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 monitor your progress. This is often called follow-up.

This booklet describes the care and support you can expect after your treatment. There’s also space to fill in details of your treatments, your personal follow-up plan, and a diary for your appointments. Your partner, family or friends might also find it useful.

This is a general guide. Every hospital does things differently, so ask your doctor or nurse what happens when you finish treatment.

We haven’t included information about long-term hormone therapy for cancer that has spread to other parts of the body (advanced prostate cancer) – read about this in our booklet, Living with hormone therapy: A guide for men with prostate cancer.

The following symbols appear throughout the booklet to highlight different sources of information:

- Prostate Cancer UK Specialist Nurse helpline
- Prostate Cancer UK publications
- Sections for you to fill in
If you would like to know more about anything you read in this booklet, you can call our Specialist Nurses on our confidential helpline.

Your main contact or ‘key worker’
After your treatment there will usually be one person who is your main contact for your follow-up care. They might be your specialist nurse, hospital doctor, GP, radiographer, or another health professional. You may hear them called your ‘key worker’.

They help co-ordinate your care, answer your questions, and can suggest useful sources of information. You will be given details of who your main contact is and how to get in touch with them.

Throughout this booklet when we talk about your doctor or nurse, we are usually talking about this main contact or ‘key worker’.
## Contents

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

Summary of your treatment .................................................................................................. 6

Follow-up: an overview ........................................................................................................ 8

My follow-up plan ............................................................................................................... 15

What symptoms should I look out for? ............................................................................. 17

Side effects .......................................................................................................................... 19

What can I do to help myself? ........................................................................................... 27

Common thoughts and feelings ......................................................................................... 30

What is the chance of my cancer coming back? ................................................................. 36

More information from us ................................................................................................. 48

Other useful organisations ................................................................................................. 49

About Prostate Cancer UK ................................................................................................. 52
### Sections for you to fill in

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment summary</td>
<td>6</td>
</tr>
<tr>
<td>My follow-up appointments</td>
<td>15</td>
</tr>
<tr>
<td>Between appointments</td>
<td>16</td>
</tr>
<tr>
<td>Other symptoms your doctor or nurse might ask you to look out for</td>
<td>17</td>
</tr>
<tr>
<td>Other problems</td>
<td>18</td>
</tr>
<tr>
<td>Managing side effects from my treatment</td>
<td>24</td>
</tr>
<tr>
<td>Further support with side effects</td>
<td>26</td>
</tr>
<tr>
<td>Advice about things I can do myself</td>
<td>28</td>
</tr>
<tr>
<td>Questions to ask your doctor or nurse</td>
<td>40</td>
</tr>
<tr>
<td>Appointment diary</td>
<td>42</td>
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Summary of your treatment

You might find it helpful to have a summary of your diagnosis and your treatments. This could be useful, for example, if you see health professionals who don’t have detailed information about your treatment. If you don’t know these details, you could ask your doctor or nurse to fill them in.

Knowing about your own cancer and your treatment can help you make sure you get the support that’s right for you. It can also help you feel more confident speaking to your doctor or nurse.

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<th>Treatment summary</th>
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<td><strong>Date you were diagnosed</strong></td>
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<td><strong>PSA level when you were diagnosed</strong></td>
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<tr>
<td><strong>Gleason score</strong></td>
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## Stage of your cancer
This shows how far the cancer has spread.

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<td>This shows how far the cancer has spread in and around the prostate.</td>
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<td>This shows whether the cancer has spread to the lymph nodes.</td>
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## Summary of treatment
You may be given a summary of your treatment by your doctor or nurse.

**Treatment:**

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<td>From:</td>
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## PSA level at the end of treatment

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<th>Date:</th>
<th>PSA level:</th>
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Find more detailed information about PSA, Gleason score and the stage of your cancer in our Tool Kit fact sheet, **How prostate cancer is diagnosed.**
Follow-up: an overview

What is follow-up?
After you’ve finished treatment for your prostate cancer, you will still have regular appointments to monitor your progress. These are known as follow-up appointments or check-ups. The aim is to:
• check how your cancer has responded to treatment
• deal with any side effects of treatment
• give you a chance to raise any concerns or ask any questions.

