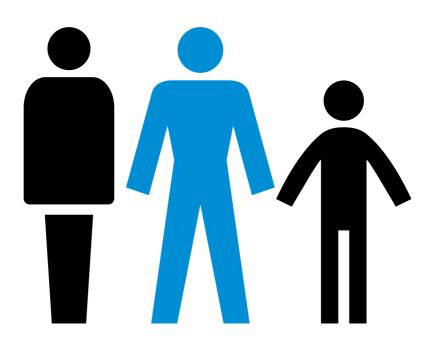
# When you're close to someone with prostate cancer

A guide for partners and family





## About this booklet

When you're close to someone with prostate cancer, the diagnosis can affect you just as much as them. As well as affecting how you feel, it may also change your relationship with them as your plans and priorities change.

This booklet is for anyone who is close to someone with prostate cancer, whether you're a partner, family member or friend. It looks at ways you can support someone with prostate cancer, where to get more information and how you can look after yourself.

You can find out more about prostate cancer and treatments in our other fact sheets and booklets. These are free and available to order or download online. You can also speak to our Specialist Nurses, in confidence, on 0800 074 8383, or chat to them online.

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



Speak to our Specialist Nurses



Read our publications

Some of the photos in this booklet are of people affected by prostate cancer. The guotes are not the words of the people in the photos.

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#### Supporting someone at the end of their life

Many men with prostate cancer will have treatment that gets rid of their cancer. Others will have treatment that keeps their cancer under control, often for several years. But some men will die from prostate cancer. If your loved one is coming to the end of their life, we have information that might be useful for both of you on our website at prostatecanceruk.org/dying-from-prostate-cancer



## What is the prostate?

The prostate is a gland. It is usually the size and shape of a walnut and grows bigger as you get older. It sits underneath the bladder and surrounds the urethra, which is the tube that carries urine (wee) out of the body. The prostate's main job is to help make semen – the fluid that carries sperm.

#### Who has a prostate?

The following people have a prostate:

- men
- trans women\*
- non-binary people who were assigned male at birth\*\*
- some intersex people.\*\*\*

#### Trans, non-binary or intersex?

The information in this booklet has been developed based on guidance and evidence in men. If your loved one is a trans woman, male-assigned non-binary or intersex, some of this information is still relevant to them – but their experience may be slightly different. For more information visit prostatecanceruk.org/trans-women

<sup>\*</sup> A trans woman is someone who was assigned male at birth but identifies as a woman. Trans women can develop prostate problems, even if they have taken hormones. The prostate is not removed during genital reconstructive surgery.

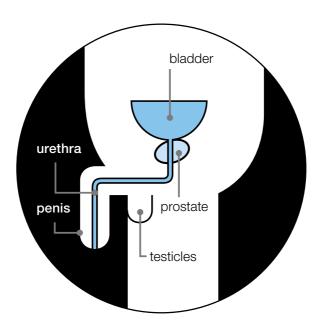
<sup>\*\*</sup> A non-binary person may not identify as a man or a woman.

<sup>\*\*\*</sup>An intersex person may have both male and female sexual characteristics and so might have a prostate.

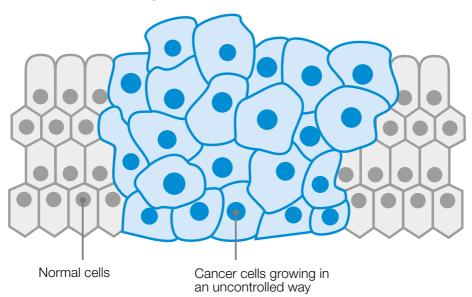
### What is prostate cancer and how is it treated?

Normally the growth of all cells is carefully controlled in the body. As cells grow old and die, new cells take their place. Prostate cancer can develop when cells in the prostate start to grow in an uncontrolled way.

Prostate cancer is the most common cancer in men in the UK. About 1 in 8 men will get it at some point in their lives.



#### How cancer develops



For some people, prostate cancer grows too slowly to cause any problems in their lifetime. This means many men with prostate cancer will never need treatment. But some prostate cancer grows quickly and is more likely to spread. This is more likely to cause problems and needs treatment to stop it spreading.

