



what *WOMEN* & their men
need to know about
**prostate
cancer**

— SECOND (REVISED) EDITION —

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Prostate Survival Alliance Inc., Newcastle NSW, 2008
(Hunter Prostate Cancer Alliance)

What Women (And Their Men) Need To Know About Prostate Cancer

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about this book

This book was written to help women (and the men they care about) become more informed about prostate health, prostate tests, and prostate cancer, and to help them decide what action, if any, to take. If you are a woman, with a husband/partner, father, brother, son, or a male friend, aged between 40 and 80 years of age, who is an important part of your life, you should probably read this book.

And if you are a man in any of the above categories, and have not (yet) given much thought to what you need to know about the topic, perhaps you should read it too.

If you are a woman or a man, with someone you care about who has recently undergone tests or been diagnosed with prostate cancer, and do not know a great deal about the disease, then this book might be a good starting point. If prostate cancer has touched your friends or members of your family, perhaps this book will help you understand something of what they are going through, and allow you to be more open and supportive in your interactions with them.

Our aim is to lift the veil of silence from the topic of prostate cancer, and to suggest what men can do to reduce their risks of developing prostate cancer and, if they are in the minority who will develop it at some point in their lives, to suggest what they can do to ensure that they are diagnosed early and treated successfully.

But why write a book primarily for women on the topic of cancer that affects only men? After all, women do not have a prostate gland and therefore cannot develop prostate cancer! The reason is that women have always been, and continue to be, family health managers. To take care of their families - which often includes encouraging the men in their lives to have medical checkups, to pay attention to symptoms they would rather ignore, and to take greater responsibility for their own (men's) health - women need to be informed.

This book is a direct outcome of a research project on community perceptions of prostate cancer conducted in the Hunter and New England regions of New South Wales in 2004-2005. The findings indicated very strongly that, when it comes to men, the topic of prostate health and prostate cancer remains veiled in awkward silence. Men are embarrassed by it and reluctant to talk about it, and consequently, many are poorly informed, even at the time of diagnosis. The following comment was typical of the men we interviewed:

“ I knew absolutely **nothing**, nothing at all. I hadn't had a lot of symptoms. Just felt it was part of your age where you are slow on wee and slow on sex. No pain, just absolutely nothing... No, I thought I was bullet proof, like probably most men. I was fit; I do a lot of walking. I hadn't had any problems. No pain; absolutely nothing to indicate that I had anything wrong with me whatsoever. Even though my brother died of a similar sort of thing, in that area... I hadn't followed that through, which I probably should have done... Well, I knew absolutely nothing. *(56 year old man, diagnosed 6 months earlier)*

What the women in the study told us was that they did not want to wait until their men had prostate cancer and then have to “pick up the pieces”; they wanted to be proactive. But that requires knowledge which many women simply did not have. Women whose husbands had recently been diagnosed with prostate cancer regretted not knowing more and not acting sooner to ensure that their men were aware of the risks and were tested regularly.

This book will give you some basic information about the prostate gland, why men have it, and what can go wrong with it; why testosterone is important; who is at risk of developing prostate cancer and what men can do about it; what is involved in being tested for prostate cancer; what happens when prostate cancer is suspected and diagnosed; what treatment options are available and what their effects are. And finally, we discuss how people live through the impact of prostate cancer, largely through personal stories of women whose husbands have been diagnosed and treated for prostate cancer over the past few years. The women who contributed their stories to this book are unapologetically and sometimes painfully honest, but they are also optimistic and determined to share what they believe other women need to know.

Our common aim is to inform and encourage women, and their men, to be personally proactive and to do what they can to reduce the impact prostate cancer currently has on our community. It is important, however, that information provided be used as a general resource only. Any individual issues or concerns, and especially any symptoms you might have, should be discussed with an appropriately qualified health practitioner.

Preface to the second edition

In 2006, when we embarked on the task of writing a book about prostate cancer directed primarily to women, we did not realise what a challenging project it would become, or how much impact it might end up having on ordinary men and women in the community. We certainly did not expect to be writing a second edition only a year later. But given that the initial print run is almost gone, and the requests for the book keep coming in, we have decided to update and expand the book, rather than simply reprint the original edition.

