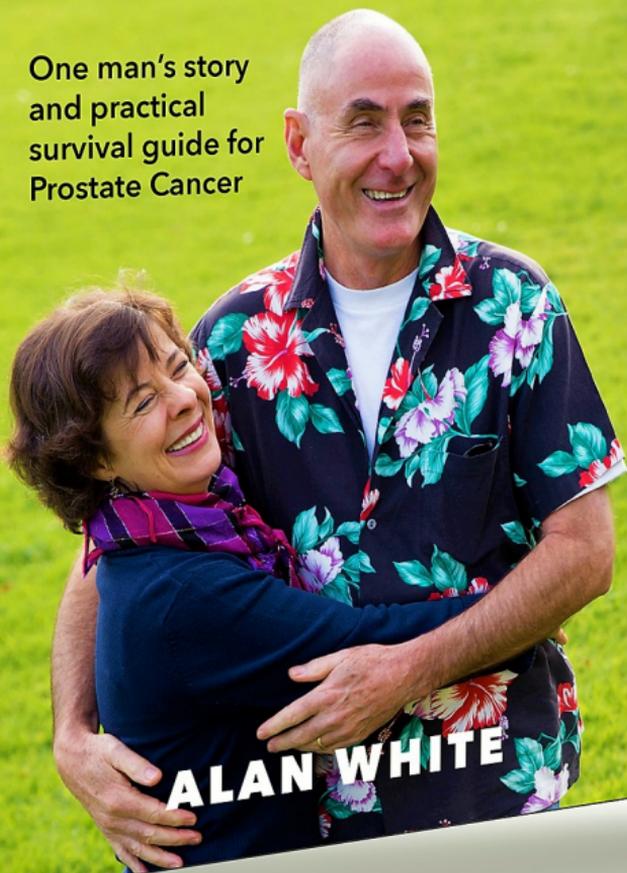


# WE'VE LOST MY PROSTATE

**MATE ... AND LIFE GOES ON**

One man's story  
and practical  
survival guide for  
Prostate Cancer



**ALAN WHITE**

WE'VE LOST MY PROSTATE MATE ... AND LIFE GOES ON

ALAN WHITE



**WE'VE LOST MY  
PROSTATE, MATE!**

*And life goes on ...*

Alan White

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## *Testimonials*

“Alan’s candid account of his journey reflects his obvious passion for empowering men. His story is reader friendly, infused with good humour and an enormous sense of empathy. It encapsulates not only the practical aspects of managing the diagnosis but references the variety of conventional and alternative treatments available. Implications for quality of life and especially intimate relationships are also presented with an astounding honesty. This is an enlightening read for any man diagnosed with prostate cancer, their family members and clinicians working in the field.”

**Ms Sarah Rudd**

*APA Continence and Women’s Health Physiotherapist  
Women’s and Men’s Health Physiotherapy, Hampton*

“Alan is such a committed practitioner, so it made perfect sense for him to write this book; in order to benefit men and their families in understanding the process of prostate cancer.

“His informative and somewhat humorous take on his cancer certainly helps reduce the fear factor. Fiona’s story is invaluable from a partner’s perspective. The silver lining, as well as, Alan’s remission would be the strengthening of Alan and Fiona’s relationship.”

**Cynthia Chenier-Hinde**

*Consultant*

Loved the book - it's not easy for men to have first-hand information about the diagnosis and treatment of prostate cancer. Your personal account provides some of the emotional impacts not available in a clinical setting.

**Roy Francis,**

*Founder and Secretary/Convenor of the Mornington Peninsula Prostate Cancer Support Group*

In this book Alan describes in great detail his journey and experiences with prostate cancer, from his early diagnosis in 2000 followed by active surveillance for 10 years and the ultimate treatment of his cancer through robotic laparoscopic prostatectomy. It's a warts and all story covering his first hand experiences dealing with emotions, social and practical issues of the side effects of erectile dysfunction and incontinence. His experiences are very intimate and detailed and provide an insight on how Alan and his wife Fiona have overcome many problems realising there is light at the end of the tunnel through making life-changing decisions on the way and being capably supported by family and friends. In writing this book Alan has also drawn on resources/books relevant to his journey and experiences. Despite the serious nature of the topic, Alan has maintained a sense of humour as reflected by the cartoons in the various sections of the book.

