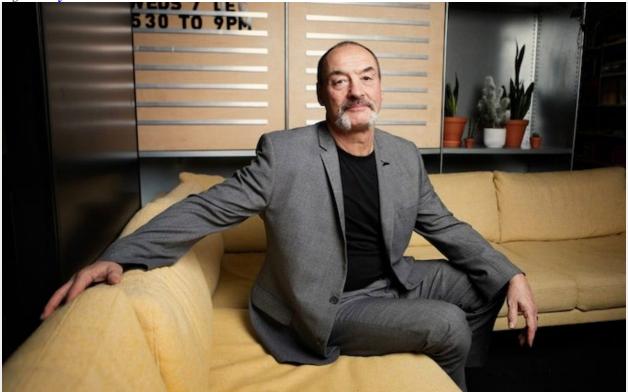
The Telegraph

'My treatment for prostate cancer saved my life – but almost destroyed my marriage'

Life-saving interventions to treat the disease can affect a man's ability to have sex. Our writer talks to one survivor about how he coped

ByHilary Freeman12 December 2022 • 6:00am



Elvin Box was diagnosed with aggressive prostate cancer in 2016 CREDIT: Rii Schroer for The Telegraph

When business consultant, Elvin Box, was diagnosed with aggressive prostate cancer in 2016, and told he needed urgent treatment, his first question was: "Will I die?" His second was: "Will I be able to get an erection again?"

For Elvin, now 65, and his wife Judith, also 65, from Laindon, Essex – childhood sweethearts who met at 16, and now have two daughters and six grandchildren – sex was a very important part of their "intensely passionate and loving" 41-year marriage. Aware that treatment was likely to leave him both unable to ejaculate and impotent, he admits his first instinct was to bury his head in the sand and run away.

Loss of sexual function following prostate cancer treatment is, for most men, far more than just an unpleasant side effect; it's life-changing. Last month, the devastating impact of sexual dysfunction was finally recognised, with new guidelines for prostate cancer care published in The Journal of Sexual Medicine.

The guidelines are based on 25 years of research and combine expert perspectives from 37 international clinicians and researchers, as well as prostate cancer survivors and their partners. They

acknowledge sexual dysfunction as the most reported health-related quality-of-life outcome and the greatest unmet need in prostate cancer care.



Elvin and Judith have been married for 41 years

They also encourage healthcare professionals to provide tailored care to enhance the sexual health and quality of life of every patient, and to facilitate shared decision-making between clinicians, patients and their partners. And they emphasise the importance of tailoring counselling to the cultural, ethnic, racial, sexual and gender needs of individual patients and their partners.

One in eight men in the United Kingdom will receive a diagnosis of prostate cancer in their lifetime, with approximately 1.4 million men diagnosed globally in 2020. In England, 86 per cent of these men will be alive five years after diagnosis, and between 25-80 per cent of them will have some form of erectile dysfunction.

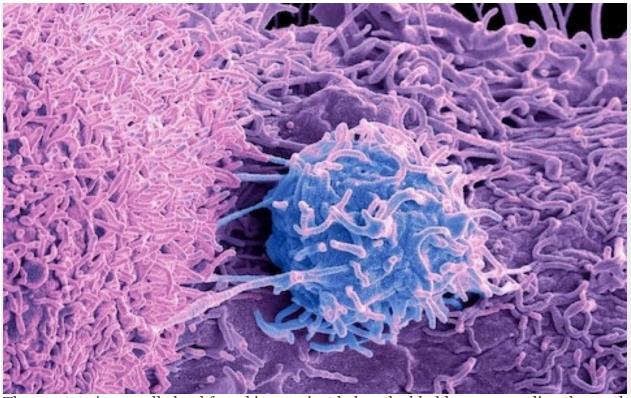
It's not the cancer that affects sexual performance, but the treatments. "While different treatments (surgery, radiation, hormonal therapy) have somewhat different effects, all cause erectile dysfunction, loss of or diminution of ejaculation," explains Daniela Wittmann, Associate Professor of Urology at the University of Michigan, and a certified sex therapist.

"Men on hormonal therapy lose their sex drive because of the loss of testosterone, and have diminished erectile function, diminished ejaculation and possible loss of orgasm. Surgery can damage nerves that are responsible for erections, and erectile dysfunction (ED) occurs immediately after surgery. Even when surgeons attempt to save those nerves, they take a long time to recover (two plus years) and it's likely they will not recover fully. With the loss of the prostate, men can still orgasm, but they lose the ability to ejaculate."

Wittmann says the impact is biological, psychological and social: "Men may become anxious about their sexual performance and depressed about a perceived loss of masculinity. Younger men suffer more, and a minority become suicidal, particularly those who are single. The fear of impotence has also been known to lead to men avoiding screening and/or treatment for prostate cancer. All these issues mean it's vital that the issue of sex is discussed."

Yet patients aren't currently receiving specialist advice or support. Results from the 2016 UK Life After Prostate Cancer Diagnosis (LAPCD) study revealed that few men with prostate cancer were offered help with sexual problems (medication: 41 per cent; devices: 23 per cent; specialist services: 15 per cent). Overall, 57 per cent of men were not offered any of these interventions at all.

