



A WOMAN'S GUIDE TO
PROSTATE
CANCER

SUPPORT AND GUIDANCE FOR WOMEN WHOSE PARTNERS
HAVE BEEN DIAGNOSED 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.

A WOMAN'S GUIDE TO PROSTATE CANCER

This guide has been created for you, the woman affected by prostate cancer. When you consider the prostate cancer dialogue to date, you'll notice one glaring omission – women 'living with' prostate cancer can be overlooked.



SAM OWEN

How could the partner of someone suffering from prostate cancer have been forgotten? As a relationship coach who helps people improve or transform their relationships and mental well-being, I was astonished to learn of this strange reality. My experience has taught me that relationships are incredibly powerful; they are a source of emotional and practical support and they can help us heal, live longer and live happier.¹ Romantic relationships are also physically and emotionally intimate, something prostate cancer can disrupt for both partners. So when I was asked to help address this problem for the sake of all men and women affected by prostate cancer, I was humbled

and excited to be involved in such a monumental change. To help us, a group of women very generously agreed to share their experience of 'living with' prostate cancer to help you and your partner have a more positive journey as a result.

On that very intimate, and sometimes vulnerable, journey with your man is you, the wife or partner. Not only might you be devastated by the diagnosis because of your love for him, but your life has also just changed. You are about to experience a changing partner, a changing role within your marriage or partnership and, sometimes, a changing self-image. How do you reconcile all that might be in your future when nobody gives you much of a thought leaving you thinking you're not meant to either? As the women taught me, that's quite the misconception so let's change that together for two very important reasons:

- you play an important role in your partner's recovery;
- you are also 'living with' prostate cancer and so you need support, too.

Let's tweak the focus, for everyone's benefit.

Sam Owen, the author of this guide, is a renowned relationship coach, psychologist, author, blogger and vlogger.

OUR CONTRIBUTORS

Jenny Stanger

Husband diagnosed in 2002;
has primary prostate cancer

Pam Skone

Husband diagnosed 2007;
has advanced prostate cancer

Marion Pollard

Husband diagnosed in 2014;
has advanced prostate cancer

Gillian Murphy

Husband diagnosed 2015;
has primary prostate cancer

WHAT IT'S LIKE WHEN HE'S FIRST DIAGNOSED

*The women were asked about their
early experiences.*

Jenny described it vividly when she said:

“

The initial diagnosis is of course absolutely terrifying and you're like a rabbit in the headlights really because you don't know which way to turn and you can't really process the whole thing.

”

Marion speaking of her experience said:

“

He was diagnosed five years ago and we never thought that he'd still be here.

”

HOW PROSTATE CANCER CAN AFFECT HIM AND YOUR RELATIONSHIP

Physical symptoms

Some of the main physical symptoms your husband or partner may experience with treatment for advanced prostate cancer, either because of the cancer itself or because of the treatments commonly used are tiredness, weight gain, hot flushes, erectile dysfunction, incontinence and difficulty urinating.^{2,3}

If you notice your partner experiencing any of the following symptoms, it is important that you/they speak to a healthcare professional as soon as possible as it may indicate their disease is progressing:^{4,5}

- Fatigue
- Aches, pain, or discomfort
- Trouble falling or staying asleep
- Weakness/numbness
- Bowel/bladder changes
- Issues with sexual function
- Loss of appetite
- Weight loss
- Difficulty doing normal activities
- Generally feeling unwell



Sexual-dysfunction

Sometimes permanently and sometimes temporarily, he may suffer from a low sex-drive and/or erectile dysfunction.⁶



Emotional side-effects


The physical symptoms and sexual-dysfunction can impact your partner's self-esteem and his identity as a man. He may also feel frustrated at his inability to pursue the same life he once lived, and can make him anxious or short-tempered.⁷



Relationship side-effects

From speaking with the women I quickly learnt how these physical and emotional effects on the men undoubtedly had a profound effect on them and their relationship together. How could they not? To watch your partner change personality must be alarming. To have your husband need you so much more than before could be challenging, even if you love them deeply. It must be difficult to have him suddenly stop wanting to cuddle or kiss you and go from feeling like husband and wife to brother and sister, as one lady put it. They revealed it's hard to suddenly not be able to have sex with your loved one, and can even lead you to feel unattractive because he doesn't have 'those feelings' for you at the moment.