This book is a valuable resource for any newly diagnosed man considering surgical intervention for his prostate cancer and having to contemplate resulting side effects such as erectile dysfunction and incontinence. The book provides encouragement, hope and ideas for the best outcome and maintenance of quality of life.

**Wolfgang Schoch**

*Prostate Cancer Survivor, PCFA Ambassador and Support Group Leader of Prostate Heidelberg, Victoria*

Alan and I are friends who met when we both became Ambassador Speakers for the Prostate Cancer Foundation. Both of us have been through prostate cancer procedures and, although my path was different to Alan's, the book brought up lots of similarities in the emotions involved before and after treatment. Alan has always been such a positive person in the time I have known him and he is always completely down to earth. This practical down to earth approach really comes through in this book. Most importantly the book touches on subjects that are not always covered in dealing with cancer – i.e. the emotional aspects which we experience in coming to terms with this illness. I thoroughly recommend this book to anyone who is touched by prostate issues – either themselves or in their loved ones. Well done Alan in writing such an insightful book.

**Rod Smith**

*Prostate Cancer Survivor, PCFA Ambassador, Victoria*

Well done, Alan and Fiona.

This is an easy to read, informative and very educational book about a very complex issue. Written in layman's language that explains complicated medical topics extremely well. All men, and their partners, should read this excellent guide book!

**Pete Fraser**

## Contents

Disclaimer	i
Acknowledgements	iii
Preface	v
1. Understanding the Male Anatomy	1
2. My Diagnosis	5
3. We've Only Just Met!	13
4. The Operation and the Aftermath	19
5. Let the Healing Begin	27
6. Wake-Up Calls, with the Advantage of Hindsight	43
7. Dressing Percy	51
8. The Measuring Cup	59
9. So Many Problems Solved	61
10. What We All Want to Know	65
11. Trial, Error and Success.	69
12. Consequences	73
13. Coming to Terms with Change	79
14. A Wife's Perspective – Over to Fiona	87
15. Be Kind to Yourself and Ask for Help	91
16. There is Light at the End of the Tunnel	93
17. Things to Consider If Diagnosed with Prostate Cancer	97
Postscript: Two Years On	103
Postscript: Five Years On	107
Final Word from Fiona – Five Years On	115
References	119
Resources	121

## *Disclaimer*

**T**he contents of this book do not purport to offer any medical advice whatsoever to the reader.

Any man who may be having issues with his bladder, prostate or sexual function, or experiencing any other health concerns, needs to seek advice from a qualified health professional pertaining to his own circumstances.

It is also not the intention of this book to support one form of treatment over another, as there are ongoing advances occurring in the different fields of medicine, and those therapies that are being used to treat prostate cancer here in Australia and overseas.

At the time of publishing, pathologists currently use the Gleason scoring system to grade the level of cancer within the prostate. The Royal College of Pathology in Australia and New Zealand has recently accepted a new standard of grading. The World Health Organisation (WHO) has also accepted the revised scoring system. The original Gleason score will continue to be used alongside the new grading system. Where the Gleason score is mentioned in this book, it refers to the older system that was in place at the time of my diagnosis.

Each man needs to discuss the options and possible outcomes with his specialist(s); and this discussion will be influenced by what stage the prostate cancer is at for each individual.

This is a story of my own journey and experiences, as well as information that I have gleaned along the way, some of which has come from talking to other men when doing presentations on men's health, who have also been dealing with prostate related issues that affected them physically, emotionally, and within their relationships.

I have also included the practicalities of dealing with the day-to-day recovery and what I found worked for me. Along the way, I have come across men and their partners who have demonstrated courage, humour, honesty, vulnerability, and a willingness to talk and share their experiences with others. Having a sense of humour when dealing with prostate cancer, from my point of view, helps one to get through each day – not that it's a laughing matter, losing your prostate, mate!

## *Acknowledgements*

There have been many people who have been very supportive over the years, from when I was initially diagnosed with suspected prostate cancer back in 1996 while living in Albury-Wodonga, such as Elsie and Michael Pobjoy, members of the local Reiki group, Ginny and Michael Bydder and many others.

