

MAN **VERSATION**

**SONS &
DAUGHTERS
GUIDE
TO PROSTATE CANCER**

**HELPING YOU HAVE THOSE ESSENTIAL CONVERSATIONS
WITH YOUR FATHER 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.

TALKING TO YOUR DAD ABOUT THE IMPORTANT THINGS MAY NOT ALWAYS BE EASY. BUT YOU'RE NOT ON YOUR OWN!

In this guide, we want to help you talk to your father about prostate cancer.

To give you the information you need, we've asked the experts – sons and daughters across the UK whose fathers are living with prostate cancer – to share their experiences.

You might not know that prostate cancer is the most common cancer in men in the UK¹. It affects one in eight men over their lifetime¹ (1 in 4 for black men²) and in the UK, more than 47,000 men are diagnosed with prostate cancer every year.¹

Yet, our national survey of sons and daughters of men with prostate cancer³, found many are struggling to communicate with their loved ones. In fact, more than half out of the 200 sons and daughters we surveyed, told us they and/or their father avoid talking about prostate cancer. That's a lot of important things being left unsaid.

We've created this guide to help you understand the condition, learn more about your father's experience and equip you with practical ways to talk to him. All the quotes you'll read are from a son or daughter who has a father with prostate cancer and all stats refer to our national survey of sons and daughters of men with prostate cancer.³

Everyone's relationship with their father is individual, so choose tips you feel comfortable with so you can try to talk to him confidently and openly.



WHY YOU NEED TO TALK ABOUT ... 'IT'

'IT' CAN BE SCARY.

When your father has been diagnosed with prostate cancer, everything can feel different. But if you're struggling to talk to your father about his prostate cancer – like many other sons and daughters across the UK – family life might be unusually strained.³

It's natural to have questions. But highly-charged emotions and worries about the future might feel so overwhelming that communication is shutting down.

According to our research, more than half of fathers, sons and daughters avoid speaking about prostate cancer.³


Sometimes these conversations may feel unnatural, but avoiding them completely might only cause more difficulty.

Sons and daughters across the UK told us they often feel stress, sadness, frustration and disappointment when they're unable to talk openly to their fathers, leaving important things unsaid.³

Don't suffer in silence. Prostate cancer can affect your dad, you and your family, and good communication can help support you in tackling it together.³

 **54% OF FATHERS, SONS AND DAUGHTERS ...**
avoid speaking about prostate cancer³

 **57% OF SONS AND DAUGHTERS ...**
told us they worry about their father's condition several times a week³

 **ALMOST 1 IN 2 SONS AND DAUGHTERS ...**
have questions they don't feel able to discuss with their father³

“

I JUST DON'T TALK TO HIM ABOUT THINGS LIKE THIS.

RUPERT, 40

“

If you don't know what's going on it can be quite difficult to think about and talk about it.

But if you know about it ...you know what to ask... you know what's good and what's bad...

IT'S ALMOST LIKE YOU'RE ALL FIGHTING IT.

MATT, 26

YOUR GUIDE TO PROSTATE CANCER



- 1. PROSTATE
- 2. BLADDER
- 3. SEMINAL VESICLE
- 4. LYMPH NODE
- 5. CANCER

WHAT IS PROSTATE CANCER?

Prostate cancer is a male specific cancer. It occurs in the prostate gland – a male reproductive organ which is responsible for secreting prostate fluid, one of the components of semen.⁴ This gland sits between the bladder, the penis and the rectum.⁵

Prostate cancer is the most common cancer in men, affecting 1 in 8 men in the UK.¹ Prostate cancer mainly affects men aged over 50.⁶ The risk of getting prostate cancer is even higher in black men, with 1 in 4 black men getting prostate cancer at some point in their lives.²

HOW IS PROSTATE CANCER DIAGNOSED?