Is my cancer cured?
Your doctor or nurse won’t usually use the word ‘cure’. Instead they may say that you’re ‘in remission’. This means that there is no sign of cancer at that time.

Unfortunately, your doctor or nurse can’t tell you whether your cancer is going to come back. Each cancer is different and it depends 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 between six weeks and three months after treatment. To begin with, you might have appointments every three or four months. After this, they could be every six months. After two years, you might have check-ups once a year. But your appointments might be more frequent than this, so check with your doctor or nurse.

Where you have your appointments will depend on the services in your area and on your own circumstances.
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.

If your PSA level remains stable a year or two after treatment, you might be monitored remotely. This means that you won’t have appointments with anyone. Instead, you will be sent a letter when you need to have a PSA test done. The results of the test will be checked by the hospital or your GP. You’ll also be sent a letter with the results. If your PSA rises, you will be sent an appointment at the hospital. See page 11 for more information about the PSA test.

The place where you have follow-up 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 follow-up, you will be given the details of someone to contact at any time if you have any concerns, such as new symptoms or side effects. See page 16.

Managing side effects
If you have problems with side effects, you might also be referred to a specialist service to help with this. For example, if you have problems with leaking urine (incontinence), you might be referred to a continence service. Or if you have problems with getting and keeping erections (erectile dysfunction), you can be referred to an erectile dysfunction (ED) service. See page 19 for more about side effects.
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 doctors, nurses and other specialists involved in your care. You may hear it called your specialist team. The team could include:
- a specialist nurse
- a consultant urologist
- a consultant oncologist
- a radiographer
- other health professionals.

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

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, the 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 might continue to have PSA tests. And you can 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.
What happens at a follow-up appointment?

Discussion with your doctor or nurse
At each appointment, your doctor or nurse will talk to you about 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 about how you are feeling emotionally as well as physically, and about any practical problems you might have. You may be given a questionnaire about your physical, social, emotional and practical needs.

Your doctor or nurse can help you deal with side effects, or refer you to someone else who can. They can also refer you for support with emotional or practical problems. It can be embarrassing talking about some of the side effects of treatments, such as erection problems, but remember – they’ve heard it all before, so be as honest as you can. They are there to help.

See page 19 for more 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 hospital, depending on the services in your area.
PSA tests are a very effective way of checking how successful your treatment has been. 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 42. And there’s more about PSA levels after different treatments on page 37.

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. They may also recommend you have these tests if you have new symptoms which suggest that the cancer might have come back (see page 17). Your doctor or nurse will explain these tests to you if you need them.

**In a clinical trial?**

If your treatment was part of a clinical trial, how and when you have follow-up appointments will vary. It depends on the particular trial you took part in. The research nurse or doctor should be able to give you more information about your follow-up plan.
Get the most from your follow-up appointments

• **Write down any questions or concerns beforehand.** It is easy to forget what you want to say once you are at your appointment. There’s space for questions in the appointment diary on page 42.

• **Bring someone with you.** There can be a lot to take in at your appointments. You might find it helpful to bring someone with you, to listen and discuss things with later.

• **Make notes.** You might find it useful to write things down during or after your appointment. There’s space for this in the appointment diary on page 42. Or if you’d prefer, you can ask if you can record the appointment, on your phone for example.

• **Don’t be afraid to ask for help.** If there is anything bothering you, let your doctor or nurse know.

• **If your appointment is at the hospital, ask for a copy of the letter that is sent to your GP.** You might be sent it automatically. It will help to remind you of what was said at your appointment. If you have any problems understanding the letter, you can call our Specialist Nurses on our confidential helpline.
What happens between appointments?

You should get in touch with your doctor or nurse if you have any concerns or develop any new symptoms or side effects between your follow-up appointments. There’s space to note down their contact details on page 16.