There are several treatments available for prostate cancer. Some treatments aim to get rid of the cancer completely, while others aim to keep it under control. The stage of the cancer (how far it has spread), how quickly it might be growing and a man's personal preference will all affect which treatments he has. If a man's cancer is growing slowly, he might be able to delay or avoid treatment altogether and have the cancer monitored instead.



For more information on how prostate cancer is diagnosed and the different treatment options, read our booklet, Prostate cancer: A guide for men who've just been diagnosed.

# **Getting information about prostate cancer**

Many partners, family and friends find it helps to learn more about prostate cancer. Some people like to read lots about prostate cancer, while others prefer not to know as much.

### Why is getting information useful?

Learning about prostate cancer can help you and your loved one feel more informed and confident about making decisions. It may also help you both feel more prepared for what will happen during and after treatment.

If you choose to get information, it's important to get it from places and people that you trust. Health professionals may give you information, or you can find information online or in print, like booklets and fact sheets. You can also download or order information from our website at **prostatecanceruk.org/publications**, or speak to our Specialist Nurses.





I've tried to learn as much as I possibly can so that I know what he's going through and so that I can try to help.

A personal experience

#### **Making decisions**

Often men with prostate cancer will have a choice about what treatment to have. This is because there isn't always an overall best treatment, and each treatment has its own advantages and disadvantages. Some men may also have a choice about whether or not to have treatment straight away, which can be a difficult decision to make. Finding out more about treatments and side effects can help.

Some men find having support from their partner, family or friends helps when making this decision. For example, you could talk through the advantages and disadvantages of each treatment together and think about what's right for him.

Read our fact sheets for more information on each treatment.

#### Knowing what to expect

Knowing more about prostate cancer and treatment can help you prepare for what will happen and the possible side effects of treatment. Treatments for prostate cancer can all cause side effects, such as:

- difficulty getting or keeping erections (erectile dysfunction)
- urinary problems (incontinence)
- bowel problems
- extreme tiredness (fatigue).

A common treatment called hormone therapy can also cause other side effects such as hot flushes, loss of sex drive, breast swelling, weight gain, muscle loss, forgetfulness and mood changes, such as feeling more irritable or emotional. Read more in our booklet, Living with hormone therapy: A guide for men with prostate cancer.



Side effects can affect a man's everyday life and the lives of those close to him. Dealing with these feelings, as well as with the cancer itself, can make men feel worried and sometimes depressed. But there are ways to manage side effects. And getting information about prostate cancer can often help you both feel more reassured about side effects and what to expect in the future.



Read more in our booklet, Living with and after prostate cancer: A guide to physical, emotional and practical issues.

#### Talking to health professionals

Some people find it helps to have someone with them at their appointments. It's hard to take everything in, ask questions and make notes all at the same time. Having someone else there to remember and ask questions can be useful.

Health professionals involved in your loved one's care may not be able to discuss his diagnosis, treatment or care with you, unless he gives them permission. If he is happy for you to know about these things, he needs to let his doctor or nurse know. He can request this for anyone – whether that's a partner, family member or friend.

Some people don't feel confident talking to health professionals. But it's always worth asking if you're not sure about something, or if you have a question or concern. Sometimes health professionals will ask if you have any questions. But if they don't, it could be because they assume you understand what has been said, or that you would ask if you had any questions.

As a partner or relative, you also have the right to information and support for yourself. If you don't feel able to talk to the doctors or nurses treating your loved one, make an appointment with your GP



to discuss where you can get support for yourself. Or you can call our Specialist Nurses, who are here for you too.

#### What else can help?

All our fact sheets include a list of questions to ask a doctor or nurse. Take the questions to appointments to use as a starting point. You might also find them a useful way to bring up sensitive subjects, such as urinary or sexual side effects.

#### How can I find out more?

There are lots of ways to get more information.



- Read our publications, visit our website and talk to our Specialist Nurses. We are here for you too.
- Talk to the health professionals who are supporting your loved one.
- Some hospitals have an information centre where you can get practical information and support.
- Talk to people with similar experiences. You can meet people through support groups, our online community or our one-to-one support service (see page 24).
- Contact other charities and organisations for information and support (see page 39).
- You and your loved one could go on a course or training day about living with and after cancer. Macmillan Cancer Support, Self Management UK, Penny Brohn UK, Maggie's Centres, Carers Trust and Carers UK all run courses. The hospital that provides your loved one's care may also hold health and wellbeing events that you could go to.



