

## THE AUSTRALIAN

# ‘Cease to be men or cease to be’

He was a fit 50-year-old surfer when he received a shock diagnosis – advanced prostate cancer. Nothing could prepare Tim Baker for the treatment’s drastic, emasculating side effects.

By TIM BAKER

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**I** miss my cock. The size and appearance of my old fella was nothing remarkable. Circumcised, a tad over the average six inches when hard (I’ll admit to measuring my erection as an insecure teenager to confirm its normality), it nevertheless possessed what I’d like to consider a certain sleek elegance. A no-nonsense, dependable appendage that stood reliably when needed without leading its owner into too much trouble with its appetites.

A cancer diagnosis tends to lend itself to nostalgia. I’m trawling through old photos, marvelling at my carefree former existence, when I stumble upon an image of myself in my late 20s, getting changed out of a wetsuit during an extended surf trip through South America. I’m posing brazenly for the camera, naked but for the black neoprene rolled down around my ankles, arms joyfully aloft like a Vegas showgirl,

my phallus boldly swinging in the chilly morning north Peruvian desert breeze. Even accounting for the frigid Humboldt Current, my manhood is of modest dimensions, yet to my middle-aged eye it now appears enormous, impressive in both its girth and length, dangling proudly from a thick, dark thatch of pubic hair like a swollen bratwurst.

Today, both the hair and phallus have been dramatically abridged. Hormone therapy is presumably called hormone therapy because if it went by its more accurate descriptor, chemical castration, many of the men diagnosed with advanced prostate cancer might balk at it as a recommended treatment. If you had told me before my diagnosis that millions of men around the world were effectively chemically castrated as a routine medical treatment for one of the most common types of cancer, my response would have been a gormless, *You're shitting me?!*

We are accustomed to the stark, harrowing realities of conventional cancer therapies, their brutal nature, the devastating toll they can take – the perils of toxic chemotherapy drugs, disfiguring surgery, the ravages of radiation. Almost every family has been touched by cancer and many of us have witnessed the eviscerating effects of treatment. Women with breast cancer can be heroically blunt about having their breasts removed. Hollywood star Angelina Jolie, the modern embodiment of desirable femininity, famously had hers surgically removed as a purely preventive measure because of a genetic predisposition to breast cancer.

So, hands up who knew chemical castration was the frontline treatment for advanced cases of the most common form of cancer among men? Why are we so coy on the subject? Is it that men are embarrassed to discuss its emasculating effects? Or are doctors afraid of scaring men off? Is it because prostate cancer, particularly the incurable advanced variety, is considered an old man's disease, and ageism allows us to castrate old men without too much outcry or squeamishness?

In Australia, one in seven men will be diagnosed with prostate cancer and most will die with it rather than from it. For many older men, where the cancer is contained within the prostate and deemed not so aggressive, a strategy of active surveillance is considered prudent. However, statistics show an increase in the prevalence of younger men (generally defined as under 60) being diagnosed, for reasons no one

has been able to divine. In cases like mine, where the cancer (stage four) has already spread or metastasised to the bone, aggressive treatment is considered essential, though holds no promise of a cure. Prostate cancer feeds on testosterone, so the younger you are and the higher your natural levels of testosterone, the more aggressive the cancer tends to be (the aggressiveness of prostate cancer is measured by a Gleason score; mine registers a nine out of 10). The recommended treatment, therefore, is to block or suppress your testosterone with what's politely termed hormone therapy or androgen deprivation therapy, but in effect amounts to chemical castration.

This news takes some time to sink in when I receive the diagnosis out of the blue in 2015, as do the side effects – complete loss of libido and sexual function. Other likely side effects include lethargy, mood swings, depression, an increased risk of heart disease and diabetes, loss of muscle tone, bone density and body hair, weight gain, shrunken genitals and breast swelling. Just to complete the picture, you are also advised to expect hot flushes, like a menopausal woman. Consent to all this or allow the cancer to spread throughout your body. I'm shocked to learn from my oncologist that this has been the accepted treatment for more than 50 years.

It seems to me barbaric, inhuman, cruel, presenting men with an impossible choice – to cease to be men or to cease to be. And yet, many men like me are alive today because of hormone therapy's ability to halt the spread of prostate cancer.

**Life without testosterone is a peculiar experience.** I sometimes feel like I am being hollowed out from the inside, emptied, that some vital essence or core is being siphoned away. "Men are basically machines that run on testosterone," one doctor tells me helpfully. I am not who I was. I tire more easily. I can't push past fatigue. It's difficult to summon the drive to get things done. My nervous system seems more easily rattled. I find I need more time on my own, quiet, still, at peace, preferably in a natural setting. Nature is my balm. My time in the ocean was always precious, now surfing is therapy. Absorbed in something greater than the self, the intellectual mind and its barrage of cycling anxieties is quietened by the other-worldly magic of riding waves, the enormity of the ocean – vast, undulating, indifferent.