It’s important that you contact them if you’re concerned about anything – don’t worry about them being too busy. You might be able to get support or advice over the telephone, or bring forward the date of your next follow-up appointment.
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. Record these details in this section.

You may be offered a written care plan at the end of your treatment which will have this information. Or you can ask your doctor or nurse to help you fill in this section.

If there is anything you are unsure or concerned about, speak to your doctor or nurse about it. They may be able to help, or can refer you to someone who can.

<table>
<thead>
<tr>
<th>My follow-up appointments</th>
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<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 42 to record the details of each appointment.
**Between appointments**

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

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<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? See page 17 for symptoms to look out for.

Name:

Phone:

Name:

Phone:

Contact details for my GP (if different to above)

Name:

Phone:

Prostate Cancer UK Specialist Nurses 0800 074 8383
What symptoms should I look out for?

There are certain symptoms that can be a sign that your cancer has come back. But they can also be caused by other things, like an enlarged prostate or urine infection. Or they can be side effects of treatments.

Symptoms to look out for include:

- blood in the urine or semen
- needing to urinate more often, especially at night – for example if you often need to go again after two hours
- difficulty starting to urinate
- a weak flow of urine and straining to go
- taking a long time to finish urinating
- a feeling that your bladder hasn’t emptied properly
- needing to rush to the toilet – you may occasionally leak urine before you get there
- dribbling urine
- pain when urinating
- persistent aches and pains in your bones that last more than a week
- continuous pain in the pelvic region – the area below your stomach
- unexplained weight loss
- swelling in your legs.

Other symptoms your doctor or nurse might ask you to look out for:
If you do get any of these symptoms it is a good idea to get them checked out, so let your doctor or nurse know. They’ll look at your PSA level and any other test results to confirm whether or not your cancer has come back. A rise in your PSA level will usually be the first sign that cancer has come back, rather than symptoms.

Other problems

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

Name:

Phone:
Side effects

Treatments for prostate cancer can cause side effects, which might carry on after your treatment has finished. For example, you might get erection problems after surgery or radiotherapy. Some side effects can even start several months or years after treatment finishes, including some of the side effects of radiotherapy.

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. They can refer you for further help. For example, if you’re having problems with erections, they can refer you to an erectile dysfunction (ED) clinic for treatment.

Surgery

The most common side effects of surgery are leaking urine and problems getting an erection. There are treatments and support to help with these, as well as things you can do yourself.

Many men carry on leaking urine for several months after their operation. This should improve with time and most men will notice an improvement three to six months after surgery. But some men still have problems a year after surgery.
Erection problems are also a common side effect of surgery. It can take anything from a few months to three years for erections to return. You may find that your erections aren’t as good as they were before surgery. Some men will always need to use aids, such as tablets or a vacuum pump, to get an erection.

Read more in our Tool Kit fact sheets, Surgery: radical prostatectomy, Urinary problems after prostate cancer treatment, and Pelvic floor muscle exercises, and in our booklet, Prostate cancer and your sex life.

**External beam radiotherapy**

The side effects of external beam radiotherapy can include urinary problems such as needing to urinate urgently and more often and, sometimes, blood in the urine. You might also get erection problems.

Some men also find that their bowel habits change. You might pass loose or watery stools (diarrhoea), need the toilet more often or more urgently, leak mucus – especially when you pass wind – have pain around your abdomen or back passage, or have bleeding from the back passage.

Many men get side effects during their radiotherapy treatment which settle down after treatment finishes. But it is possible to develop side effects months or even years after radiotherapy has finished. There are treatments which can help, and things you can do for yourself.

Read more in our Tool Kit fact sheets, External beam radiotherapy and Urinary problems after prostate cancer treatment, and in our booklet, Prostate cancer and your sex life.
I finished radiotherapy six months ago. I didn’t have many side effects during treatment, but over the past few weeks I have had some diarrhoea and a small amount of bleeding from the back passage.

Personal experience

**Brachytherapy**

The most common side effects of brachytherapy are problems urinating and erection problems. Some men also get bowel problems, which tend to be mild.