What I learnt from the women was that the above problems can be temporary, how you respond to these side-effects can either draw a wedge between you or bring you closer together, and so learning coping mechanisms and staying optimistic is very important.



LEARNING
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HOW TO MANAGE THE JOURNEY FROM DIAGNOSIS

Be a team

Make it clear from the outset that you're on this journey together and are going to help each other. Whenever possible, attend appointments and support groups together so you can both gather important information, and so you understand your partner's journey as best you can. Your attendance also signifies that you are in this together which will help both of you, emotionally. Research demonstrates that people who simply feel lonely or isolated, even if they are not in reality lonely or isolated, risk a shortened lifespan.⁸ Your compassionate presence on this journey will also likely help his recovery and could help buffer him from some of the physical and emotional pain. Feeling like a team, rather than merely his carer, will also help you retain your sense of security and identity on this journey.

Use communication to clarify and strengthen

The women made it clear that communication from the start is really important for several reasons.

1. Frank conversations with good questions help him to make sense of his thoughts and emotions and recognise any changes he wants/needs. This way you're also less likely to accidentally frustrate or stifle him and his recovery. For example, 'How can I help you to maintain your feeling of masculinity?'; 'What makes you feel frustrated and how can we prevent it?'; 'What do you find helps you to feel good day-to-day?'

2. You can let him know what you need during this difficult time, too, for example: 'Even if we're not able to have sex, I'd still like to cuddle and kiss as I want to feel close to you.'
3. You can frequently vocalise your love and support for one another, reinforcing the message in each other's brain. You both need this and this can be as simple as: 'You know we're both going to work at getting your sexual function back!' or 'Give me a shout if you get tired and want me to finish the gardening for you,' or 'I love you so much.'

Make sure you both maintain self-care

Ensure you both make self-care a priority and ask good questions to help, e.g. 'Which activities do you/we/I find emotionally/physically soothing?' If you feel guilty about looking after yourself physically and emotionally, look at it this way: you maintaining self-care is vital to your health and your partner's recovery. If you feel sad or depressed, you'll be miserable and he'll sense it even if you say you're 'fine' and that could knock him emotionally which could impact his health.

Be aware of and prevent identity loss

From talking with the women I learnt that prostate cancer can make your partner lose his identity as a man and his sense of self. It must feel so strange and frustrating to suddenly feel fatigued all the time or become sensitive and

weepy or have no sex drive or be unable to have sex. I also learnt that the wife or partner can also lose her identity as a woman. Gillian, when talking about her husband's loss of sexual desire, explained, 'It's made me lose confidence in myself as a woman, especially about how I look because I'm not being shown any affection...I feel a bit sexless'.

To help maintain some sense of her former identity, Gillian continues working instead of retiring and highlighted that if you stop making an effort with your appearance, you can further lose your identity and so suggests you make an effort still, just for your own identity's sake.

Use humour to help

What we say to ourselves and to each other makes a massive difference to our emotions, behaviours and the quality of life that we live. I heard comments that I felt sad to hear, like, 'He's living on borrowed time.' I also heard comments of optimism and joy like, 'It's all very exciting when things do start to go right'. To help you manage the emotional turmoil and lighten the intensity, humour can help.

Gillian talked of how humour has helped: 'I'm quite quick-witted and quite sarcastic...and he knows that... and we have little jokes about all of that side of it and I think that takes the pressure off because we've now started to joke about all the inefficiencies...it's lightening it more. Because if we can't fix it, we've just got to deal with it in the only way we can, which is not letting it take over our lives and just try, you know, have a bit of a laugh about it and both take it on the chin. That's all we can do...I've got to learn to live with it as well.'