Early prostate cancer often shows no symptoms, which can make it hard to spot.² Men over the age of 50, or those with a history of prostate cancer in the family are at higher risk.^{2,6}

YOUR FATHER'S GP APPOINTMENT: WHAT MIGHT HAPPEN?⁷

- ▶ TAKE A URINE SAMPLE TO CHECK FOR INFECTION
- ▶ TEST THE BLOOD'S LEVEL OF PROSTATE-SPECIFIC ANTIGEN (PSA) - CALLED PSA TESTING
- ▶ EXAMINE THE PROSTATE THROUGH A PHYSICAL EXAMINATION (DIGITAL RECTAL EXAMINATION)
- ▶ ASK QUESTIONS ABOUT YOUR FATHER'S GENERAL HEALTH, SIGNS AND SYMPTOMS

The patient is usually referred for an MRI scan of the prostate and a biopsy.⁸ The biopsy can be uncomfortable or painful so it may either be conducted under local or general anaesthetic.⁹

WHAT ARE THE STAGES OF CANCER?

There are different ways doctors refer to the different stages of cancer, but the most common is the TNM system:

TUMOUR (T) ...

describes the size of the tumour starting at T1 at its smallest, and growing to T4 when the cancer has spread into other organs in the area

NODE (N) ...

indicates whether the cancer is present in the lymph nodes (N1) or not (N0)

METASTASIS (M) ...

is whether the cancer has spread to other parts of the body outside the pelvis (M1) or not (M0)

You can find out more at:

www.cancerresearchuk.org/about-cancer/prostate-cancer/stages/tnm-staging

THE GLEASON SCORE REVEALS HOW 'AGGRESSIVE,' OR HOW LIKELY THE CANCER IS TO SPREAD OUTSIDE THE PROSTATE.

You can find out more at:

tackleprostate.org/the-gleason-score.php

YOUR FATHER OR MOTHER MAY ALSO DESCRIBE THE CANCER AS LOCALISED, LOCALLY ADVANCED OR ADVANCED PROSTATE CANCER⁹



LOCALISED PROSTATE CANCER ...

which is contained completely inside the prostate gland



LOCALLY ADVANCED PROSTATE CANCER ...

which means it has broken through the prostate gland and may have spread to surrounding tissue, organs and lymph nodes



ADVANCED PROSTATE CANCER ...

is cancer which began in the prostate and has spread to other parts of the body.

LYMPH NODES, SOMETIMES CALLED LYMPH GLANDS, ARE FOUND THROUGHOUT THE BODY, HELPING TO PROTECT US FROM DISEASE.⁹

UNDERSTANDING THE TREATMENT OPTIONS

Most prostate cancer grows slowly, with some men living with prostate cancer without any major problems. However, unfortunately for other men it may grow quickly.¹⁰

YOUR FATHER MAY BE UNDERGOING ONE OR A COMBINATION OF THESE TREATMENTS¹⁰:

MONITORING ...

Sometimes referred to as 'active surveillance', this involves keeping an eye on slow-growing cancer through regular tests. Through careful monitoring, it avoids the need for unnecessary treatment and any side effects.

WATCHFUL WAITING ...

Is used to monitor prostate cancer that isn't causing any problems. It involves less regular testing than active surveillance, and aims to avoid unnecessary treatment unless you get symptoms.

SURGERY TO REMOVE THE PROSTATE ...

If the cancer is localised, taking the prostate out to remove the cancer is an option. The doctor will also remove the two glands behind the prostate and potentially some lymph nodes too. The operation can be performed through key-hole or open surgery.

EXTERNAL RADIOTHERAPY ...

X-ray beams are used to destroy cancer cells from outside of the body.

INTERNAL RADIOTHERAPY ...

Called brachytherapy, there are two types: permanent seed and high dose-rate. They both involve targeting radiation into the prostate.

HORMONE THERAPY ...

Also known as Androgen Deprivation Therapy (ADT), it is used to keep cancer under control. Hormone therapy either stops the body from making the male hormone testosterone – which prostate cancer needs to grow – or prevents testosterone reaching cancer cells.

There may also be other treatments not detailed here.

LOOK OUT FOR SIGNS OF ADVANCED PROSTATE CANCER

Prostate cancer can progress.² When you're familiar with the symptoms, you can help spot changes in your father quickly. Symptoms may include:¹⁰

- **FATIGUE**
- **WEIGHT-LOSS FOR NO REASON**
- **DULL ACHE IN THE SURROUNDING BONES OR BACK PAIN**
- **PASSING URINE MORE OFTEN, OR DIFFICULTY PASSING URINE**

Encourage your father to talk to his doctor if you recognise the above signs.