Then, in 2000, I had returned to Melbourne to live, when having a check-up on my prostate I was diagnosed with prostate cancer with a PSA of 10 and a Gleason score of 6. I am thankful for the support from my partner at the time, Joy, and the staff at the Hilton on The Park Spa complex, where I was working.

In 2011, when the prostate cancer decided to return, following ten years of active surveillance, I had to make a hard decision. There were my family; staunch friends Robert and Cynthia Hinde, Peter Fraser, Doug and Kate Parkinson, Kaylene and Brian Andrews, Charlie Brown, Stan and Dianne Harris; committee members of the Royal Australian Air Force Vietnam Veterans' Association; board members of the Air Force Association (Vic); along with Professor Tony Costello, his nurse Helen Crowe, and my GP, Dr Robyn Green, all in support.

After the operation, I had the help of The Women's and Men's Health Physiotherapy Group, in particular Rebecca and Sarah; Dr Eric Dowker, Chiropractor; Kate Madigan, Reflexologist; Dr David Wang, Acupuncturist; as well as Dr Kristen Manallack and Dr Eliza Gleadell, Osteopaths.

Our friend Lianne Kernahan made a special contribution to this book, in the form of her cartoons, provided along with her sense of humour, patience and suggestions whenever I wanted her to make changes to the drawings.

No book would be complete without an engaging cover. My thanks go to our friend, Ai Tsuruma, of Pudding Creative, for her excellent designs and creative input. I also want to thank Ai's partner, Justin Leijon, for his outstanding photography and ability to make us look good.

Finally I would like to offer a big, deeply heart-felt thank you to my wife, Fiona, for her unfailing love, support, encouragement, sense of humour, and willingness to remain intimate. I am also grateful for her skill and input to this book by way of layout, editing and suggestions. Fiona did whatever was necessary, physically and emotionally, so that I would not feel I was any less a man, just because I was unable to gain an erection, and dealing with incontinence in the months following the operation. My enduring love for you always.

## *Preface*

This story had been in the back of my mind for a couple of years or more, instigated by my own experience of prostate cancer and of conducting active surveillance for ten years prior to the operation. It is a bit of a warts and all story concerning my experiences in the months that followed the operation. Hopefully some of this information will prepare the reader in some way, should they, in the future, face a similar experience.

I was influenced also by my involvement for over ten years with the Department of Veterans' Affairs (DVA) as a Men's Health Peer Educator (MHPE), presenting information to ex-service organisations on health and wellbeing and talking to men about their health, especially prostate issues.

I have also been involved for over four years with the Prostate Cancer Foundation Australia (PCFA) as a Men's Health Ambassador Speaker, delivering presentations on prostate health and wellbeing to a wide variety of public and private organisations. Delivering talks to these organisations gave me the privilege of talking to individual men who, having had the prostate operation, felt they just

needed to talk things over, and maybe these talks provided them with their first opportunity to do so.

And, of course, there was *Movember*, for the previous three years, with a team of fellow Bros, growing the Mo to raise funds, increase public awareness around prostate cancer, and to encourage men to take care of their health and wellbeing.

Then there is the local Bayside Kingston Prostate Cancer Support Group, where I was further privileged to meet men who had their own experiences and treatments; the good, the bad and the ugly.

All these connections and experiences were bubbling away in my mind, but I was not really sure what exactly I would have to say or contribute to men's understanding about prostate cancer.

For every man who is diagnosed with prostate cancer, each will have a different prognosis. A man's treatment will be influenced accordingly by his age, genetic background, general health, and whatever stage the cancer has reached. The level of the Prostate Specific Antigen (PSA) that is present in his blood sample will also be a factor, along with anything that the digital rectal examination reveals, as well as the results from any biopsy of the prostate. All these matters will need to be considered in relation to treatment.

So, it is a matter of having the right attitude and mind-set towards your own health and wellbeing, not just for your own sake, but for your family too. There is also the ripple effect that comes from having been diagnosed with prostate cancer that affects your partner and family.

As I have always stated at the many talks I have given over the years, make visiting your doctor a normal part of your life. Develop a relationship with him/her, get your figures done regularly; this means your blood pressure, cholesterol levels, glucose levels (diabetes), plus your weight/waist measurement. If you have a family history of prostate disease, it is my opinion that you should have your PSA levels (and free-to-total PSA) checked once you reach the age of 40. This will give you a baseline from which

you can monitor your PSA levels. If you have no family history of prostate disease, it is generally considered that 50 years of age is the appropriate starting point for annual PSA checks, along with a digital rectal examination to check the condition of the prostate and rectal area.