Maintaining routine and normality feels good

When you're living with prostate cancer, the focus returns again to living life and making the most of what you do have. Pam talked about how important routine is for maintaining a healthy mind and body. Living in a retirement village, Pam's husband, Ted, goes to the gym in the morning and then they keep busy together or individually throughout the day so that Ted maintains good habits and avoids creating bad habits that would be unhelpful for his condition, for example, a sedentary lifestyle. Ted is currently in remission and monitored annually by his hospital. Despite sex no longer being an option for them, they maintain plenty of emotional and physical intimacy in other ways like frequently telling each other 'I love you' and being tactile and loving when in one another's company. Listening to Pam you sense their togetherness and thoughtfulness about what's healthy for both of them.

Marion mentioned that her husband, who enjoyed being active before cancer, is still working now. Gillian also talked about how downsizing to a bungalow in a new area gave them a new focus and a new project to work on together. Staying busy and living life is important as otherwise it would be easy for the worry, fear and/or sadness to take over your lives.

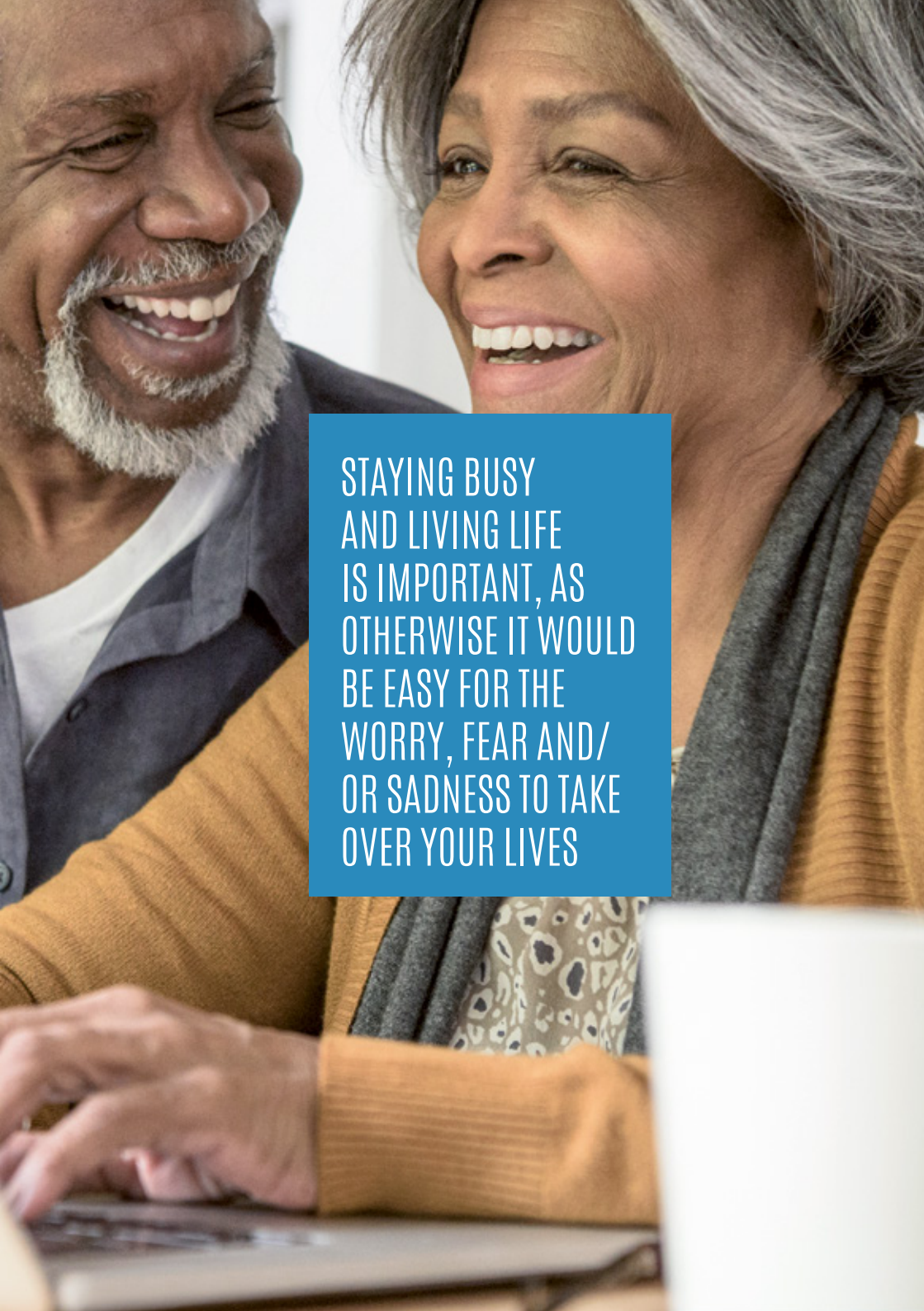


HOW THE DIAGNOSIS POSITIVELY CHANGED RELATIONSHIPS

These women introduced me to a world of male and female fighters, a world in which they had lost things, albeit temporarily at times, and had gained things too. Most women, if not all, mentioned feeling closer to their husbands/partners now.

Pam also talked of how she and her husband are now more tolerant with each other, don't easily get cross with each other, are more thoughtful about each other's feelings, and are grateful for what they do have.

For most, the diagnosis has also helped their families to become even closer than they might have been. It has helped their adult sons and daughters to demonstrate greater emotional and/or practical support for both parents and thereby further tightened family bonds.



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HOW YOU CAN SUPPORT YOUR PARTNER

The women shared the numerous ways in which they have supported or continue to support their husband/partner:



Practically

- helping with physical care
- organising his medication and medical appointments
- keeping an eye out for any new or worsening symptoms and encouraging him to mention these at his next doctor's appointment
- helping him regain sexual function if possible
- helping him to eat more healthily and live a healthy and active lifestyle
- ensuring he gets rest when he clearly needs to



Emotionally

- reassuring them
- providing them with a place for sharing their innermost feelings
