



PATIENT GUIDE

HELPING YOU HAVE A CONVERSATION
ABOUT PROSTATE CANCER

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



MANVERSATION IS A CAMPAIGN WHICH AIMS TO CHALLENGE OUTDATED STEREOTYPES, RAISE AWARENESS OF THE SYMPTOMS OF ADVANCED PROSTATE CANCER AND ENCOURAGE MEN TO SPEAK UP ABOUT POTENTIAL SYMPTOMS AS SOON AS THEY EXPERIENCE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 LIFETIME²
- 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 HALF THE RISK OF WHITE MEN³
- IN MOST CASES IT CAN BE MANAGED AND MEN LIVE MANY YEARS AFTER THEIR DIAGNOSIS.^{4,5}

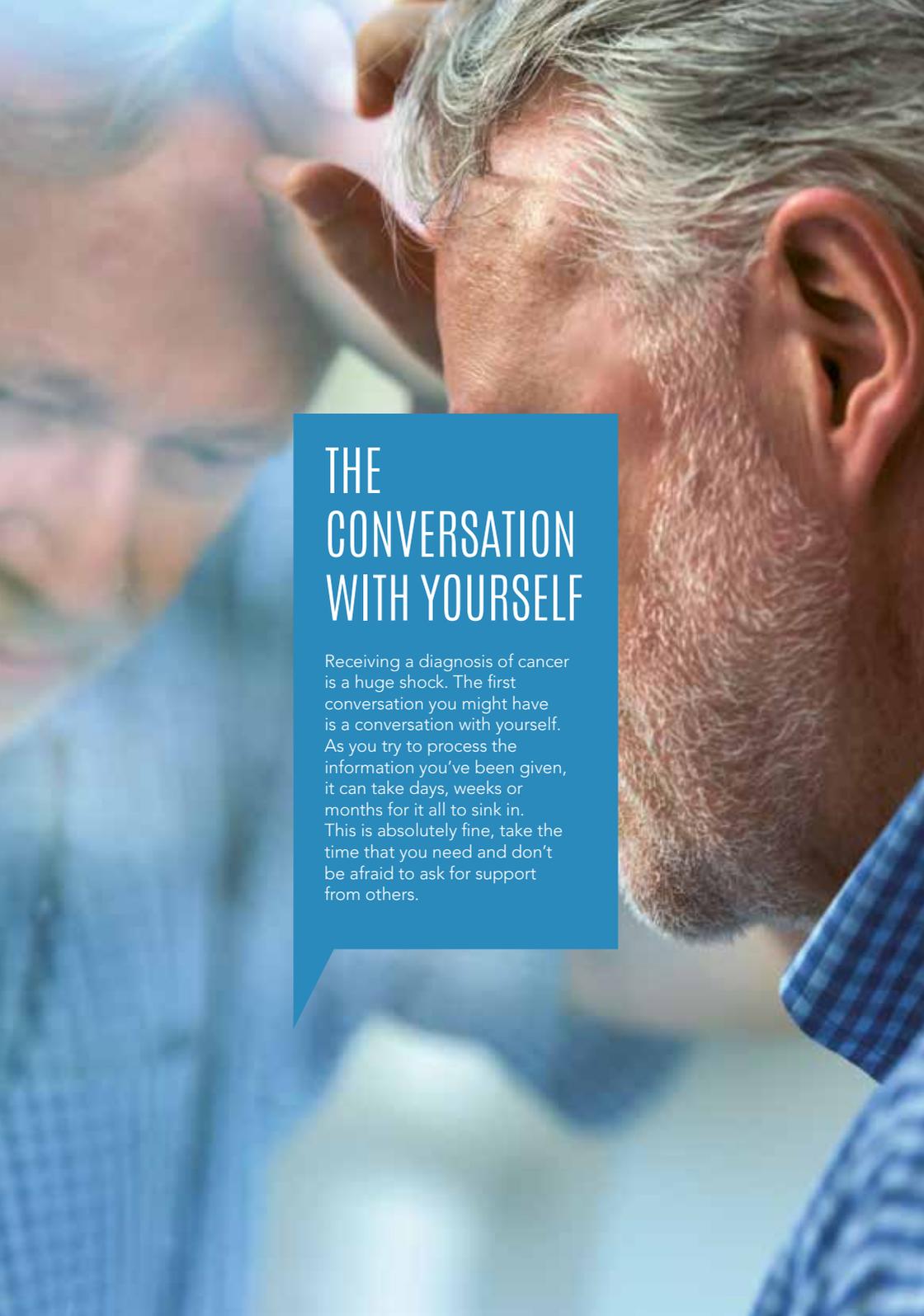


A man in a light-colored suit is looking out a window. The window has a grid pattern, possibly from a security screen or a window blind. The background outside the window is blurred, showing what appears to be a building or structure. The overall tone is somewhat somber and reflective.

