



FAMILY & FRIENDS GUIDE

HELPING YOU HAVE A CONVERSATION
ABOUT PROSTATE CANCER

The Manversation campaign has been developed in consultation with leading prostate cancer charities, Orchid – Fighting Male Cancer and Tackle Prostate Cancer. The campaign has been organised and funded by Bayer.



MANVERSATION IS A CAMPAIGN WHICH AIMS TO:


- 1 CHALLENGE OUTDATED
STEREOTYPES
- 2 RAISE AWARENESS OF THE
SYMPTOMS OF ADVANCED
PROSTATE CANCER
- 3 ENCOURAGE MEN TO SPEAK UP
ABOUT POTENTIAL SYMPTOMS AS
SOON AS THEY EXPERIENCE THEM



We would like to thank all of the patients and healthcare professionals who have advised and contributed towards the development of this guide.

PROSTATE CANCER...

- THE MOST COMMON CANCER IN MEN IN THE UK¹
- 1 IN 8 MEN IN THE UK DEVELOP PROSTATE CANCER IN THEIR LIFETIME¹
- IN THE UK, BLACK AFRICAN AND BLACK CARIBBEAN MEN HAVE DOUBLE THE RISK OF DEVELOPING PROSTATE CANCER COMPARED TO WHITE MEN; AND ASIAN MEN HAVE AROUND HALF THE RISK OF WHITE MEN.²
- HAVING A FATHER OR BROTHER WITH PROSTATE CANCER INCREASES YOUR RISK BY 2 TO 3 TIMES COMPARED TO A MAN WITH NO AFFECTED RELATIVES¹
- IN MOST CASES IT CAN BE MANAGED AND MEN LIVE MANY YEARS AFTER THEIR DIAGNOSIS.^{3,4}



THINGS TO CONSIDER WHEN A LOVED ONE HAS BEEN GIVEN A DIAGNOSIS OF PROSTATE CANCER

When you find out that a loved one has prostate cancer it can be as scary for you as it is for him. You are likely to have a lot of questions and to want to try to support your loved one as best you can.

Through this journey there are likely to be times when you need to have difficult conversations, from speaking to your loved one to speaking to the doctors and nurses and telling other family members and friends.



YOUR REACTION TO THE NEWS

Receiving news that a loved one has prostate cancer is a huge shock and everyone will react differently. There is no right or wrong way to respond. Some things that people might worry about are:

- Showing emotion to your loved one with prostate cancer
- Expressing your fears or concerns to him
- The way your loved one will react to their diagnosis

It's important that you acknowledge that this is really difficult for you too and you may find it challenging to deal with. Don't be too hard on yourself.

“

The day after diagnosis, it felt like your whole world had imploded into a black hole that is the word 'cancer'. Numb with shock, we floundered to make sense of it all. However, with treatment and time, we started to reclaim our life.

”

KATE, A PATIENT'S PARTNER

“

When he first told me he had prostate cancer, it felt like a bereavement.

”

JO, A PATIENT'S PARTNER



THE CONVERSATION WITH YOUR LOVED ONE WITH PROSTATE CANCER

In the same way that you might react to your loved one's diagnosis in a very different way to someone else in your situation, so might your loved one.

No matter how well you know him, it's still hard to predict how he will react and what he might want and need from you. It can be really helpful to have an open conversation with him to find out:

- The type of support he wants you to provide
- How he would like you to talk about his diagnosis
- What signs and symptoms you should be looking out for that may indicate changes in the disease, such as progression

You are likely to have a lot of questions, particularly about the disease and management options. Keep in mind that this is a difficult time for your loved one and he may not know all of the answers. Try not to overwhelm him and remember that there are places that you can go to seek information and support. (See section 'Knowing where to go for support and more information for yourself and your loved one'.)

It can be very difficult to deal with unexpected responses or situations. Remember that there is always someone who can help you and your loved one deal with them including your healthcare team, patient helplines and patient groups which are open to family and friends.

“

I have found, through both my own experience and observations of the many patients I have come to know, that one of the keys to successfully dealing with prostate cancer is full of frank discussions with, and involvement of, a loved one.

”

SANDY, A PROSTATE CANCER PATIENT AND CHAIRMAN OF A PATIENT GROUP

HOW YOU CAN SUPPORT YOUR LOVED ONE

There are many different ways in which you can support your loved one through his journey with prostate cancer. Hopefully through having a conversation with him you have an idea of what he needs from you. There may be areas that he hasn't thought of that you can discuss with him. Here are some ideas.

“

Together with your loved one, take pleasure in anything and everything — living for the moment. If they start to feel better, you can together make even bigger plans. Don't get into the mindset that you can't do things because of the cancer

”

KATE, A PATIENT'S PARTNER

Practical support

- Running errands
- Taking him to appointments
- Helping him prepare for appointments by making a list of questions for his healthcare team
- If you accompany him to the appointment, you could make notes of the answers

Information support

Researching information about his diagnosis, signs and symptoms of disease progression, management options or support available

Emotional support

Providing a listening ear and encouragement, attending appointments with him

Social support

Offer a distraction, be it a night in watching a film or a trip out doing something that he enjoys

Lifestyle support

Many men choose to adapt their lifestyle, by changing their diet and increasing their activity. Encouraging and supporting him with this and even making the same changes yourself can help, making him feel less alone or 'different' to everyone else

Advocate support

It is often a patient's relative or close friend that becomes the driving force behind ensuring he receives the best care possible. Looking into different treatment options and supporting him in having conversations with his healthcare team are all part of that support