## **Supporting someone with** prostate cancer

If you're close to someone with prostate cancer you're likely to want to give them support and be there for them. Research suggests that family and friends who offer emotional and practical support may help men deal better with the daily challenges of having prostate cancer.

Doing something to help might also ease your own feelings of distress and help you feel more in control. But be aware of your limits and try to remember that you don't have to do everything on your own. Think about whether your friends or family could help out with some things. Social services and charities can also be good places to get support.

Dealing with a diagnosis of cancer, having treatment and managing side effects can be challenging. We know from research that men with prostate cancer and their partners have a higher risk of depression and anxiety.

If you notice that your loved one is feeling very down, worried or is finding it hard to cope, encourage him to speak to his doctor or nurse. There are treatments and support available. They can also call our Specialist Nurses or ring the Samaritans.





Read more about the feelings men might go through in our booklet, Living with and after prostate cancer: A guide to physical, emotional and practical issues and see page 21 for information on dealing with your own feelings.

#### How can I help someone with prostate cancer?

All men with prostate cancer are different and what helps one person may not be right for another.

#### Talking about it

Many men with prostate cancer value being able to talk to those close to them about how they are feeling. It can help get things out in the open. There is no right or wrong thing to say – sometimes you might just need to listen. Macmillan Cancer Support has information about how to talk to someone with cancer.

You and your loved one might not always want to or feel able to talk. Some people need some support to open up and express how they are feeling. Talking to someone else, such as a friend, health professional or counsellor might be helpful, either together or separately.

And remember, you will be dealing with your own feelings too and may also need time to talk about them.

#### What if he doesn't want to talk?

Some men prefer to cope on their own and don't want to talk about things, or want any outside help.

You might find this frustrating or upsetting. But try to remember that they might not see things the same way as you. Even if you think that they need some practical help or should be talking about their emotions, they might feel that they're coping fine.

Try to help them think about what they want, rather than telling them what they should do. You can do this by asking questions or saying what you think, and then asking what they think.

It may take some men longer to accept that they have prostate cancer than others. Their initial response could be disbelief, denial or shock. They might find it hard to take in information about their cancer or accept help. It may help to give them information in small chunks, at times when they seem ready to take it in.

You could let them know that you are there for them if they need anything. Be specific about the kind of support you can offer – practical as well as emotional. You might need to give them space to come to terms with things in their own time or deal with things in their own way.

Make sure you find ways to get support for yourself as well (see page 23).



Dad was very angry about his cancer. He felt intense frustration which affected his mood. He didn't want to talk or join a support group. We had to let him cope in his own way.

A personal experience

#### Just being there

For some men just having family and friends around is enough. You don't always have to talk about prostate cancer. Just chatting about normal things and doing some everyday activities together might help. Encourage your loved one to see family and friends and to keep up with social activities and hobbies if they feel up to it.

### How you can help day-to-day

#### Supporting lifestyle changes

When someone you're close to is unwell, it's natural to try to protect them and make their life as easy as possible. But a lot of men will want to keep doing things for themselves and to stay active.

Many men with prostate cancer say they want to keep things as normal as possible. They may want to manage any side effects, or changes they're experiencing, themselves. This is called selfmanagement. It means being actively involved in looking after your own health and wellbeing. For example, changing your diet, getting more active or learning other ways to look after yourself. It also involves being aware of any changes to your health and letting your doctor or nurse know about them.

But not all men will want, or be able, to make changes to their lifestyle. For some it may take a long time to make any changes, especially if they've been doing something for a long time. But remember that making small changes gradually can still make a big difference to their health and the way they feel. Supporting your loved one to make positive lifestyle changes can help keep them motivated. Self Management UK runs courses for people who want to take control of their health, including courses for carers. Visit www.selfmanagementuk.org to find out more.



Read our booklet, Living with and after prostate cancer: A guide to physical, emotional and practical issues, for tips on self-management. You may also find our interactive online guides helpful. Find them at prostatecanceruk.org/guides

#### Going to appointments

You might be able to go along to appointments with your loved one. Men often say they like having someone with them for company and to help remember information. Attending appointments with your loved one may also help you feel more involved in his care and treatment.

