

The silent rise of stigmatised cancer

Henrietta Cook

By the time Wayne Earle received a diagnosis of penile cancer, he had only one option for survival.

His doctor told him he needed a penectomy – surgery to remove his penis.

“That’s all I heard,” the now 58-year-old recalled. “You don’t hear anything after that.”

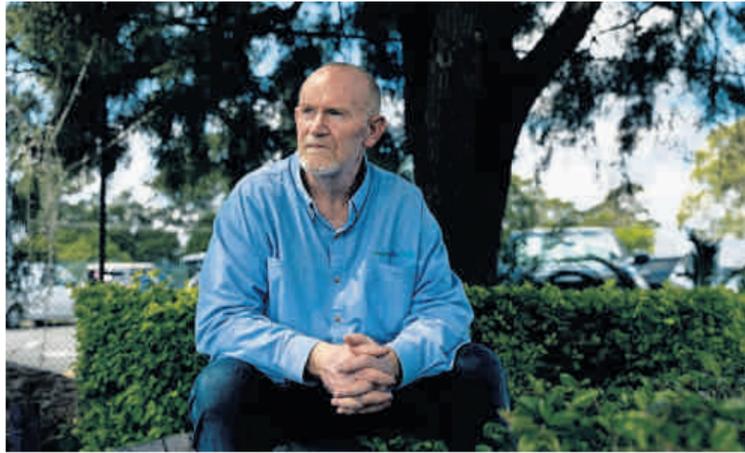
Earle, who lives in the Blue Mountains, is among a small but growing number of Australian men who have been diagnosed with penile cancer, a stigmatised and devastating disease. The number of new cases has more than doubled in Australia over the past two decades, with 165 cases last year, up from 73 in 2005.

The human papillomavirus (HPV) is linked to about 60 per cent of penile cancer cases, but other risk factors include being uncircumcised, smoking, advanced age and skin conditions such as psoriasis or UV exposure.

While health experts don’t know exactly what is driving the rise in cases, urological surgeon Associate Professor Dixon Woon suspects that an ageing population and fewer boys being circumcised could be factors.

But Woon, who holds a leadership position at the Urological Society of Australia and New Zealand, said the risks associated with circumcision did not outweigh its benefits.

“The HPV vaccination offers much better protection against



Wayne Earle started charity Check Your Tackle. Photo: Max Mason-Hubers

penile cancer while also preventing cervical and oropharyngeal cancers,” he added.

The greatest hurdle remains the stigma surrounding the disease.

Woon said it was common for men to delay seeking help due to embarrassment. This can lead to fewer treatment options and worse outcomes for patients. While treatment of early-stage penile cancer might involve circumcision, excising the lesion or topical chemotherapy, later stage treatment involves the partial or full removal of the penis.

Up to 80 per cent of men who undergo treatment before the cancer spreads to their lymph nodes are cured of the disease, according to Woon. “Early detection is crucial for survival,” he said. To try to speed up

the time between symptoms and a diagnosis, Woon is working with researchers to develop an AI tool to help doctors identify suspicious lesions.

Earle detected a small red spot on his penis 11 months before he was diagnosed. His dermatologist initially thought the lesion was a patch of psoriasis – a skin condition he has suffered from since he was a child.

When the lesion didn’t respond to steroid cream, his doctor recommended wart treatment. But the spot didn’t respond to that either.

It wasn’t until his fourth visit to the dermatologist in 2014 that a biopsy of the skin of his penis was taken and sent for testing. The results came back as invasive penile squamous cell carcinoma. Unlike

many men diagnosed with penile cancer, Earle’s case is not linked to HPV. He believes his cancer was caused by the UV light therapy he received to treat his psoriasis.

Jonathan Hallett, an associate professor of health promotion at Curtin University, expects penis cancer cases will fall in coming years due to the rollout of the HPV vaccine to high school girls in 2007 and boys in 2013. “We’ve already seen really dramatic reductions in HPV prevalence and genital warts in younger Australians since the program started,” he said. “However, because these cancers take decades to develop after initial infection, we likely won’t see significant declines in rates for some time, as vaccinated cohorts reach the age when these cancers typically emerge.”

He said HPV was a common sexually transmitted infection that most people cleared within a year or two. But a persistent infection can switch off the body’s natural tumour suppression mechanisms and allow cells to grow uncontrollably.

Last week Professor Maarten Albersen, a Belgium urologist and cancer researcher, spoke at the Urological Society of Australia and New Zealand’s conference in Melbourne about the profound sexual and psychological impacts of penile cancer.

“Unlike many other cancers, the disease and its treatment directly affect a part of the body that is fun-

damental to sexual function and self-perception,” Albersen wrote in a recent paper. He said patients often faced significant functional and aesthetic challenges, including difficulties with urination, reduced mobility, persistent pain, sexual dysfunction, and lymphedema (swelling in the body).

More than 60 per cent of penile cancer patients require psychological care.

The mental toll of Earle’s treatment was profound. “I didn’t see myself as a man any more,” he said. “In our society, that’s what defines you.” His marriage broke down after the surgery, and his self-esteem hit an all-time low. While Earle still suffers from painful lymphedema in his legs from having lymph nodes removed, his outlook on life is a lot more positive these days. He sees a psychologist and has founded a charity, Check Your Tackle, which raises awareness of penile cancer.

He also manages a global support network on Facebook for more than 800 men diagnosed with penile cancer. The men are aged between their 20s and 70s, and the group helps them navigate the trauma of surgery and the identity crisis that often follows. “I tell the guys, ‘it’s only a part of who you are – it doesn’t make you a man,’” he said.

Earle has remarried and found ways to be intimate again. “There’s kissing, cuddling and true partnership,” he said.

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