Side effects are generally at their worst a few weeks or months after treatment. They should improve over the following months. But some side effects develop later. If you have brachytherapy and external beam radiotherapy together, the side effects might be worse. There are ways to manage the side effects of brachytherapy.

Read more in our Tool Kit fact sheets, [Permanent seed brachytherapy](#), [Temporary brachytherapy](#) and [Urinary problems after prostate cancer treatment](#), and in our booklet, [Prostate cancer and your sex life](#).
**Hormone therapy**

Side effects from hormone therapy can include erection problems, losing your desire for sex (libido), hot flushes, weight gain and mood changes.

For most men, side effects will gradually improve after they stop hormone therapy. But it can take several months for them to wear off. There are ways to manage them.

Read more in our booklet, *Living with hormone therapy: A guide for men with prostate cancer*.

**Other treatments**

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

Read more in our Tool Kit fact sheets, *Cryotherapy* and *High intensity focused ultrasound (HIFU)*.
Fatigue (extreme tiredness)
Fatigue is extreme tiredness or exhaustion, which makes it hard to carry out your daily activities. Some men describe feeling weak, lethargic, knackered or drained. It can affect your energy levels, motivation, ability to concentrate, emotions and sex drive. Many men find it difficult to cope with fatigue – and it’s not always relieved by rest alone.

Fatigue might be caused by any prostate cancer treatment. It could improve after your treatment has finished, but some men find it lasts longer. Hormone therapy in particular can cause fatigue.

We have a telephone support service called Get back on track that can help with managing fatigue. Find out more on our website at prostatecanceruk.org or call our Specialist Nurses on our confidential helpline.

Read more about dealing with the side effects of treatment and where to get support in the following publications.

- Prostate cancer and your sex life
- Urinary problems after prostate cancer treatment
- Pelvic floor muscle exercises
- 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
- Diet, physical activity and prostate cancer

You can also call our Specialist Nurses on our confidential helpline.
Managing side effects from my treatment

You can record your side effects and ways to manage them here.

You might have an assessment with your doctor or nurse to identify your needs, and this information may be included in your care plan, if you have one. Or you might find it helpful to fill this in with your doctor or nurse.

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<thead>
<tr>
<th>Side effect</th>
<th>Things I can do myself to manage or reduce it</th>
<th>Treatment I am having for side effects (if any)</th>
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Details of any side effects that I might develop in the future (ask your doctor or nurse to help you fill this in):

<table>
<thead>
<tr>
<th>Side effect</th>
<th>Things I can do myself to manage or reduce it</th>
<th>Treatment I am having for side effects (if any)</th>
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## Further support with side effects

To get extra help with a side effect, your doctor or nurse might refer you to someone who can give you more advice and support. You can record their details here.

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<thead>
<tr>
<th>Who?</th>
<th>Why?</th>
<th>Contact details</th>
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<tr>
<td>Counsellor or psychologist</td>
<td>To help deal with the emotional effects of having prostate cancer.</td>
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<tr>
<td>Continence service or physiotherapy service</td>
<td>For advice and support with urinary problems.</td>
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<tr>
<td>Erectile dysfunction (ED) clinic or sex therapist</td>
<td>For advice and support with sexual problems.</td>
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</tr>
<tr>
<td>Gastroenterologist</td>
<td>For advice and support with bowel problems following radiotherapy.</td>
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<tr>
<td>Other</td>
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</table>
What can I do to help myself?

There are things you can do yourself to look after your own health. This is sometimes called self-management. Find out more in our booklet, *Living with and after prostate cancer: A guide to physical, emotional and practical issues* and our Tool Kit fact sheet, *Diet, physical activity and prostate cancer*. You can also ask your doctor or nurse for advice.

Some hospitals have cancer information centres where you can get information about cancer, treatment and side effects. And some hospitals also run courses for people living with or after cancer. These can provide information and support about work, relationships, diet and physical activity. Macmillan Cancer Support and Maggie’s Centres also run courses. Ask your doctor or nurse about what’s available in your area.

