
• Amanda Ford, Macmillan Radiotherapy Radiographer Specialist, Ipswich Hospital NHS Trust
• Netty Kinsella, Uro-Oncology Nurse Consultant, The Royal Marsden NHS Foundation Trust
• Jonathan Rees, GP specialising in Urology, Backwell and Nailsea Medical Group, North Somerset
• Nona Toothill, Urology Clinical Nurse Specialist, Airedale NHS Foundation Trust, West Yorkshire
• Cathryn Woodward, Consultant Clinical Oncologist, Addenbrooke’s Hospital, Cambridge and West Suffolk NHS Foundation Trust
• Our Specialist Nurses
• Our Volunteers.

Tell us what you think
If you have any comments about our publications, you can email: literature@prostatecanceruk.org
Donate today – help others like you

Did you find this information useful? Would you like to help others in your situation access the facts they need? Every year, 40,000 men face a prostate cancer diagnosis. Thanks to our generous supporters, we offer information free to all who need it. If you would like to help us continue this service, please consider making a donation. Your gift could fund the following services:

- £10 could buy a Tool Kit – a set of fact sheets, tailored to the needs of each man with vital information on diagnosis, treatment and lifestyle.

- £25 could give a man diagnosed with prostate cancer unlimited time to talk over treatment options with one of our specialist nurses.

To make a donation of any amount, please call us on 0800 082 1616, visit prostatecanceruk.org/donate or text PROSTATE to 70004†. There are many other ways to support us. For more details please visit prostatecanceruk.org/get-involved

†You can donate up to £10 via SMS and we will receive 100% of your donation. Texts are charged at your standard rate. For full terms and conditions and more information, please visit prostatecanceruk.org/terms
Speak to our Specialist Nurses
0800 074 8383*
prostatecanceruk.org

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To be reviewed December 2018

Call our Specialist Nurses from Monday to Friday 9am - 6pm,
Wednesday 10am - 8pm
* 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.