Before you go, talk about any questions you both have. You could write them down, or use the questions listed in our fact sheets. At the start of the appointment ask the doctor or nurse if you could have some time to ask questions.

Some men find it helps if someone talks to the health professional for them. But only do this if he asks you to. Some people like to take notes, or you could ask to record the conversation using a phone or another recording device. This is often a good way to keep track of important details and means your loved one can go back over what was said in their own time. They have the right to record their appointment if they want to, because it's their personal data. But let the doctor or nurse know if and why you're recording them, as not everyone is comfortable being recorded.

If you're going to be waiting a long time for appointments or treatments, take some things to do. For example, travel games or cards, magazines, books and crosswords. Or you could listen to music or watch films if you have a smart phone, laptop or tablet.

#### **Raising concerns**

If you're concerned about anything to do with the treatment your loved one is getting, talk to their doctor or nurse.

If you're raising any concerns without your loved one's knowledge, the doctors and nurses can listen to your concerns, but they might need to tell him about the conversation if it affects his care and treatment. Other services where you can raise concerns include:

- your local Healthwatch or Patient Advice and Liaison Service (PALS) in England
- your local NHS board in Scotland
- your local Community Health Council in Wales
- the Health and Social Care Board in Northern Ireland.



My husband went to chemo sessions with a friend. They would buy the daily papers and sit putting the world to rights during the lengthy appointments. Apparently I fussed too much.

A personal experience

#### **Getting help with travelling costs**

You might be able to get help with the cost of travel to and from hospital, and hospital parking. This varies depending on where you live. Some people are eligible for free hospital transport. To find out more, talk to the hospital that is caring for your loved one, or his GP, or contact Macmillan Cancer Support. Some hospitals have a support and information service that may also have information about local travel costs and parking.

#### Helping at home

Some men with prostate cancer have difficulty carrying out their usual day-to-day tasks. This could be because of side effects, symptoms such as pain, or because they find it harder to move about than they used to.

You might find you take over some of their usual activities, but try not to take on too much. This will help make sure that you don't get too tired and will help your loved one keep their independence and some normal routine to their day-to-day life.

If you could do with some extra help at home, speak to your GP or contact your local council and ask about social services. You can ask social services to assess your loved one's needs – and your own needs if you are providing them with care. This could include:

- equipment or changes to your home
- help at home, for example with getting dressed, cooking, housework, or shopping
- breaks away from home for you or the person you're caring for – you might hear this called respite care.

It's important to have breaks if you're caring for someone. Respite care is temporary care to give carers a break. Carers Trust and Crossroads Caring Scotland have professional carers who can provide respite care in your home, if you decide to go away for a short time.

Applying for support sometimes means filling in forms. For help with this, contact your local Citizens Advice or Macmillan Cancer Support.

#### Being a carer

A carer is someone who provides unpaid support to a family member or friend. Caring can include helping with day-today tasks such as housework, providing transport, or giving emotional support.

Some people who care for someone with prostate cancer also provide medical and personal care. For example, help with using a catheter after surgery, organising medicines, ordering incontinence pads, or help with washing or dressing.

If you are providing this type of care, make sure you're getting all the help available to you. Nurses such as community, district and Macmillan nurses can offer medical care at home and give you advice about ways to look after yourself. You might also be able to arrange to have other care staff visit you at home. You can arrange this through your GP or ask the health professionals at the hospital.

The levels of care that your loved one needs may change over time. You might have managed fine in the past and not needed any help caring for him. But this may change from time to time, and some weeks may feel harder than others. If you find you're having a bad week or caring for your loved one is becoming too much, get advice and support from health professionals. You can also speak to our Specialist Nurses, or contact one of the other organisations listed in this booklet.



Caring can be tiring and sometimes stressful, so remember to look after yourself.

## Looking after yourself

The diagnosis of a loved one can have a big impact on your life and it's likely that you'll also have a lot on your mind. So make sure you find time to look after yourself. This is important for your own health and so that you can support your loved one.

### **Common feelings**

How you react and feel when someone close to you has prostate cancer will be different for everyone. But you may be dealing with some of the feelings below.