Record any advice you’re given on the next page.
### Advice about things I can do myself

Advice about diet

Advice about physical activity

Advice about managing fatigue

Advice about relationships and sex

Advice about managing stress and anxiety
| Advice about complementary therapies – some men find these help with side effects |
| Advice about finances |
| Advice about other practical issues, for example, holidays and insurance |
| Event or course about life after cancer treatment |
| Local support groups |
Common thoughts and feelings

You may feel all sorts of things after you have finished 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, it’s only after they have finished treatment that the emotional impact of what they have been through hits them. You might feel angry – for example, angry at what you have been through, or angry at how side effects have affected you. Or you might feel sad, or anxious about the future.

Follow-up appointments can also trigger different emotions. You might find it reassuring to see the doctor or nurse, or you may find the appointments stressful, particularly in the few days beforehand.

Worries about the 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.

It can help to know what symptoms might be a sign of the cancer returning. We have listed these on page 17. If you are worried about any symptoms, speak to your GP or doctor or nurse. If the cancer does come back, there are further treatments that you can have which aim to control or get rid of the cancer.

Read more in our booklet, Recurrent prostate cancer: A guide to treatment and support.
Feeling isolated

During follow-up, you might find it difficult seeing your doctor or nurse less often than you did when you were having treatment, and miss their regular support and reassurance. Some men describe feeling isolated and abandoned when they finish their treatment. Speak to your GP if you have any concerns. Or you could call our Specialist Nurses on our confidential helpline.

“I was told that I might be signed off by my doctor. I felt quite upset that I wasn’t actually overjoyed about getting that news. I felt so abandoned, it was like “Ok, you can go now, you’re on your own again”.

Personal experience

Dealing with side effects of treatments

Some men find that the impact of the side effects only sinks in once their treatment has finished. Getting some support in managing side effects can help. See page 19 for more information.

Depression and anxiety

Some men with prostate cancer get depression and anxiety, even after treatment has finished. Being depressed doesn’t always mean being tearful or low. Some men who are depressed find they get angry more easily, start drinking more and stop taking care of themselves.
If you recognise these kinds of changes in yourself, there are things that can help. Speak to your GP or doctor or nurse. If you need to speak to someone immediately, you could ring the Samaritans on 08457 90 90 90.

**What can help?**

There are different ways to deal with this period of change. Go easy on yourself and don’t expect to have all the answers. Some men deal with things on their own, but plenty of others make use of the support that’s on offer. If you are finding things hard, you can ask for help – from someone you know or from people trained to help.

Your partner and family may also need support in emotional and practical ways. This information could also be helpful for them.

**Getting support from others**

**Friends and family**

Some men get all the back-up they need from friends and family. Try getting things off your chest by talking to them. Explaining how you feel can help them understand and give you support if you want it.

**Talking to someone who’s been there**

You might find it helps to speak to someone who knows what you’re going through. There are prostate cancer support groups across the country where you and your family can meet other people affected by prostate cancer. Find details of your local group on our website at [prostatecanceruk.org](http://prostatecanceruk.org) or ask your doctor or nurse. You can make a note of them on page 29.

You can also speak to one of our peer support volunteers. They are all people affected by prostate cancer, including men who have
finished treatment. They’re trained to listen and offer support over the telephone. We can match you to volunteers who can talk to you about:

• their experience of treatment
• practical tips for coping with side effects
• the impact of prostate cancer on relationships or your sex life
• living with a partner or family member who has prostate cancer
• a range of other issues.

Call our Specialist Nurses on our confidential helpline to arrange to speak to a volunteer.

If you have access to the internet, you can join our online community, where men and their families share their experiences of prostate cancer. Visit our website at prostatecanceruk.org to sign up.

**Health professionals**

You could speak to your doctor, nurse, GP or another health professional. They should be able to answer your questions and concerns, and offer support. They can also put you in touch with other services and organisations that can offer practical and emotional support.

You can also call our Specialist Nurses on our confidential helpline.