- helping them to maintain emotional stability however they can

They also shared other important lessons to benefit you and your partner.

During conversations with the women, it was mentioned that medical professionals had stressed the importance of quickly regaining sexual function as soon as he felt able to, as he could either 'use it or lose it'. It was also discussed how being physically supportive and adaptable is important because you are in it together, and how the partner can become part of the therapy and recovery.

I really sensed their togetherness on this journey and it's something a lot of women expressed, the importance of being a team and retaining closeness from the day of diagnosis.

Gillian stressed the importance that you both be aware from the outset that the cancer is going to change both your lives and that you'll need some coping strategies to deal with the changes. She highlighted that just because it may take one part away from you, it doesn't mean you're not still a man/woman or you're not still a couple. She explained, 'I think you get so caught up with the treatment and everything that's happening that you shelve a lot of the emotional side of it until after the treatment stops but then you've lost each other on the journey' and of course it's easier to maintain what you have than recreate it. Therefore, maintain emotional and physical intimacy right

from the start, working within the parameters you have. The importance of adaptability was also discussed.

Pam urged wives/partners to attend the actual appointments with their husband/partner, rather than sit outside in the waiting room. She explained: 'A lot of men these days, they don't talk about things but if their wives know about it, they'll know what they're going through and they can be supportive.'

Jenny and her husband seem to have developed a great deal of strength and hope from researching, raising awareness of prostate cancer, and talking with others in similar situations. Jenny mentioned that it helps to not overly mother your partner as he may already feel emasculated enough by the whole journey. She also says 'I think you have to try very hard not to let it control your day to day life especially when it's been going on for such a long time. Try to push it to the back of your mind when you're not actually waiting for the next test, as far as you can, otherwise you'd be living on a knife's edge all the time, wouldn't you?'

“

TRY VERY HARD NOT TO LET IT BECOME TOO MUCH OF AN OVERHANGING SHADOW IN ALL YOUR LIFE AT ALL TIMES.

”

JENNY

Marion simply said that in addition to supporting him however you can, you have to live in the moment, enjoy each other's company, enjoy every day, and make the most of the time you have as a couple and as an individual.