NOW YOU HAVE A BETTER UNDERSTANDING OF YOUR FATHER'S CONDITION, TURN THE PAGE FOR TIPS ON HOW TO COMMUNICATE WITH HIM ABOUT HIS PROSTATE CANCER.

TALKING TO YOUR DAD

Chatting to your father about his new gadget? Easy. Talking about the match last weekend? No problem. Asking about his prostate cancer? Not so simple.

You may be contending with feelings of fear that you will upset, anger or embarrass him. You may even feel like you're suddenly expected to connect with your father in a way that you never have before.

And, it can be difficult to know who to talk to when you've always turned to your parents for advice.

We spoke to sons and daughters from across the UK whose fathers have prostate cancer to find out what has helped them break down some of the barriers to speaking more frankly with their fathers.

If your father avoids speaking about his condition, you may want to try initiating the talk. But finding the courage is sometimes the hardest part, especially if you've never spoken about it before.

HERE, YOU'LL FIND TIPS ON:

▣ **HANDLING YOUR FATHER'S REACTION**

▣ **APPROACHING THE CONVERSATION WITH CONFIDENCE**

▣ **HANDLING YOUR OWN EMOTIONS**



“

It was a lot easier to broach the subject once he knew what was going on...

THEN IT WAS MORE MATTER OF FACT.

MATT, 26

HANDLING YOUR FATHER'S REACTION

OF THOSE SONS AND DAUGHTERS WHO'VE NEVER TRIED TO START A CONVERSATION WITH THEIR FATHER, OR HAVE QUESTIONS THEY FEEL UNABLE TO ASK...



50%

worry their father will be upset by the conversation³



OVER 40%

fear their father will be embarrassed³



25%

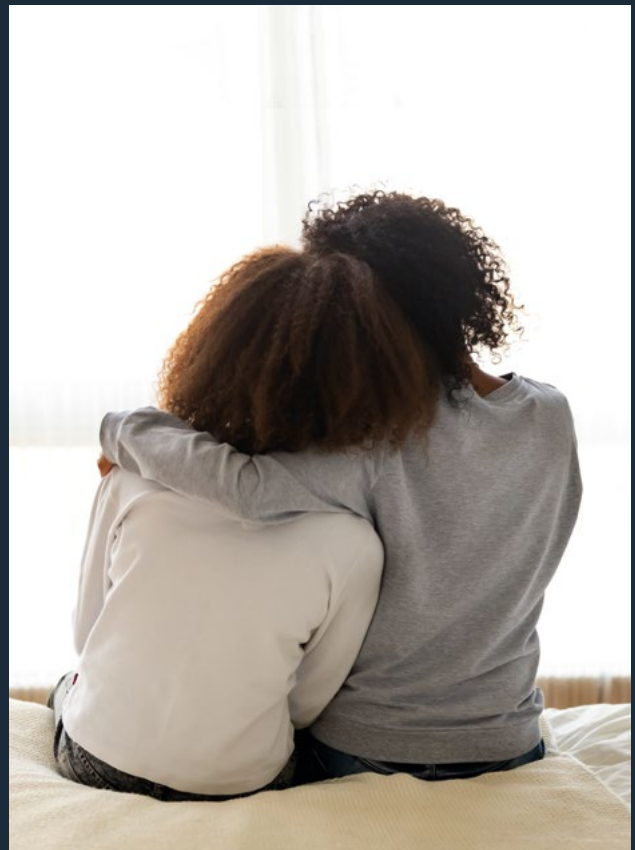
believed their father might get angry³

Many sons and daughters said they find it easier to start the discussion of prostate cancer in a typical conversation or normal setting, such as while watching TV or when the family are all together.³ These situations may help keep the mood lighter and take the pressure off you and your father.

Some fathers use humour to defuse difficult situations, so use your judgement to decide whether a typical 'dad joke' might help provide light relief in an intense conversation. But be careful not to be insensitive.