Some people find talking to a counsellor helps. They are trained to listen and can help you to understand your feelings and find your own answers. Your GP or doctor or nurse may be able to refer you to a counsellor, or you can find one yourself. There are different types of counselling available. The British Association for Counselling and Psychotherapy has more information and a list of counsellors in your area.
More information
Read more about different ways of dealing with things in our booklet, Living with and after prostate cancer: A guide to physical, emotional and practical issues. It has lots of tips for things you can do yourself, as well as sources of support.

Some hospitals run courses to provide information for men who have finished prostate cancer treatment. Macmillan Cancer Care and Maggie’s Centres also run courses.

Partners and family members might want to read our booklet, When you are close to a man with prostate cancer: A guide for partners and family.

I found it very 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
I was grateful to have counselling. Later, I joined a stress management class. And I joined my local prostate cancer support group. The support and friendship we give each other has meant so much to me.

Personal experience
What is the chance of my cancer coming back?

Many men have their cancer successfully treated. But there may be a chance of it coming back (recurrent prostate cancer). One of the aims of your follow-up appointments is to check for any signs of this.

Your doctor can’t say for certain whether your cancer will return. They can only tell you how likely it is. When prostate cancer is diagnosed, it’s often divided into risk groups. This is the risk of the cancer coming back after treatment. To work this out, your doctor will have looked at your PSA level, your Gleason score and the stage of your cancer when it was diagnosed. If you don’t know these details, ask your doctor or nurse.

**Low risk**

You may have a low risk of the cancer coming back if:
- your PSA level when you were diagnosed was less than 10ng/ml, **and**
- your Gleason score was less than 7, **and**
- your cancer had not spread outside the prostate gland – stage T1 or T2 (localised prostate cancer).

**Medium or moderate risk**

You may have a medium risk of the cancer coming back if:
- your PSA level when you were diagnosed was between 10 and 20ng/ml, **or**
- your Gleason score was 7, **or**
- your cancer did not appear to have spread outside the prostate – stage T2b or T2c (localised prostate cancer).
**High risk**
You may have a high risk of the cancer coming back if:
• your PSA level when you were diagnosed was over 20ng/ml, or
• your Gleason score was over 7, or
• your cancer had broken through the capsule of the prostate, or had spread to the surrounding areas such as the seminal vesicles, lymph nodes or bladder neck – stage T3 or T4 (locally advanced prostate cancer).

Read more about Gleason scores and the stages of prostate cancer in our Tool Kit fact sheet, **How prostate cancer is diagnosed**.

**How will I know if my cancer has come back?**
A rise in your PSA may be the first sign that your cancer has come back. This will be picked up by the regular PSA tests you have. If you have any of the symptoms on page 17, let your doctor or nurse know. These can be a sign that the cancer has come back – but they are often a side effect of treatment, or caused by something else which has nothing to do with your cancer, such as an enlarged prostate.

The exact change in PSA level that suggests your cancer has come back depends 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 42. Or you can order one of our PSA record cards.

**PSA level after surgery (radical prostatectomy)**
After surgery, your PSA level should drop to an undetectable level, usually less than 0.1ng/ml. This is because the prostate gland, which produces PSA, has been removed. If your cancer has returned, there would be a measurable amount of PSA which rises over time.
Some hospitals use ‘super sensitive’ PSA testing, which can measure PSA levels as low as 0.01 or 0.02. This may be able to detect signs that the cancer has come back at a very early stage. If a hospital uses super sensitive PSA testing, they will have their own guidelines of what an undetectable PSA level is. This is a fairly new way of measuring PSA, and it is not used in all hospitals.

**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. Some PSA will still show up in tests because healthy prostate tissue will continue to produce PSA. Sometimes men may have a rise and fall in PSA around one to two years after treatment. This is called ‘PSA bounce’. It is normal, and does not show that the cancer has returned. A sign that your cancer may have come back is if your PSA level has risen by 2ng/ml or more above its lowest level, or if it has risen for three or four PSA tests in a row.