Taking care of your health and wellbeing includes exercising regularly and observing your food intake – energy in, energy out – as this affects your weight. You also need to watch your alcohol intake and stop smoking. Reduce your saturated fat intake, make sure you eat plenty of fruit and vegetables, complex carbohydrates – i.e. not processed stuff – and lean protein.

It is important to have a varied diet and, of course, drink plenty of water to keep hydrated. And most importantly, keep your stress levels to a minimum, as constant and chronic stress will impact on your immune system's ability to deal with any infections and inflammation that arise in your body.

Getting your figures done establishes a baseline from which you can see how you are tracking with your health each year. Then you, and your doctor, can pick up any early changes in any of those figures, and take appropriate action. Make sure that you get a copy of the results so you have a record also.

## *1. Understanding the Male Anatomy*

**A** number of men are probably not fully conversant with what the prostate does, or any of the other parts that make up the male reproductive system. So here is a brief overview; all male mammals have a prostate. Interestingly, it seems only men and male dogs have a problem with the prostate. I wonder what that means?

The prostate gland is about the size and shape of a walnut. It is attached to the underneath of the bladder, whilst surrounding the urethra which is attached to the bladder, deep within the pelvic region. The prostate provides nutrition for the sperm, along with secretions that make up the ejaculation fluid. The seminal vesicles located on top of the prostate also provide secretions to this fluid.

The testicles (your balls) produce testosterone – the male hormone – and in the epididymis the sperm – those little tadpole-looking wrigglers – are produced. When you are about to ejaculate, the sperm travel up the vas deferens, with fluid being added to them by the seminal vesicles and the prostate. Then they travel out via the ejaculatory duct down into the urethra and out through the penis.



## 2. *My Diagnosis*

In November 2010, I had my regular blood test to check my Prostate Specific Antigen (PSA) level, and the other usual figures. A week later the results came back and the score/level was 1.9, which for my age – 60 years at the time – was not high. Interestingly, between 2008 and up to 2011, my PSA had been up and down, going from 1.8 in 2007, to 1.1 in 2008, to 1.4 mid 2009, and in 2010 it was 1.5.

So, in November 2010, when those results came back showing 1.9, I got a sense that something wasn't right, despite the GP saying that no action was required. Again, the level was not high; I had been doing active surveillance for the previous ten years, and the PSA had been fairly low during that period.

Active surveillance is an alternative to treatment that not all men know about. It is an approach that is becoming more widespread for men who meet specific criteria. Generally speaking, men whose biopsy results show a localised, low-grade, low-risk prostate cancer can look at this option. Active surveillance avoids the immediate side-effects from treatment, such as incontinence, infertility and erectile dysfunction. It is always best for men to discuss all possible

treatment options, including active surveillance, with their specialist physician.

Now, on reflection, I realise that I had been getting cold sores regularly and had been stressed out for a number of years, although I felt I was staying on top most of the time, and taking the appropriate supplements. Yet something was not right; had the immune system been under too much stress for too long? Yes, I was 60, and the PSA for my age can creep up, but why? There was a nagging doubt at the back of my mind about what was going on.

In the following month, December 2010, I had my regular visit to see my urologist, Professor Tony Costello, which included a digital rectal examination, or *DRE*. As it had been a few years since I had a biopsy of the prostate, Tony decided to do one in January 2011. This time there would be an anaesthetic so I would be out to it; thank goodness for that!

This procedure went well. I was a bit sore for a day or so after, but it certainly was easier than having a biopsy while being awake. My wife, Fiona, and I met with Tony a week later to get the results from the biopsy. Helen, his nurse, was also in the room when Tony came in. For an instant I thought that was a bit strange, but then Tony said he had the results – the cancer was back!