## shock powerlessness loss sadness frustration uncertainty worry fear anger stress

You may find that some of these feelings fade over time. Or you might continue to have these feelings even if your loved one's prostate cancer is treated. You might feel worried or scared that their cancer will come back or start to spread. There's no right or wrong way to feel.

Some people who are close to someone with prostate cancer may have anxiety or depression. If you're feeling very down, worried or are finding it hard to cope, there are treatments and support available. If you're depressed your GP may be able to prescribe you some medication, or refer you to talk to a psychologist or 🔖 counsellor. Speak to your GP, call our Specialist Nurses or contact Carers UK. If you need to speak to someone immediately, ring the Samaritans.



#### Uncertainty about the future

It's natural to find it difficult and upsetting to think about the future, particularly if your loved one has advanced cancer. Many men with advanced prostate cancer will have treatment that keeps the cancer under control for many years, but the outlook for some men won't be as good.

You might find that making plans helps you feel more prepared for what the future may hold, and reassured about the future for your family. But you may also find it difficult to make plans, especially if you're not sure how your loved one's prostate cancer may change. Your own personal plans, such as work or holidays, may also change, which some people find frustrating or upsetting.

Talking about the future isn't always easy and you may feel worried about how to bring up the subject with your loved one. This is normal, and it may take some time before you both feel ready to talk about the future. It's important to ask for support if you need it.



🔖 Our Specialist Nurses are here to support you.

If your loved one has advanced prostate cancer, you can read more about planning ahead and the support available in our booklet, Advanced prostate cancer: Managing symptoms and getting support.

### What can help?

#### Be kind to yourself

Try to go easy on yourself, and don't expect to have all the answers. There's no right or wrong way to deal with your feelings. Everyone has their own way of coping.

Some people struggle to deal with things on their own. It might be difficult to talk to the person you're supporting about how you are feeling – especially if they are dealing with their own emotions. You could get some separate support for yourself, especially if you have different needs and worries. Try talking to a friend or going to a support group (see page 24).



It's not easy to be the main supporter. You're often consoling other relatives and you can feel very isolated. Staying well and being kind to yourself is important.

A personal experience

### **Getting support for yourself**

#### **Health professionals**

You could talk to your own GP, practice nurse, or any other health professionals about how you're feeling. As a partner or family member of someone with prostate cancer you are entitled to discuss your own needs and concerns with the health professionals treating or supporting your loved one, such as the specialist nurse or doctor. You can also call our Specialist Nurses.



#### Friends and family

Your friends and family can provide a good support network. This might be practical support or having someone to talk to about how you feel. Not all of your friends or family will understand what you're going through, but you might just want to chat about other things.

Don't feel that you have to manage everything on your own. Try to accept help from others when it is offered. Remember that it's also okay to ask for help even if it's not offered. People often want to help and show their support but may not want to keep contacting you. Or they may find it difficult to know what to say, or worry that they might upset you.

But asking for help could give you more time and energy to support your loved one. Think of friends or family who might be able to help with certain tasks. For example, driving to appointments, collecting prescriptions, doing some shopping or cleaning, or looking after the children for a few hours.



I grudgingly agreed to let a friend do the shopping. They got everything right. And put it all away. I used to drift around in a trance and come back with strange purchases, so this was a big help.

A personal experience

#### **Support groups**

At local support groups people get together to share their experiences of 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 health professionals, others by people with experience of prostate cancer. Many groups welcome partners, friends and relatives. Other groups have separate meetings just for partners, friends and relatives.

Support groups can also help you get information and feel reassured, hopeful and connected to others. Many support groups have regular guest speakers or an education session for part of the meeting. People who attend support groups often say they find these talks interesting and helpful.

To find your nearest support group visit our website at **prostatecanceruk.org/get-support**, ask your nurse or speak to our Specialist Nurses.



#### **Our online community**

This is a place to talk about whatever's on your mind – your questions, your ups and your downs. Members include men with prostate cancer, their family and friends, and people who have supported someone who's died from prostate cancer. Anyone can ask a question or share an experience. It's a place to deal with prostate cancer together. Sign up on our website at **prostatecanceruk.org/online-community** 



It was such a relief to find other people who understood what I was going through. The Specialist Nurses and people on the online community have been particularly helpful.