If you had hormone therapy before radiotherapy or brachytherapy, your PSA level should drop to a lower level quite quickly. If you continue to have hormone therapy after radiotherapy, your PSA level may continue to fall further. There may be a small rise in PSA after you finish the hormone therapy. This is normal and does not mean that your cancer has come back. However, a rise of more than 2ng/ml from your lowest level may suggest that your cancer has come back. But even if your PSA does rise more than 2ng/ml from its lowest level, your doctor may want to know how quickly (or slowly) it is rising before deciding on what treatment to offer you. In this case you may have your PSA monitored for at least six months before deciding on a treatment.
PSA level after high intensity focused ultrasound (HIFU) or cryotherapy
Because these treatments are relatively new, we don’t know so much about what level of PSA might indicate that your cancer has come back. Speak to your doctor or nurse about your own situation.

If your cancer does come back, there are other treatments you can have which aim to control or get rid of it. Speak to your doctor or nurse about your options. Read more in our booklet, Recurrent prostate cancer: A guide to treatment and support.

You can also call our Specialist Nurses on our confidential helpline.
Questions to ask your 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?

What rise in PSA might suggest my cancer has come back?
Appointment diary

You can fill in this diary before and after your follow-up appointments, to help you get the most out of them. You might want to photocopy one of the pages 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

My questions or concerns
Fill in during or after your appointment

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

My questions or concerns
Fill in during or after your appointment

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

### My questions or concerns
Fill in during or after your appointment

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 is treated and how it may affect your lifestyle. Each treatment fact sheet also includes a list of suggested questions to ask your doctor.

Leaflets and booklets
Other leaflets and booklets about prostate cancer and other prostate problems can be ordered free of charge from Prostate Cancer UK.

To order publications:
• Call us on 0800 074 8383
• Visit our website prostatecanceruk.org

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 email the nurses using the contact form on our website. Visit prostatecanceruk.org and click on ‘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 Foundation
www.bladderandbowelfoundation.org
Helpline 0845 345 0165
Information and support for all types of bladder and bowel problems.

British Association for Counselling and Psychotherapy
www.itsgoodtotalk.org.uk
Phone 01455 883300
Information about counselling and details of therapists in your area.

CancerHelp UK
www.cancerresearchuk.org/cancer-help/
Nurse helpline 0808 800 4040
Cancer Research UK’s patient information resource.

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

Macmillan Cancer Support
www.macmillan.org.uk
Helpline 0808 808 00 00
Practical, financial and emotional support for people with cancer, their family and friends.
Follow-up after prostate cancer treatment

Maggie's Centres
www.maggiescentres.org
Phone 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 treatments, conditions and lifestyle. Support for carers and a directory of health services in England.

NHS Inform
www.nhsinform.co.uk
Phone 0800 22 44 88
Information about treatments, conditions and lifestyle, and a directory of local services in Scotland.

NHS Wales
www.nhsdirect.wales.nhs.uk
Phone 0845 46 47
Information about treatments, conditions and lifestyle, and a directory of local services in Wales.

nidirect
www.nidirect.gov.uk
Information about government services in Northern Ireland, including health services.

Penny Brohn Cancer Care
www.pennybrohncancercare.org
Helpline 0845 123 23 10
Complementary care for people with cancer and their families.
PromoCon (Promoting Continence and Product Awareness)
www.disabledliving.co.uk/PromoCon
Helpline 0161 607 8219
Impartial information and advice about bladder and bowel problems.

Samaritans
www.samaritans.org
Helpline 08457 90 90 90
Confidential, non-judgemental emotional support, 24 hours a day, by telephone, email, letter or face to face.

Sexual Advice Association
www.sda.uk.net
Helpline 020 7486 7262
Treatment information for erection difficulties and other sexual problems.
About Prostate Cancer UK

Prostate Cancer UK fights to help more men survive prostate cancer and deal with other prostate diseases so they can enjoy a better life. We support men by providing vital information and services. We find answers by funding research into causes and treatments and we lead change, raising the profile of all prostate diseases and improving care. We believe that men deserve better.

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 on our website.

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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/donations 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