THINGS TO CONSIDER FOLLOWING A DIAGNOSIS OF PROSTATE CANCER

Following your diagnosis there may be a lot of difficult conversations you need to have, from speaking to doctors and nurses about symptoms and treatments, to telling your family, friends and loved ones about your diagnosis. This can be scary, but these conversations can make a difference to the way your disease is managed, your day-to-day life and the long-term outcome of your disease.

The information here gives you some guidance on the different decisions and conversations that you may need to have following your diagnosis. But everyone is different and it's important that you make decisions based on what you feel is right for you. There is no right or wrong way to do things.



THE CONVERSATION WITH YOURSELF

Receiving a diagnosis of cancer is a huge shock. The first conversation you might have is a conversation with yourself. As you try to process the information you've been given, it can take days, weeks or months for it all to sink in. This is absolutely fine, take the time that you need and don't be afraid to ask for support from others.

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Families are very important for support and help. My wife had the most contact with our family and had to learn the best individual approach to our children, grandchildren, relations and friends.

”

TONY

THE CONVERSATION WITH YOUR FAMILY, FRIENDS AND LOVED ONES

You will need to think about who you want to tell about your diagnosis and how much you want to tell them. This is likely to differ across the range of people you may have in your life, such as your partner, children, brothers (whose risk of prostate cancer may be increased)³, wider family, friends and work colleagues.

HAVING A FATHER OR BROTHER WITH PROSTATE CANCER INCREASES YOUR RISK BY 2 TO 3 TIMES.³

Having a conversation about your prostate cancer can help you and your loved ones.

- They can understand and support you better if they know what you're going through
- It gives them a chance to ask questions and get a better understanding which can help make it less scary for them — but don't worry if you can't answer their questions
- They can help you tell your wider family and friends or tell them on your behalf
- They may also be at risk and by telling them you may encourage them to check out symptoms or get tested
- They can go to appointments with you, it's hard to take on board all of the information you are given by yourself.

“

It's often not as bad a diagnosis as it first seems, because in many cases you can live a long time with prostate cancer. Which actually can be quite embarrassing as you tell people and then you keep on living!

”

SANDY

You may be nervous about having a conversation with people about your diagnosis for many reasons, such as not wanting to show your emotions, not wanting to upset them or worrying about how they will react. People respond differently to bad news and can become angry or upset, as well as being sympathetic or supportive.

It can be very difficult to deal with unexpected responses or situations. Remember that there is always someone unconnected to you, who can help you deal with any difficult situations; or who you can speak to if you choose not to tell your loved ones. Healthcare services, patient helplines and patient groups offer a chance to speak to doctors, nurse specialists and other men living with the disease.



KNOWING WHERE TO GO FOR SUPPORT AND MORE INFORMATION

There are many sources of information, especially on the internet, including chat forums and blogs etc. It's important to make sure that the information you are accessing is reliable and accurate.*

Patient Support Groups

Many patients 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 yourself and your experience. This isn't the case. They more commonly involve talks and activities that are often nothing to do with prostate cancer, as well as offering information and advice from patients and professionals with lots of knowledge of the disease and its management. Some men like the fact that people at the group aren't linked to their personal life, so they can be more open and honest about how they feel.

Most importantly attending a group is a chance to meet other men going through a similar experience. Don't underestimate the positive impact this face-to-face contact can have, or how much you can help someone else just by having a conversation with them.

Most support groups also welcome the families of men with prostate cancer, so if you want to you can invite someone along with you, or suggest that they go if you think they'd benefit from the support the group provides.

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 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](http://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 family, friends and loved ones.

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

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Becoming involved with an active support group stopped my wife and I feeling alone. I've become friends with many people all over the country, which has enhanced my life.

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HUGH

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I was helped from the depths of despair I felt following diagnosis, mainly by talking to others with the same disease or who were knowledgeable about prostate cancer. In the main they had all found a way of coping with life 'after diagnosis'.

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TONY

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From what I've seen people live longer with prostate cancer when they have a purpose, do something important and help others. The men I know who run prostate cancer support groups seem to defy all of the survival odds!

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SANDY



UNDERSTANDING DISEASE PROGRESSION AND KNOWING WHAT TO LOOK FOR

Prostate cancer can grow and expand outside of the prostate and spread to different areas of the body.⁶ This is known as advanced prostate cancer.⁶ It's very important that you, and ideally your loved ones, know what to look out for.

You should have a conversation with your healthcare team as soon as you notice any of the symptoms of advanced prostate cancer, which may include:

- Tiredness/fatigue⁷
- Aches, pain, or discomfort⁷
- Weakness/numbness⁷
- Trouble falling or staying asleep, due to joint and bone pain⁷
- Difficulty doing normal activities⁹
- Bowel/bladder changes (e.g. how often you go to the bathroom)^{7,8}
- Issues with sexual function⁸
- Loss of appetite⁷
- Weight loss⁷
- Generally feeling unwell.⁷

Don't assume that new symptoms commonly

linked with early prostate cancer are not worth mentioning. If you are telling your GP about new symptoms, remind them that you have been diagnosed with prostate cancer. If the symptoms are related to the disease, your healthcare team may be able to change your management to better control the cancer and to help control symptoms that impact your quality of life.