A personal experience

#### Our one-to-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 talk about whatever's important to you.

We'll try to match you with someone with similar experiences. Our volunteers include both men and women whose lives have been affected by prostate cancer.

#### Counselling

Some people prefer to talk to someone they don't know, about their worries and the way they're feeling. Counsellors are professionals who are trained to listen. They can help you to think about things differently and find your own ways to deal with things. Many hospitals have counsellors or psychologists who specialise in helping people with cancer and their loved ones. You may hear these services called talking therapies. Ask your doctor or nurse at the hospital if this is available.

Counselling for families or couples could help you talk and strengthen your relationships. This might reduce any distress you are feeling.

You can refer yourself for counselling on the NHS, or you could see a private counsellor. To find out more, visit www.nhs.uk/counselling or contact the British Association for Counselling & Psychotherapy. Other organisations such as Relate can also help.



My dad's diagnosis came as a double blow just two months after my mum died. I went to see a counsellor so I could deal with my own grief, and so I could support my dad better.

A personal experience

#### **Hospices**

If your loved one is getting support from a local hospice or community palliative care team, you could ask them about getting support for yourself too. Hospices offer a range of services, including emotional and spiritual support, practical and financial advice, and support for families.

#### **Spiritual support**

You may find that your beliefs offer you great comfort or support. You might have never held strong religious beliefs, but when someone close to you is diagnosed with cancer you may start to question things.

Get spiritual support if you need it. This could be from your friends or family. Or it could be from a religious leader or faith group. They can talk to you about your concerns, whatever your religion, or even if you are not religious.

#### What else can help?

Try to do something nice for yourself at least once a week. You could have lunch with a friend, visit the library or go to the shops. It doesn't matter what it is, as long as you focus on yourself for a short time.

You could try writing down how you're feeling, for example in a diary. Write about something that is worrying you or think about the emotions you're going through. You might find this helps you to understand your feelings better.

Doing some gentle exercise, such as walking, swimming or gardening, can improve your mood and help you cope with any stress.

Try thinking about a time or situation in the past that was difficult. Think about what worked then and how you managed to get through that difficult time. You might be able to use some of the same techniques again this time.



We find keeping a diary is useful. When bad times happen, that is all you can focus on. When times are better you can look back and say - we got over that bit.

A personal experience

#### Your health

People close to someone with cancer sometimes find that their own health gets worse. This might be because of stress, because they've become a full-time carer, or because they don't have the time to look after themselves properly.

Make sure you look after your own health. If you are feeling unwell, tired or down, talk to your GP.

#### **Tiredness**

If you're close to someone with cancer you might get particularly tired, especially if you're caring for them. Get support for any anxiety you're feeling as this can be linked to increased tiredness. For example, you might have problems sleeping because you're worrying a lot.

#### What can help?

Get support and information about managing the side effects of prostate cancer treatment. They might have an impact on your life as well. For example, if your partner gets up a lot at night to use the toilet, you might be woken each time. For more information about how your partner can manage their side effects read our booklet, Living with and after prostate cancer: A guide to physical, emotional and practical issues.



Learn some ways to relax or manage stress. This might help if you're feeling down or finding it difficult to sleep. Talk to your GP if you're having difficulty sleeping. Some people find yoga or meditation helpful. Look for classes at your local GP surgery or through charities such as Macmillan Cancer Support, Maggie's Centres, Carers UK or Carers Trust.

Some hospitals have support and information centres that may run wellbeing groups like yoga, relaxation and art. Going to groups like this can also be a good way of meeting other people who understand what you're going through.

There are some simple changes you can make to your lifestyle to boost your energy levels.

- Eat regular well-balanced meals and healthy snacks to keep your energy levels up throughout the day.
- Regular exercise can make you feel less tired and give you more energy.
- Try to get a good night's sleep having a regular routine and avoiding naps during the day may help with this.
- Stress can use up a lot of energy, so if you're stressed, try to find ways to relax each day.

#### **Work and money**

Your loved one might decide to reduce their working hours, or stop working completely if the side effects of treatment are making it difficult to work.