At the same time, I struggle in crowded surf, lacking that killer instinct to hustle for waves. I now understand what female surfers mean when they complain of line-ups being heavy on testosterone, a condition New Zealand's "fourth most popular folk duo", Flight of the Conchords, refer to as "too many dicks on the dance floor".

I still don't know whether to be grateful I'm alive or angry at what's been done to me. Perhaps it's possible, indeed natural, to feel both. I'm reminded of Samuel Beckett's poetic exhortation for endurance: "You must go on. I can't go on. I'll go on."

It's not all bad. My skin is smoother, the hair on my head thicker than it once was. Minus a libido, I can relate to women as fellow human beings without fixating on their physical appearance or the particular contours of their bodies. A friend whose teenage daughter is beginning to attract the attention of young men tells me, "I wish they would see her as a person, not an assemblage of body parts." I now understand that statement on a different level. In the age of the #MeToo movement, there is some relief in representing no threat to anyone, neutral, the Switzerland of the gender wars.

The absence of testosterone reveals itself at odd occasions. I'm inching through a beach car park at the height of summer, with impatient kids desperate to hit the surf, trawling for a free parking spot, when I see a car reversing out and quickly put on my indicator. When the car pulls out a bearded bloke in a van is facing me with his indicator on, also waiting for the spot. He puffs up, begins remonstrating and mouthing inaudible expletives. He looks ridiculous, a grown man throwing a toddler tantrum over a parking spot. Once, I might have responded in kind. Instead, I smile, wave, leave it to him and continue on my way. I find a free spot about 20m away.

My brother-in-law Tom and I take our young children indoor rock climbing, holding their ropes with unwarranted vigilance as they effortlessly scale the vertical walls. Towards the end of the session, Tom suggests we have a crack ourselves. I get no more than a couple of metres off the ground and am paralysed with fear, unable to heave myself from one handhold to the next. When I try to dig deep and push

through my paralysis, I find I have nothing in reserve, no emergency fuel tank to draw on. It's deeply disconcerting. What, in this state, am I fit for? The life of a monk? Celibacy would be no problem. A servant or slave to a royal court, like the eunuchs of antiquity? A poet, quietly observing life's curious machinations?

In an era of gender fluidity, in middle age perhaps I am finally on trend. When filling in forms and confronted with the gender question, I've begun considering the non-binary option. Perhaps my preferred pronouns should be they/them. The younger generation's nuanced understanding of gender provides genuine comfort. If a three-monthly injection can gradually erase my gender, then perhaps it is a more fluid condition than most of us acknowledge. The implications for my marriage and sexuality are obvious and devastating. And yet somehow, much of the time, I seem to be living a thoroughly worthwhile, meaningful, even joyful existence.

Prostate cancer has redesigned my life in ways few other things could have, much of it for the better. I work, when and if I feel like it. I don't do stress. If the surf is good, I surf. After a morning surf, a friend asks me if I'm working today. I have to stop and think about it. "If it fits into my lifestyle," I eventually answer, with a grin. I have a sensation of wanting to pour myself into my children, to prioritise time with them and savour the small things. I recognise I am in a privileged position and can't imagine how much harder it must be for men without supportive family and a decent income, those from marginalised minorities or rural and remote areas for whom services may be harder to access.

A cancer diagnosis is not an aphrodisiac for the diagnosed or their partner, if they have one. In the weeks and months post-diagnosis, sex is the last thing on my or my wife's mind as we struggle with our new reality. During chemotherapy, even my bodily fluids are considered toxic. I'm told to flush the toilet twice with the lid down and avoid allowing my semen to come into contact with anyone, though there's little danger of that.

Even before my libido completely evaporates it is dealt some serious blows. Little to no advice is offered on the importance of maintaining intimacy and closeness in a relationship, or recommendations for therapies to maintain sexual function. I'm still angry about this. We have an amazing health system in Australia but when it comes

to cancer care, the provision of supportive services lacks co-ordination and consultation between disciplines. The newly diagnosed patient is left to navigate a confounding maze of mainstream and alternative treatment options and fend for themselves when it comes to maintaining quality of life.

In all the various forums, support groups and newsletters I've joined I've heard precious little discussion from other men about how they deal with the myriad side effects of hormone therapy – the loss of libido, the challenge to their identity and relationships, the breast swelling, the hot flushes, the loss of body hair and muscle mass. Men, it hardly needs saying, are not good at talking about this stuff. If it were groups of women dealing with this, I suspect the conversations would be much more frank, open and supportive.