If your father does get upset by the conversation, don't blame yourself. He may just need some time to process information from a recent appointment or he may be affected by his treatment.

Don't be disheartened, and try again when it feels right – it's important to remember that your father may still see protecting you as his job. For him, not telling you the details may be his way of keeping you safe.



SPEAKING TO YOUR MUM OR OTHER FAMILY MEMBER FIRST

It can help to speak to another family member, such as your mother, your father's partner or a close family friend before you approach your father.

This can be particularly valuable if this person has been attending hospital visits with him; they can act as the point of contact to keep you informed and give you guidance on when to speak to him.

APPROACHING THE CONVERSATION WITH CONFIDENCE

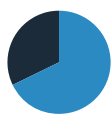
Understanding the condition, the treatment your father is having and how it may be affecting him will hopefully give you some courage in getting the conversation started.

Prostate cancer and the treatments for it can have certain side effects, which your father may feel embarrassed by, such as problems urinating.¹⁰ Some men may feel emasculated by their diagnosis and hormone treatment, which may make them uncharacteristically emotional (among other physical side effects).¹²

Having a good grasp on the facts can help dispel any fear of embarrassment. And hopefully this will enable you to ask questions sensitively and at the right times so your conversation can be more open and satisfying.

Some changes may be more difficult to talk about but are important to be aware of. For example, your father may be experiencing impotence and any discussion should be handled sensitively, and on his terms.⁹

Remember, the more you try talking, the easier it may become.³ If you've never spoken to your father about his prostate cancer, the first step will be to initiate conversation. If you've only had brief, uncomfortable chats with your father, the next step is to have a conversation that allows you to connect a little more each time.



**3 OUT OF 5
SONS AND DAUGHTERS**
we spoke to wished they
felt more confident when
starting conversations.³

“

**SOMETIMES WE'VE HAD
THE DISCUSSION AT
FOOTBALL MATCHES...**

Other times we've sat down and watched a bit of television with my mum and the conversations have arisen then.

AIDEN, 31

“

I'd say, his generation, I don't think they're really open about things. So it's sometimes hard to start things off. But once you do

IT IS A LITTLE EASIER.

LUCY, 33

HANDLING YOUR OWN EMOTIONS

It's important to be honest. You may wish to tell your father how you're feeling, discuss your fears and offer him your support. There may be a family history of prostate cancer, sons may have concerns about their own health, which may be a way into the conversation.

Understandably, emotions can run high in these conversations, so it can be helpful to practise it beforehand. This might be with a friend or family member, or by jotting down some notes, so you can express yourself clearly and listen carefully.

There are lots of ways to communicate available. While direct dialogue – face to face or over the phone – is hugely important at this time, you may feel there are some things you just can't ask or express in this setting.

Writing down those words you can't say out loud may help; you may want to pen a note to your father, send him a text message or write him an email. Try to check in with your father to ensure he's read your message and knows you're there if he wants to chat.

TALK TO YOUR FRIENDS AND FAMILY

Speaking to friends and family can provide some relief from this highly emotional situation, particularly if your father simply doesn't want to talk.

Sons and daughters told us that talking to friends can be easier because they're removed from the situation and provide a less emotional space for speaking freely. For some, opening up to their mother or siblings is helpful because they may be having similar feelings.³

Through talking, you may feel better supported, giving you the strength to help your father. You could use these chats to help put your thoughts into words, almost like a rehearsal, before you speak directly to your father. Friends may have been through similar situations and might be able to offer some helpful advice too.

Everyone handles these situations differently. There are no rules, other than doing what feels right for you, your family and your relationship with your father.

“

I don't ask (about) everything that's going on all the time, but the fact that we can sit down and have open conversations about anything.

I DO FEEL LIKE WE'RE A LOT CLOSER.

SARAH, 31



28% OF SONS AND DAUGHTERS find it easier to speak to someone other than their father³

FURTHER SUPPORT

YOU MAY HAVE MORE QUESTIONS OR NEED MORE SUPPORT TO PROCESS YOUR FATHER'S CONDITION. YOU CAN FIND MORE INFORMATION ONLINE, OR SPEAK TO SOMEONE OVER THE PHONE:

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

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manversation.co.uk

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