Ken, 70

PCaHELP Founder and Chair who developed ED after surviving prostate cancer, *PERTH*

Founder and Chair of the Prostate Cancer Help Association Inc. (PCaHELP), father, grandfather, and business owner, Ken, 70, Perth, was diagnosed with erectile dysfunction (ED) after undergoing prostate cancer surgery in September 2013.

One of the most common urological problems,¹ ED involves the persistent inability to achieve, or maintain a penile erection sufficient for satisfactory sexual performance.^{2,3} Predominantly afflicting men aged 40+ years,⁴ one of the potential side-effects of prostate cancer surgery is ED.^{2,5}

Ken has a strong family history of cancer. His father lost a protracted battle to stage IV prostate cancer in 1999. His mother passed away from breast cancer in 1965. Ken's brother was diagnosed with prostate cancer in 2013, and six months later, in July, 2013, Ken too, was diagnosed with the potentially devastating disease.



At the time of Ken's diagnosis, prostate cancer treatments carried a high risk of side-effects, including ED. Ken was informed by his doctor, that should he fail to regain sensation within one-to-two years post-prostate cancer surgery, he would most likely never recover normal sexual function. A concerning prospect for sexually active Ken, this made him strongly consider forgoing prostate cancer treatment altogether. After much deliberation however, Ken chose to undergo a radical prostatectomy for his disease, which regrettably, resulted in ED.

Living with ED after surviving prostate cancer, had a profound effect on Ken's physical and mental health, and wellbeing. Physically, he struggled to maintain intimacy with his wife, while emotionally, he felt as though his manhood had been stripped from him.

Ken spent three years trialling a plethora of options to treat his ED, each of which, however, offered him only short-term relief. As each treatment attempt failed, Ken's frustration and desperation began to spiral. In 2016, he visited a urological specialist for further professional advice, after which he eventually found a long-term treatment option that worked for him.

Over time, Ken chose to put his lived experience with ED to good use. He founded and continues to Chair the non-profit association PCaHELP. He has personally chosen to support and empower men living with ED, and to urge those affected, to seek medical help without delay.

Today, Ken has chosen to share his story, to raise community awareness and understanding of ED, and to encourage men nation-wide, to prioritise their sexual health. He reinforces that those living with ED are not alone, and that men's sexual health should be prioritised, as reflected in
The Australian Government's National Men's Health Strategy 2020-2030.6">Men's Health Strategy 2020-2030.6

This is Ken's story.

Ken has always prioritised his personal sexual health and wellbeing, and intimacy with his wife.

"I originally told my wife that I didn't want to undergo prostate cancer surgery in order to maintain our sex life. I wanted to be able to continue to satisfy her needs as well as mine. But she insisted I go ahead.

"She said she would rather have some part of me not work, than to lose me completely," said Ken.

"I didn't know anything about ED at the time, apart from it being a potential side-effect of undergoing prostate cancer surgery. It was never a topic I discussed with my GP.

"Right up until the day before surgery, I was functioning normally. I remember discussing ED with my urologist, even on the operating table. He couldn't save the nerves on one side due to the location of the tumour, but he was hoping those remaining would recover. But they never did," Ken said.

"My wife and I got married young. We had a good sex life. So maintaining that was important to both of us.

"A lot of the treatment options we trialled after my prostate cancer surgery made us lose spontaneity with our sexual function. Everything had to be pre-planned, so it became a cold event. It didn't feel natural," said Ken.

Living with ED has created many physical and mental "roadblocks" for Ken, including fear, which over time, thrust Ken into anxiety and depression.

"When I learned I would never regain sexual function, I was devastated. I thought my life was over, and was very concerned about my future.

"The biggest challenge of living with ED was mental. Despite surviving prostate cancer, living with ED was totally devastating," Ken said.

According to Ken, living with ED questions one's ability to "be a man".

"Sexual function is such an important part of being a man. When you don't have it, you don't feel complete anymore," said Ken.

The fall-out from his ED, and the subsequent wellbeing of his wife, also played heavily on Ken's mind.

"I was afraid our relationship would suffer. That was one of my biggest, initial concerns when considering prostate cancer surgery, and the reason for my initial hesitation.

"Fortunately, my wife and I are very close, so we were able to talk about it," Ken said.

"Eventually, four years after my prostate cancer surgery, I found an ED treatment option that worked for me. It was a last resort, but it changed my life completely. Had I failed to find this treatment though, I would have been constantly concerned about my wife's wellbeing, and her ability to be satisfied. Although these are more my insecurities than hers. She's a strong woman.

Ken's concerns further extended to his son's welfare.

"My 45-year-old son is now acutely aware that he too, is at high risk of developing prostate cancer, and ED.

"Fortunately, he knows I'm here to talk if he needs me," said Ken.

Given his lived experience of ED, and the associated physical and emotional stressors, Ken founded the not-for-profit, WA-based association, <u>PCaHELP</u>, to support men, and their families, during and following prostate cancer treatments.

"As Founder and Chair of <u>PCaHELP</u>, we run several events each year, to raise awareness of prostate cancer, and to support those affected by all of its side-effects, including mental health concerns.

"Maintaining general health and wellbeing is essential for any man who has undergone prostate cancer treatment. But many fail to understand that they can't maintain the same sex life they have always enjoyed, if they don't look after their general health and wellbeing, which in turn, affects their sexual health," Ken said.

"When I was diagnosed with prostate cancer, I made a conscious decision to live longer, and to function well. So, I overhauled my entire life, and I am now physically, and mentally, fit and well and still prostate cancer free."

Ken has a simple, but poignant message for other Australian men living with ED.

"A lot of guys don't want to talk about ED. Those who do, want reliable information about treatment options.

"Every man needs to find a tailored ED treatment option to support their physical, mental, and social function," said Ken.

"Help is available. All you have to do is ask. There are many brilliant doctors out there."

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References

- 1. Langarizadeh MA, Salary A, Tavakoli MR, Nejad BG, Fadaei S, Jahani Z, Forootanfar H. An overview of the history, current strategies, and potential future treatment approaches in erectile dysfunction: a comprehensive review. Sexual Medicine Reviews. 2023;11(3):253-67.
- 2. HF About ED fact sheet. Boston Scientific; 2019.
- 3. Rew KT, Heidelbaugh JJ. Erectile Dysfunction. Am Fam Physician. 2016;94(10):820-7.
- 4. Leslie SW, Sooriyamoorthy T. Erectile Dysfunction. StatPearls. Treasure Island (FL)2024.
- 5. Erectile dysfunction: a partner's point of view. In: Scientific B, editor.: Boston Scientific; 2017.
- 6. National Men's Health Strategy 2020 2030. Australian Government Department of Health; 2019.