Oncologists and urologists routinely prescribe this treatment knowing the awful side effects, handing you a cursory information sheet listing them and offering only the consolation that not all men suffer all of them. Mercifully, I seem to have been spared the hot flushes that leave some men awash in sweat at random moments, having to change sheets in the middle of the night, carrying spare clothes to change into when required. Or the incontinence that forces some men to wear nappies, to plot their every move according to the proximity of a toilet.

My wife Kirsten and I make a few fumbling attempts at sexual intimacy but I find it fairly humiliating, and it leaves us both unsatisfied and awkward and uncomfortable about trying again. Author Nikki Gemmell once wrote that sex after childbirth was like throwing a sausage down the Sydney Harbour Tunnel. Obviously that's, um, a stretch... I'd suggest our predicament is more akin to putting a baby to bed in an adult-sized sleeping bag. It will flop around unhelpfully and not stay in its warm cocoon. We need help, but in the midst of my existential turmoil – navigating treatments, blood tests and scans, dealing with chemotherapy, radiation and surgery, overhauling diet and lifestyle, exercising to retain muscle mass and bone strength, trying to maintain an income – finding a sexual therapist never seems to come to the top of the to-do list.

When I finally make an appointment with a men's sexual health specialist at the recommendation of my GP, it is four years since my diagnosis and my libido and

sexual function are effectively non-existent. I am shocked to discover that something as simple as Viagra may have allowed me to maintain sexual function from the outset. Why wasn't I told? The specialist tells me this is a common story, that men are so focused on simple survival in the first few years after diagnosis that they fail to address their sexual challenges early on, by which time the chances of recovery are greatly reduced. This would seem a fairly simple oversight in the system to correct, to encourage every man on hormone therapy to consult with a sexual health therapist at the outset, or at least offer some basic information on the topic.

Kirst and I have had our challenges, but we're a happy couple who've enjoyed a rich, loving and warm relationship, producing two adorable kids, pursuing work we find fulfilling, living in a beautiful home near the beach. We have much to be grateful for, but the absence of sex is an insidious force that has a corrosive effect over time. How many times has make-up sex soothed a minor domestic spat? That physical closeness, the expression of passion, the sweaty animal outlet of surrendering to our desires can be a glue that binds, a buttress against the many challenges of married life. Without it, even small resentments can linger and fester. Gradually, over time, a space opens up between us that is difficult to bridge. There are no longer just the two of us in this relationship, but a third, dark and sinister presence. "Cancer is a selfish bastard," Kirst observes ruefully. We're not the same people and our relationship, inevitably, is profoundly altered. We love each other but we are both dealing with our own grief, which can leave us feeling marooned on separate islands of despair.

I can't say I miss sex because I don't have a libido, but I miss the closeness, our old life, and I envy other couples their simple domestic normalities. Sex scenes on TV and in movies make me uncomfortable, a fun park I can no longer enter. Kirst is upfront about how difficult celibacy is for her. "It's hard to accept that I'll never be looked at in that way again," she tells me, and my heart breaks a little. I'm sure there must be some sort of tantric workshop in northern NSW we could sign up for but to be honest, I don't know if that's really our jam. Various pumps, injections and implants promise some relief, but I find it hard to imagine these devices offering much in the way of spontaneity.

Can you miss something you no longer have the desire for? Absolutely. This might sound like an odd analogy, but I imagine it might be similar to how retired elite athletes feel. The physical body may no longer be capable of the athletic peaks they once drove it to. Intellectually they may understand this part of their lives is behind them, but it can still leave a great emptiness.

I wish I had more to offer other men and their partners here, but this is an area where we have been acutely let down by the medical system. My best advice would be to seek help from a qualified men's sexual health specialist early on, even though it might not seem like a high priority when you are fixated on survival. I dream of a time when we can successfully treat advanced prostate cancer without the horror show of chemical castration, and not treat patients in the way paedophiles or rapists are punished in some jurisdictions. I seize upon news of new treatment options or research breakthroughs, only to discover they are some new combination of existing hormone therapies and chemotherapy that extend life by just a limited number of months, with little consideration of quality of life.

I'm happy to be alive and, given a choice of dying with a libido and sexual function or surviving without it, I'd still choose survival. I just wish I didn't have to choose.

*Tim Baker is an award-winning surf writer and author. [Patting the Shark – A Surfer's Journey, Learning to Live Well with Cancer](#) (Ebury Australia, \$34.99), out Aug 2.*