Offered a choice between radiotherapy followed by testosterone-lowering hormone treatment, or a radical prostatectomy (surgical removal of his prostate), Elvin opted for the surgery because he was told it would be nerve-sparing, and he might, with assistance, be able to manage intercourse again in the future.



The prostate is a small gland found in men just below the bladder, surrounding the urethra, the tube urine passes through. Pictured here are prostate cancer cells CREDIT: Science Photo Library RF He learned that if he hadn't been operated on in August 2016, his tumour would, within weeks, have broken out of his prostate and spread, making his cancer incurable. Although he feels lucky and grateful to be alive, he says the treatment took a huge toll not only on his ability to have sex, but also on his confidence, his personality and, ultimately, on his relationship.

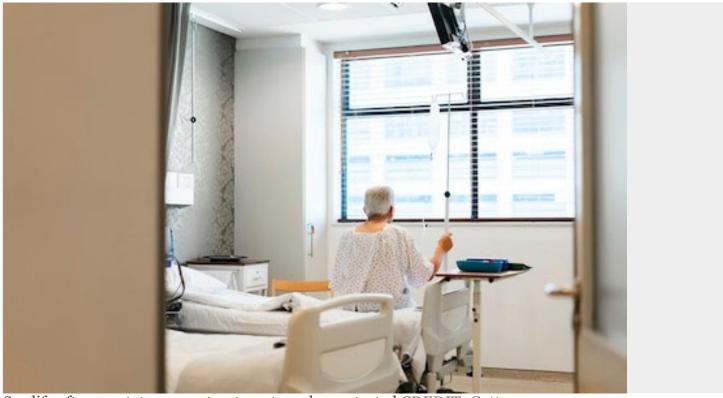
"I tried pumps and masturbation, pelvic floor exercises and Viagra, all of which helped to a certain extent, but by July 2017 I was becoming increasingly frustrated and agitated," he recalls. "I missed the spontaneity of sex. I started to feel very unsure of myself, with my confidence seeping away, and worse, I felt very, very angry.

"It wasn't Jude's fault at all, but I began to argue with her all the time. The arguments were about things that had happened years before – I was completely unreasonable and irrationally jealous. The truth is, I knew I wasn't the man I was before my cancer, and I couldn't come to terms with that."

Matters came to a head on a trip to Barcelona to celebrate his 60th birthday, when, to his great shame and regret, he lost control and attacked his wife physically. "Following another argument, I got into such a blind rage that I actually lifted her up and threw her against some shutters. It scared the life out of her, and me. It was horrific.

"The next morning, we spoke about it. She said I had been unrecognisable and she'd been frightened for her life. We both came to the conclusion that I desperately needed help."

Wittmann says sex life after prostate cancer treatment can be protected if men and their partners are encouraged to recognise and grieve the sexual changes they're experiencing. They need to be open to adopting non-penetrative strategies to achieve sexual pleasure.



Sex life after prostate cancer treatment can be protected CREDIT: Getty

"It is not necessary for men to lose their sex lives just because their erections are not working well," she explains. "There is plenty more of their sexuality to draw on. And for some men, erections will not be very affected or will return fairly well over time. There are also practical tools – vacuum devices, injections, pills, penile implants – and sex therapy and support groups, which can help too."

Following his violent outburst, Elvin agreed to see a psychologist and had two years of therapy to work through his feelings and come to terms with his loss, as well as to find new ways to enjoy sex. He says that in the long run, what happened has made his marriage stronger: "Before, we never talked about our sex life. Now we have to talk openly and candidly. I am so grateful to Jude that she never left me when I was at my worst. She said she wanted to, on many occasions, but she couldn't because her love was unconditional."

The new prostate cancer care guidelines take partners like Judith into account, recognising how they too are affected. Wittmann says they too end up with unmet sexual needs, but don't always feel entitled to be upset about this, as everyone's priority is saving their partner's life, and they feel they should be grateful for this.

"Helping couples to approach sexual changes after prostate cancer as a team strengthens their bond and enables partners to develop a deeper emotional connection and, in some cases, a more satisfying sex life as a result."

The guidelines also take into account the needs and experiences of men from different ethnic backgrounds, or who are LGBTQ+. "For too long, sexual health research in prostate cancer has focused on white, heterosexual men," says Karen Robb, a chartered physiotherapist and programme

implementation director for Cancer Movember UK. "The guidelines are an important step in acknowledging these limitations and ensuring that equity, diversity, and inclusion sit at the centre of high-quality care.

"For example, they articulate how surgical removal of the prostate represents the full loss of a sexual organ. For many gay and bisexual men, this may constitute an even bigger loss than it is for heterosexual men because of the increased role the prostate often plays in erotic stimulation and sensation."

Elvin was involved in the early stages of designing the guidelines and he is now an ambassador for the men's health charity, Movember. "If only the guidelines had been there for me," he says. "They have been so needed for generations, and if they're now taken up and used by healthcare professionals, it will help so many men faced with the trauma of dealing with prostate cancer to make an informed decision about their choice of treatment and how they can rehabilitate. I think we all need to learn to talk about our sexual health just as easily as we do about our dental health."

To read the guidelines see: movember.com/SexualHealthGuideline

To donate to Macmillan Cancer Support via the Telegraph Christmas Charity Appeal 2022, please visit <u>telegraph.co.uk/2022appeal</u> or call 0151 284 1927