I looked at Fiona and then back at Tony. I was glad she was with me. I said that was not what I was expecting. Tony stated that he was not surprised, as the gland had felt firm when he did the DRE back in December. Funnily enough, I did not ask how the prostate felt at the time of the DRE, and Tony didn't comment either, which was odd. We discussed the Gleason scores of the core samples from the prostate biopsy. These cores had multi-focal scores of 6 (being 3 + 3) and a score of 7 which was deemed to be aggressive. The PSA had been only 1.9 – thank goodness I had a biopsy. Now I was between a rock and a hard place, with active surveillance no longer an option due to the prostate showing aggressive cells.

The *Gleason score* refers to a grading system used by the pathologist when they examine tissue taken from the

prostate to determine how aggressive the cancer is likely to be. The PSA and the Gleason score may not always match; in that you can have a low PSA (say, 3-4) and a Gleason score of around 6-7; or it can be any combination. The Gleason score is discussed in more detail later on in this book. In 2011, my free-to-total score for PSA was running around 12%; anything below 25% may indicate the possibility of cancer in the prostate. I clearly had not been checking my free-to-total PSA levels regularly.

So, even with a low PSA, there may be other factors to consider, such as whether the prostate feels firm or lumpy. PSA is a protein which is secreted by the cells in the gland of the prostate, and a high reading can be due to any number of reasons and does not always mean that there is prostate cancer present. It may mean there is an infection, or you may have an enlarged prostate that is pumping out more PSA than usual. It's useful to have a second test done somewhere between three and six weeks later to check the level again.

Part of me had thought, during the week following the biopsy, well if the cancer does come back it will be small, and I will do what I did before to deal with the cancer. This time, however, I am not so sure.

Tony wanted to start things rolling. I needed time to get my head around what had happened and why – what was different this time? Had I been slack in looking after my health? Had there been too much ongoing stress for the last, well, ten years and, in particular, the last couple of years? Now, on reflection, I feel that this may well have played a part, as ongoing stress will impact on the immune system.

I wanted to look at options, and as I was talking to Helen, Tony's urology nurse, about what papers I needed to fill in, it felt like everything was moving way too quickly. Helen suggested that I see an incontinence physiotherapist for specific exercises pre- and post-operation. The suggested physiotherapy practice was close to home so I didn't have to go far.

Every time I reflect on that day, I am still not sure what I was feeling. A bit numb? Confused and blank? I think I was a bit separated from my body for a while, and went into auto-

pilot, with my left brain attempting to work out what to do next. Getting the prostate out was not my desired option, yet. Tony stuck his head around the door and said, with a grin, something to the effect, "Don't let him out without the papers signed".

The next two weeks or so were a bit surreal. I had an appointment with the physiotherapist to check me out. I was attempting to look at other options, and did not feel particularly strong about having another go at alternative methods to deal with prostate cancer this time round. Now, when I reflect on that time, I realise that active surveillance or taking the alternative therapy route were no longer viable options. With aggressive cells sitting within the prostate, I could not possibly know how long it would be before they could spread and go walk-about.

Being diagnosed with prostate cancer, I felt at times as if I was walking around inside a bubble, separate from everyone and from day-to-day events. Sometimes, I would walk down the street feeling that I wanted to yell at people – "I've been diagnosed with prostate cancer!" I wanted people to acknowledge somehow that a major change was occurring in my life.

Then there was the decision regarding who to tell about the results and the treatment to be undertaken. Two days after meeting Tony and being confronted by the return of the cancer, I had to take my mother to a skin specialist to have some stitches removed, as she had had an operation on her leg to remove a couple of skin cancers the week before. As I was driving her to the appointment, she asked what the result of my visit to the urologist was. I was not ready to tell her at that point, and was thinking that she might have forgotten and would be preoccupied with her own health concerns.

As I was a bit caught out and didn't think quickly enough to delay my answer, I told her and she was upset – understandably so. Over the years, my mum had her own ongoing skin cancer problems, and was tiring of the treatments that she had been having.

I was not in a good space to be dealing with mum's

emotions as well; however, having to support her while the stitches were removed, rather reluctantly, this took my mind off my own stuff and focused me on supporting mum and getting her through the procedure that day. Once that was over though, how does one go about telling other family, friends? I didn't want them finding out after the event, but was not looking for sympathy either.