If you're caring for someone with prostate cancer, you may also think about reducing your working hours. Think about telling your manager that someone you're close to has cancer, as you may be entitled to time off or flexible working. If you're worried about talking to your manager, remember that everyone has their own worries and health problems from time to time. Most people will be understanding and will want to support you in whatever way they can. Arrange a time to talk to your manager, and try working out a plan together.

If you or your partner reduce your working hours this could affect your financial situation. You may be entitled to certain benefits and grants. It can help to get some financial advice to make sure you're getting all the help you need. Read our booklet, Living with and after prostate cancer: A guide to physical, emotional and practical issues, for more information about where you can get support.

The following organisations offer more information.

- Macmillan Cancer Support provides financial information and advice to people affected by cancer, including a booklet and telephone helpline with financial advisers.
- Visit your local Citizens Advice, or go to their website for independent and confidential advice, including help with benefits forms.
- A welfare rights or benefits adviser at your local social services department or hospital can advise you on financial support.
- Carers UK and Carers Trust provide information about financial help for carers.



## Relationships and family life

Prostate cancer can change the normal pattern of your life and affect relationships, friendships and roles within the family. It can bring challenges, but can also bring some couples and families closer together.

You might find that your plans get interrupted or your priorities change after a diagnosis of prostate cancer. If a man with prostate cancer has side effects, like tiredness, his normal family role might change - for example, others may have to take on more tasks at home.

People find that they go through a process of adjusting and develop new ways of thinking about life and relationships.

You might find some of these ideas can make life easier:

- learning more about prostate cancer together by getting up-to-date information
- talking about things
- making sure you get all the support you need as a family.

Try to make sure that you make time for family activities, such as holidays and days out. Even though your loved one may not feel up to doing some activities, you could try something new together. Read our fact sheet, **Travel and prostate cancer**, for information about planning travel.





My sister and I share a lot of the support for Dad. She focuses on the medical side, while I help do things he enjoys like watching sport, having dinner out and going to the synagogue. I try to normalise his life. I know this helps his self-esteem and mood.

A personal experience

#### Talking to children about cancer

It can be difficult and upsetting to talk to children or grandchildren about cancer. It usually helps to be honest with them. Keeping things from them might only make them worry more. Children can often sense that something is wrong even if they don't understand it. They may also notice that things at home have changed, such as their day-to-day routine. This can be confusing, especially for younger children.

What they'll need to know about cancer and how they will react will depend on their age and whether they've known someone with an illness before. Creative activities, like drawing or books, may help younger children understand, while you may need to encourage teenagers to ask questions. Remember that you might not always have the answers. It's okay to be honest and say if you don't know something.

Charities such as Macmillan Cancer Support and Winston's Wish have more information about how to talk to children when a parent, or grandparent, has cancer. Fruit Fly Collective also has information and activity kits to order for children of all ages. Your local hospice may offer a support service to children and young people. You could also ask your GP or specialist nurse for advice, or call our Specialist Nurses.



#### **Changes to your relationship and sex life**

Prostate cancer and its treatments can affect a man's sex life. If you're a partner of someone with prostate cancer, you might need particular support for relationship and sexual issues. Some partners of people with prostate cancer feel very distressed and may become anxious and depressed. This can affect how you feel about sex. You may experience:

- changes to how you feel about yourself if your partner has a low sex drive this might make you feel less desirable or attractive
- feeling frustrated or unsatisfied if your sex drive is higher than your partner's or you are having less sexual contact
- anger or sadness at the loss of how things used to be
- guilt for still having sexual feelings.

Your own desire for sex may change after your partner's diagnosis and during treatment. For example, if you're feeling anxious, you may have less interest in sex. Changes in your relationship, such as changed roles, may also affect how you feel about sex.

Many partners don't talk about their own feelings because they want to protect their loved one. But it's also important to get some support for yourself, perhaps without your partner. Talking to other partners who are experiencing the same thing or getting some counselling may improve things.

Some men may distance themselves from close relationships because they feel uncomfortable with changes to their bodies and the impact of treatment on their sex life. But this doesn't mean that they no longer care for you.



