

‘After my surgery, there was a time my wife said she was scared for her life’

Prostate cancer treatment can ruin a man’s ability to have sex – causing frustration and anger. One survivor tells *Hilary Freeman* how it damaged his relationship

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. 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 UK will receive a diagnosis of prostate cancer in their lifetime, with approximately 1.4million men diagnosed globally in 2020. In England, 86 per cent of these men will be alive five years after

diagnosis, and between 25 and 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 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.

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.

‘I wasn’t the man I was before my cancer, and I couldn’t come to terms with that’



RII SCHROER; GETTY

“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.

“It is not necessary for men to lose their sex lives just because

Challenged: teamwork can be vital; below left, Elvin and Judith Box

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



PROSTATE CANCER – THE VITAL FACTS

What are the signs and symptoms to look for in prostate cancer?

The most common symptom is the need to urinate frequently, especially at night. You may also have difficulty starting urination or holding back urine, or a weak or interrupted flow of urine. Some men may also notice difficulty in having an erection, painful ejaculation or the presence of blood in urine or semen.

Other signs include frequent pain or stiffness in the lower back, hips or upper thighs, which can be a sign of prostate cancer that has spread.

These symptoms don't always mean you have prostate cancer. Many men's prostates get larger as they get older because of a non-cancerous condition called benign prostate enlargement.

When should you get checked?

If you're over 50, have a conversation with your GP about whether you need to have a PSA test. If you're black or you have a family history (your brother or father) of prostate cancer, do it at 45 because these groups are 2.5 times more likely to get the disease.

What are the benefits of getting diagnosed earlier?

Early detection for prostate cancer is key to successful treatment. Research suggests treatment at stages one and two has a near 100 per cent survival rate compared with around 50 per cent at stage four.

Who can you call for further advice/support?

If you think you might be at risk of prostate cancer or are experiencing any symptoms, speak to your GP. They can talk to you about your risk and about the tests used to diagnose prostate cancer.

You can also visit prostatecanceruk.org/get-support for more information on services and resources available to help

"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 telegraph.co.uk/2022appeal

'Surgical removal of the prostate represents the full loss of a sexual organ'

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.

Michael Fitzpatrick

The Surgery

Over-medication is not the solution



Following the disruption caused by the Covid-19 pandemic, the STOMP campaign ("Stopping Over-Medication of People with a learning disability or autism or both") is being relaunched by NHS England, with the support of the Challenging Behaviour Foundation and a coalition of professional and voluntary organisations.

STOMP was launched in 2016, following the revelation that some 30,000 to 50,000 people, many in residential care, were being prescribed long-term anti-psychotics and/or antidepressants, though they had often not been diagnosed with any specific mental illness. A parallel campaign focuses on children, with the goals of "Supporting Treatment and Appropriate Medication in Paediatrics" (STAMP).

Although there is little evidence of the efficacy of these medications among either adults or children with learning disabilities, there is considerable evidence of their potential adverse effects, which include weight gain, diabetes and heart disease. It is clear that these drugs have come to be widely used to contain "challenging behaviour", effectively as a "chemical constraint" or "liquid cosh".

At a recent focus group to promote the relaunch of STOMP and STAMP, leading clinicians noted that there had been scant progress over the past few years in achieving the campaigns' targets. A slight decrease in prescriptions for anti-psychotics was accompanied by a greater increase in those for antidepressants.

For psychiatrist Dr Roger Banks, national clinical director of the project, it must be "everybody's business" in this field to promote good prescribing, as well as seeking "non-drug" approaches to challenging behaviour. He urges clinicians to make sure that they are using "the right medication, at the right time, for the right reason and for as short a time as possible".

Comments from parents and carers for people with autism and learning disabilities revealed some familiar obstacles to withdrawing or reducing medication. A number of parents reported that when they sought help and support in relation to problems of challenging behaviour at home, they were often subjected to intrusive assessments and presumed to be guilty of neglect or abuse.

Parents whose adult children had been admitted to residential facilities found that when their behaviour deteriorated, they were prescribed medication without appropriate assessment or consultation. Access to alternatives to medication –

notably "positive behaviour support" programmes – remains uneven and staff in many residential facilities are badly paid, poorly trained and overstretched.

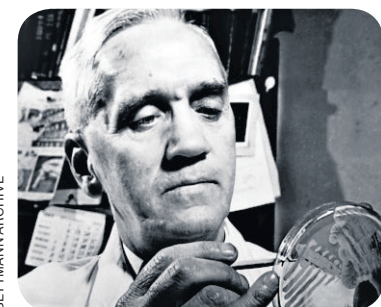
Though there are some examples of successful medication withdrawal through local teamwork, the wider success of STOMP depends on tackling these underlying problems.

Advice for Strep A raises eyebrows

The official advice that children in close contact with a serious case of Group A Streptococcal (GAS) infection should receive preventive antibiotic treatment has raised some eyebrows among GPs. For many years, we have been advised to use antibiotics only for confirmed bacterial infections because of the risks of drug resistance and untreatable superbugs.

It is actually remarkable that the drug being recommended is Penicillin V. This is essentially the extract of the same mould that Alexander Fleming famously scraped off a petri dish at St Mary's Hospital, in London, in September 1928. Fleming immediately recognised that penicillin was only effective against certain bacteria, and in 1940 Ernst Chain and Edward Abraham identified an enzyme called penicillinase – found in a strain of E. coli – which was able to break down penicillin, making it inactive. Yet more than 80 years later, penicillin, used selectively, remains a powerful antibiotic.

Though cases of invasive GAS infections are rare, the widespread use of penicillin in response to parental – and medical! – anxieties, though it may not provoke much further drug resistance, is likely to cause a significant toll of adverse effects, including a severe allergic reaction like anaphylaxis (which occurs at a rate of 1 in 1,000). While antibiotic prophylaxis may be beneficial for close contacts, panic prescribing may do more harm than good.



Pioneer: Sir Alexander Fleming discovered penicillin in 1928