UNDERSTANDING DISEASE PROGRESSION AND KNOWING WHAT TO LOOK OUT FOR

**Prostate cancer can grow and expand outside of the prostate and spread to different areas of the body.⁵
This is known as advanced prostate cancer.⁵**

It's very important that you know what to look out for. You should have a conversation with your loved one and then encourage him to tell his healthcare team as soon as either of you notice any of the symptoms of advanced prostate cancer, which may include:^{5,6}

- Tiredness/fatigue
- Aches, pain, or discomfort e.g. back ache
- Weakness/numbness
- Trouble falling or staying asleep, due to joint and bone pain
- Difficulty doing normal activities
- Bowel/bladder changes (how often you go to the bathroom)
- Issues with sexual function
- Loss of appetite
- Weight loss
- Generally feeling unwell.

- Don't assume that new symptoms commonly linked with early prostate cancer are not worth mentioning.
- If your loved one is telling their GP about new symptoms, it is worth reminding him to tell his GP about his prostate cancer diagnosis.
- If the symptoms are related to the disease, his healthcare team may be able to change his management to better control the cancer and to help control symptoms that impact his quality of life.
- Of course, the symptoms may be completely unrelated to prostate cancer, but it's better he tells someone who can reassure him and prevent you all from worrying unnecessarily.

A photograph of a man and a woman sitting together, looking at a laptop screen. The man is in the foreground, looking down at the screen with a serious expression. The woman is behind him, also looking at the screen. The background is blurred, suggesting an indoor setting.

IMPACT ON SEXUAL FUNCTION

Prostate cancer and more commonly the different treatments for prostate cancer, can cause a reduction in a man's sexual desire and function, including erectile dysfunction.⁷ While this may not be a big issue for some couples, it is often a serious concern for couples of all ages and can cause relationship challenges.

If this is affecting your relationship with your loved one, don't despair, there are things that may help. It is worth having a conversation with your loved one and together seeking advice and support as things can be done to help you both, such as:

- Speaking to your healthcare team who can explain the range of options that may assist you in continuing to lead an active sex life
- Seeing a psychosexual counsellor (you can ask for this support through the NHS)

“

Sadly, we know of many cases where relationships have suffered when a man has prostate cancer, and fails to talk to his partner about the impact the treatment has had on his interest in sex; unless it is discussed openly the partner can feel an inexplicable sense of rejection which has led to relationship breakdowns.

”

SANDY, A PROSTATE CANCER PATIENT AND CHAIRMAN OF A PATIENT GROUP



KNOWING WHERE TO GO FOR SUPPORT AND MORE INFORMATION FOR YOURSELF AND YOUR LOVED ONE

There are many sources of information, especially on the internet, including chat forums and blogs etc. Additionally there are patient support telephone helplines and groups.*

It's important to make sure that the information you are accessing is reliable and accurate. Healthcare professionals are best placed to provide you with reliable advice and to direct you to reliable sources of information.

Patient.info

patient.info/health/prostate-cancer-leaflet

The Patient.info website provides comprehensive health information, including information about the diagnosis, assessment and management of prostate cancer.

Patient Support Groups

Many patients and their families and loved ones find attending a support group really helps them. People often imagine support groups to consist of sitting in a circle and one by one telling the group about themselves and their experiences. This isn't the case. They more commonly involve talks and activities not limited to prostate cancer, besides offering information and disease-management advice from professionals and patients who have had a similar experience.

Most importantly, attending a group is a chance to meet other people going through a similar experience. Don't underestimate the positive impact this face-to-face contact can have.

To find your nearest support group, speak to your healthcare team who will be able to advise you. You can also access information via patient organisations.

Orchid - Fighting Male Cancer **orchid-cancer.org.uk**

Helpline: **0808 802 0010**

Tackle Prostate Cancer **tackleprostate.org**

Support group location finder:
tackleprostate.org/find-a-support-group-near-you.php
Helpline: **0800 035 5302**

Manversation **manversation.co.uk**

The Manversation website provides more information including a similar guide for your loved one with prostate cancer. The Manversation campaign has been developed in consultation with leading prostate cancer charities Orchid - Fighting Male Cancer and Tackle Prostate Cancer. The campaign has been organised and funded by Bayer.

* Bayer does not take responsibility for the content of materials provided from the listed organisations.

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We have observed that many men, despite being given a very poor prognosis when diagnosed, survive the disease for much longer than expected; what all these men have in common is that they are heavily involved in support groups, giving help to other men and their loved ones

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**SANDY, A PROSTATE CANCER PATIENT AND
CHAIRMAN OF A PATIENT GROUP**

“

Surround yourselves with positive, supportive people and on the days when either you or your loved one feel below par, be kind to yourselves and each other.

”

KATE, A PATIENT'S PARTNER

1. Prostate Cancer UK. Prostate Cancer and Risk. Available at <https://prostatecanceruk.org/prostate-information/are-you-at-risk> [Last accessed August 2020]
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3. Cancer Research UK. Prostate Cancer. Decisions about your Treatment. Available at <https://www.cancerresearchuk.org/about-cancer/prostate-cancer/treatment/decisions-about-your-treatment> [Last accessed August 2020]
4. Cancer Research UK. Prostate Cancer Survival Statistics. Available at <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/prostate-cancer/survival> [Last accessed August 2020]
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6. NHS Living with Prostate Cancer. Available at <https://www.nhs.uk/conditions/prostate-cancer/living-with/> [Last accessed August 2020]
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