If your disease is progressing you might be thinking about end of life care. Not everyone wants to talk about this, so you may find that your healthcare team are not bringing the subject up with you. But they are prepared for and willing to answer your questions if you want to talk — so do just ask.

Of course, the symptoms may be completely unrelated to prostate cancer, but it's better to tell someone so that they can reassure you of this and prevent you worrying unnecessarily.



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.^{2,9} While this may not be a big issue for some couples, it is often a serious concern for men of all ages and can cause challenges in their relationship with their partner.

If this is affecting you, don't despair, there are things that may help such as:

- Explaining the impact that the disease or its management is having on you, so that your partner understands what's happening
- 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).





KNOWING WHAT STANDARDS OF CARE TO EXPECT

A range of guidelines have been developed that give details of the standard and type of care you should receive as a prostate cancer patient. Some examples are listed below.*

Do not be afraid to ask questions of your healthcare professionals, refer to guidelines that outline the type of care you can expect and request additional services and support as you need them e.g. psychosexual counselling, financial benefits advice.

NICE Quality Standards

[nice.org.uk/guidance/qs91/resources/prostate-cancer-2098964001733](https://www.nice.org.uk/guidance/qs91/resources/prostate-cancer-2098964001733)

The NICE Quality Standards provides a list of statements that aim to deliver improvements in patient safety, patient experience and the effectiveness of disease management. They therefore provide a guide to the standard of care you can expect in particular situations. The information provided uses detailed medical terms and is not developed in language aimed at patients.

Patient.info

[patient.info/health/prostate-cancer-leaflet](https://www.patient.info/health/prostate-cancer-leaflet)

The Patient.info website provides comprehensive information about the diagnosis, assessment and management of prostate cancer. The information provided is written specifically for patients.

Holistic Needs Assessment and Care Plan

[macmillan.org.uk/aboutus/healthandsocialcareprofessionals/macmillansprogrammesandservices/recoverypackage/holisticneedsassessment.aspx](https://www.macmillan.org.uk/aboutus/healthandsocialcareprofessionals/macmillansprogrammesandservices/recoverypackage/holisticneedsassessment.aspx)

A holistic needs assessment and a care plan aims to ensure that people with cancer have their physical, emotional and social needs met.

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Get to know about your disease, ask questions and find out where the best treatment is.

I know that this approach has extended my life for about 8 years!

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HUGH



KEEP TALKING!

Following your diagnosis and throughout the course of your life with prostate cancer, it can help improve your journey if you keep having those important conversations.

Conversations with your healthcare team

- Continue to talk to your healthcare team about any new symptoms you develop as soon as you notice them
- Don't assume that new symptoms are no longer relevant because you have a diagnosis — they may be important in letting your healthcare team know:
 - That your disease status has changed which may need a change in your management
 - That you would benefit from additional support or something to minimise the impact of new symptoms
- To help you remember everything, before your appointments write down any questions you have for your healthcare team, and take a pen and paper along to the appointments so that you or your loved one can make a note of the answers.

Conversations with your loved ones and support networks

- If you have found it helpful, continue to talk to someone about how you're feeling as this can change over time
- Continue to let your loved ones know what you need from them, in terms of practical and emotional support, which may change over the course of the disease — people don't know unless you tell them!

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When I was diagnosed in 2005 and given 18 to 30 months to live, after the first 12 months when it became obvious that I was not going to die, my wife said, “I can't carry on being nice to you forever. We have to get back to normal.”

Never a truer word spoken.

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HUGH

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Remember a diagnosis of advanced prostate cancer is not a death sentence. Many men go on to live long, fulfilling lives after their diagnosis.

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SANDY

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I've now proven that the prognosis of 18 to 30 months, given ten years ago, was totally wrong.

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HUGH

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3. Cancer Research UK. Prostate cancer risks and causes. Available at: <http://www.cancerresearchuk.org/about-cancer/type/prostate-cancer/about/prostate-cancer-risks-and-causes> [last accessed August 2016]
4. Cancer Research UK. Treating Prostate Cancer. Available at: <http://www.cancerresearchuk.org/about-cancer/type/prostate-cancer/treatment/if-prostate-cancer-comes-back> [last accessed August 2016]
5. Cancer Research UK. Prostate cancer survival statistics. Available at: <http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/prostate-cancer/survival#heading-Zero> [last accessed August 2016]
6. Orchid. Advanced prostate cancer. Available at: <https://orchid-cancer.org.uk/prostate-cancer/advanced/> [Last accessed August 2016]
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