So, as I made the calls to let others know what was going on, I had this strange feeling as if I was ringing people up to let them know I had won TattsLotto! Now that was weird. I was only ringing family and close friends whom I had known for some time, but all the same it did feel rather surreal to be calling people up to say, "Hey, guess what? My prostate cancer is back, and it's coming out, so now I will have lost my cherry twice!"

In Vietnam, the local women who worked in the Vung Tau Air Force Base would say to the new arrivals, "You are a cherry boy." This was because the lads hadn't yet been into town to lose their virginity. The local women seemed to know who had and who hadn't been into town (Vung Tau). Thus my reference to losing my cherry twice – I referred to my prostate as the cherry – you've got to have some humour around the situation.

Of course, everybody was surprised, as I was, but I remained upbeat about my decision and outcomes, for their sake as well as mine. With some of the friends I rang, we talked about what I had done previously in dealing with the earlier prostate cancer, and whether I would be taking the approach of active surveillance again. This time I knew that I could not avoid having my prostate removed. It just remained for me to decide on the path – surgery or radiation therapy.

During the period leading up to the operation, I remember walking on the beach one morning, reviewing the events leading up to where I was then, not knowing what to do and crying at what I thought was the unfairness of what I was experiencing after all those years of surveillance.

Yet, in the months following the operation, I would often question myself as to whether it was the right decision; this

was something I had to stop doing as it was not helpful or conducive to my healing on different levels. Even in mid-2011, when I finally did get to see Dr Eric Dowker (chiropractor), to work on the problems I was having, I thought then, "Why didn't I come to see Eric sooner, like before the operation, or even sooner after the operation?" Again, it was not very helpful to dwell on the past.

I decided to look at options, with one of them being *Brachytherapy*. This procedure involves the placement of radioactive pellets/seeds within the prostate gland. There are two major forms of Brachytherapy; one involves a permanent, low-dose-rate seed insertion into the prostate, and the other method is a temporary high-dose-rate into the prostate.

Generally speaking, a man who is diagnosed with localised, low risk prostate cancer may be eligible for this type of treatment. From my reading, most literature cites the eligibility criteria as being: a PSA of less than 10, Gleason score below 8, a life expectancy of greater than 10 years, a prostate size of 20-50mls, and minimal urinary symptoms.

For further information on this, I recommend the book *Prostate Cancer, Your guide to the disease, treatment options and outcomes*, by Associate Professor Prem Rashid, 3<sup>rd</sup> edition. This book is very worthwhile for a review of all treatments and a good source of information for men about the prostate in general; even if you don't have any problems, it's useful as a resource guide.

Another useful guide is the newsletter put out by the Prostate Cancer Foundation Australia (PCFA), which reviews current treatments, their outcomes and new innovations that are being developed in the treatment of prostate cancer, here in Australia and overseas.

I also looked at the after-effects of Brachytherapy and, from my reading; some men do eventually end up with incontinence issues and erectile dysfunction due to the nerves eventually being cooked by the radiation seeds. That means some men will need to inject into their penis to gain an erection, or take Viagra<sup>TM</sup>, or use a vacuum device. Again,

every man is different and will respond to each treatment differently.

I had another meeting with Tony to discuss the options and, after some serious conversation, it was decided that Robotic surgery would be the treatment for me. As my Gleason score showed aggressive cells, my situation could not be described as "low risk" and was therefore not suitable for radiation therapy. Tony stated that his first concern was to keep me alive and that meant removing the prostate. After the operation, it would be getting the incontinence under control and then dealing with the erection problem. Tony believed that, with the appropriate exercises, the incontinence would be rectified and, within two years, my erections would be up and running!

He also stated that ten years ago I had made the right decision at the time for me, for now I would be getting Robotic surgery, as Tony had pioneered this form of treatment for the last ten years, so he knew what he was doing.

Luckily for me, the Department of Veterans' Affairs (DVA) would cover all expenses as the Department had accepted the prostate cancer as being related to my war service. So, into Helen's office to fill in the paperwork, and then Tony stuck his head through the door to say, "Tie his leg to the chair this time, so he doesn't leave without the paperwork." As Fiona and I left, we spoke to Tony again, who quipped "I told you I'd get your prostate one day."

I know that this is an expensive operation for men to pay for; however, I am aware that certain public hospitals are attempting to get the Robotic equipment into their operating rooms, not just for prostate surgery, but also for other types of operations.