“

MAINTAIN EMOTIONAL AND PHYSICAL INTIMACY RIGHT FROM THE START, WORKING WITHIN THE PARAMETERS YOU HAVE.

”

GILLIAN

HOW YOU CAN BE SUPPORTED

Recognition of how pivotal your role is

The role you play as a partner is incredibly powerful, intimate, and beautiful in its own way. You must both recognise from the start that you are part of the treatment and the recovery, not just a nurse working in the shadows, but his life source up, front and centre.

Most of the women interviewed said they were overlooked as someone deeply affected by their partner's prostate cancer as well as overlooked as someone who is highly important to their partner's recovery. On the other hand, it was brought to light that when healthcare professionals did focus on the importance of a woman's role in the recovery process, it can help put you in an empowered state of mind and fuel a proactive recovery role.

Support groups

I learnt that support groups can provide a great source of emotional support and learning for both you and your man, with educational videos, talks from medical professionals, and people sharing personal experiences. There seems a desire for women only support groups where women can talk more candidly about important challenges and solutions, as well as more support groups in general. Women's support groups are currently few and far between; however you could start your own women's support group in your local area, independently. Jenny has found that a subsidiary Women's Group, set up in her local area, has proved valuable in giving extra support to the wives and partners of members through sharing valuable personal experiences.

Know what to expect and how you'll deal with each change

There are so many changes that can occur; know what to expect by asking doctors the right questions and then work out as a couple, through open conversations and your own research, how you're going to help each other manage the changes and maintain your closeness throughout.

Here are a few example questions to get you thinking about the sorts of questions you should ask the appropriate medical professionals:

- What are the emotional and physical symptoms he's likely to experience, how long for and how can I help him manage these symptoms?
- Are there any signs and symptoms we should be looking out for that could indicate his disease is progressing, and if they appear, what should we do?
- What emotional and physical impact will the changes he experiences have on me and on our relationship?
- How quickly can we start working at getting sexual function back?
- Where else can we get specialised practical and emotional advice and support?

Here are a few questions to help you think about the types of conversations you should have with each other:

- Can we please promise each other that, as and when required, we'll devise strategies that work for both of us as you go through changes so that we can both manage those changes well, e.g. loss of sex drive, anxiety, fatigue, etc?
- Can we ensure we maintain physical intimacies such as kissing, cuddling and holding hands, even if we can't have sex?
- How can I help you to maintain normality?
- Can you do 'x' and 'y' to help me maintain normality in my life?

Specialised counselling/coaching is desirable

It seems you might both benefit from some form of specialised counselling or coaching, particularly in the early days; somewhere where you could both talk to someone who understood the journey. As one lady pointed out, it can be hard to find answers when you don't even know which questions to ask. Counselling or coaching could help at multiple stages in the journey, even if just a few sessions to help you make sense of your feelings and learn practical strategies for regulating them, and better manage your role as carer, personal assistant, friend and lover.

Speak to your GP about a referral to a specialist service.

Research empowers and provides hope and solutions

Learning about treatments' pros, cons and success rates, helps couples to feel empowered, make more informed decisions about treatments, know what to expect along the way, and learn how to deal with the challenges and changes that prostate cancer brings to all those concerned. Such information gives hope and help. Given the digital world we now live in, this research can come from credible research papers online, informational videos and guides from credible sources, such as this one, as well as books in libraries or from a store and from talking with others.

CONCLUSION

The wealth of information these women shared was eye-opening, particularly as so much of it was so similar despite their partners' differing diagnoses and time they had been living with prostate cancer. The message was loud and clear:

- recognise you are both significantly impacted by the diagnosis from the outset
- adopt coping strategies for a changing partner, relationship and life
- maintain emotional and physical closeness from the start
- embrace your vital role in his treatment and recovery
- focus on the individual and stay optimistic

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FAMILY AND FRIENDS TO
HELP THEM UNDERSTAND
WHAT YOU AND YOUR
PARTNER MIGHT BE
EXPERIENCING AND TO HELP
THEM KNOW HOW THEY CAN
BEST SUPPORT YOU BOTH

For more information, visit the Manversation, Orchid and Tackle websites.

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