Read more about dealing with the impact on sexual relationships in our booklet, Prostate cancer and your sex life. It comes with a DVD of men talking about their own experiences. The information and films are also available at prostatecanceruk.org

Check out our interactive online guides for more ideas on how to help manage sexual side effects at prostatecanceruk.org/guides

#### If you're a gay or bisexual man

Prostate cancer affects gay and bisexual men in many of the same ways as heterosexual men. But if you're a gay or bisexual man, you may have some other issues or concerns about the impact of treatments for prostate cancer. We have information specifically for gay and bisexual men, and their partners. Read more in our booklet, Prostate cancer tests and treatment: A guide for gay and bisexual men. Or you can speak to our Specialist Nurses, in confidence.



There are also support groups specifically for gay and bisexual men, and their partners. You can share your worries, ask questions and know that you're not alone in the way you're feeling. Visit our website for a list of support groups at prostatecanceruk.org/support-groups



## More information from us

#### The Tool Kit

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

#### Leaflets and booklets

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

#### To order publications:

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

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

#### **Call our Specialist Nurses**

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



<sup>\*</sup>Calls are recorded for training purposes only. Confidentiality is maintained between callers and Prostate Cancer UK.

## Other useful organisations

#### **Acas**

www.acas.org.uk

Telephone: 0300 123 1100

Information and advice on workplace issues, employment law and flexible working.

#### **British Association for Counselling & Psychotherapy**

www.bacp.co.uk

Telephone: 01455 883 300

Information about counselling and details of therapists in your area.

#### **Carers Trust**

www.carers.org

Information and support for carers.

#### **Carers UK**

www.carersuk.org

Telephone: 0808 808 7777

Information and advice for carers.

#### **Citizens Advice**

www.citizensadvice.org.uk

**Telephone:** 03444 111 444 (England), 03444 77 20 20 (Wales) Advice on a range of issues including financial and legal matters. Find your nearest Citizens Advice in the phonebook or online.

#### **Crossroads Caring Scotland**

www.crossroads-scotland.co.uk

Telephone: 0141 226 3793

Support with day-to-day activities and short breaks for carers.

#### **Fruit Fly Collective**

#### www.fruitflycollective.com

Support for adults and children when a parent has cancer.

#### **Healthwatch England**

www.healthwatch.co.uk Telephone: 03000 683 000

Independent support to ensure any concerns you have about your care are raised.

#### **Hospice UK**

www.hospiceuk.org

Telephone: 020 7520 8200

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

#### **Macmillan Cancer Support**

www.macmillan.org.uk Telephone: 0808 808 0000

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

#### **Maggie's Centres**

www.maggiescentres.org Telephone: 0300 123 1801

Drop-in centres for cancer information and support.

#### Mind

www.mind.org.uk

Telephone: 0300 123 3393

Information and support for mental and emotional health issues.

#### **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.

#### Relate

www.relate.org.uk

Telephone: 0300 003 0396

Information, advice, relationship counselling and sex therapy in England, Wales and Northern Ireland.

#### **Relationships Scotland**

www.relationships-scotland.org.uk

Telephone: 0345 119 2020

Information, relationship counselling and sex therapy in Scotland.

#### **Samaritans**

www.samaritans.org Telephone: 116 123

Confidential, judgement-free emotional support, 24 hours a day.

#### **Self Management UK**

www.selfmanagementuk.org Telephone: 0800 988 5560

Free self-management courses in England (and online in parts of Wales). Includes courses for carers.

#### Winston's Wish

www.winstonswish.org Telephone: 08088 020 021

Practical support and guidance for bereaved children and their families.

## **About us**

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

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

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

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

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- Anne Crook, Psycho-Oncology Counsellor, The Christie NHS **Foundation Trust**
- Wayne de Leeuw, Director of Patient and Family Services and Deputy Chief Executive, Dorothy House Hospice Care
- Jennifer Draper, Day Hospice Clinical Nurse Specialist, Meadow House Day Hospice, London North West University Healthcare NHS Trust
- Our Specialist Nurses
- Our Volunteers.

## Donate today - help others like you

Did you find this information useful? Would you like to help others in your situation access the facts they need? Every year, over 47,000 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<sup>†</sup>. There are many other ways to support us. For more details please visit prostatecanceruk.org/get-involved

<sup>†</sup> 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



#### Tell us what you think

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



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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.

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