We have updated technical information based on current research, sometimes adding new text but often just ensuring that the text is in line with the latest scientific evidence published since the first edition was written. Because the book has found its way to New Zealand, we have also added some relevant statistics and information related to New Zealand conditions. There is a short new section on taking personal control after the diagnosis of prostate cancer, and finally, we provide an update on the personal stories that are the real heart and soul of this book.

Prostate cancer is not an abstract term; it affects real people and disrupts real lives – those of a 40 year old professional man with a young wife and an 18 month old toddler; a 50 year old self-employed man with a new wife and a new blended family; a 60+ year old newly-retired teacher and his wife; a 70+ year old broadcaster and politician with lots of projects that keep him and his wife busy and involved in their community. Whatever the man's age, and whatever his situation in life, the impact of prostate cancer will be felt not only by him but also by his wife/partner and by their family. Without Andrea's, Renee's, Heather's and Gail's stories of their and their husband's experiences over the past few years we could not have written this book.

We hope the information contained in this book will be of help to women and men who read it.

We want to reiterate the sincere thanks we expressed in the Acknowledgements to the first edition, and to once again pay tribute to all the individuals and organisations that have provided resources, critical advice, support, and encouragement, that have made the work on this edition possible. We especially thank Professor Jim Denham for his unstinting support and expert advice and contribution; the members of the Prostate Survival Alliance Inc and their chairman, Ron Bender, and Geoff and Mandy Fry and the Greater Building Society whose generosity has made the printing and distribution of the second edition possible.

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acknowledgements

This book is the result of questions, hopes, aspirations and encouragement expressed by many women and men in the community. Some have had direct experience of prostate cancer; others have been touched by the experience of those close to them. Most wished to have known more, before having to face a diagnosis of prostate cancer and deal with the aftermath of disease and its treatment. I am very grateful to all women and men who shared their stories and helped me to understand something of their experience and thus enabled me to write this book.

I am especially grateful to Renee and Chris Bratby, Andrea Moller and Wayne Doney, and Heather and Phil Webster, for their generosity of spirit, for trusting me with their stories, and for appreciating the value of “telling it like it is”.

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I am grateful to Scott Alcorn and Vanessa Anton from the Design Centre, Hunter Institute of TAFE, for their enthusiastic support and willingness to involve their students in the design competition. Carlena Payne, a talented young designer who produced the cover and layout for the book, has been a joy to work with. She has taught me to appreciate the importance of the visual aesthetic in what would otherwise have been a very plain text.

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- Andrew Giles, Chief Executive Officer, Prostate Cancer Foundation of Australia, Sydney, NSW
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Finally, I wish to acknowledge the most important contribution from Professor Jim Denham without whose support and encouragement this book would probably not have been written.

Irena Madjar

Auckland, New Zealand, January 2007

This book opens the door on prostate cancer, and goes beyond the bounds of a normal textbook. It answers questions we want to ask, and some we aren't game to. Irena's research, knowledge, and passion for this project, have brought together a book with heart and soul as well as clinical advice. It unlocks the mystique of prostate cancer, and tells us that, as women, we are not alone!

For women like me who have been down this path and those who will follow, and for every woman who has a man in her life whom she loves, thanks Irena for having the insight to realise prostate cancer "is not just a man's disease".

Thanks also to Professor Jim Denham - one of the great humans of this world - for introducing me to Irena, and for the encouragement he has given both of us with this endeavour. He and Irena encouraged me to believe I had something to offer this project, and that my experiences during my husband John's encounter with prostate cancer were important to others.

Both Irena and Jim are committed "beyond the call of duty" to bringing prostate cancer awareness to the wider community; and stopping the unnecessary deaths of so many men. My greatest admiration!

And thanks to the men and women I listened to and spoke with at prostate cancer support group meetings on the north coast of New South Wales, for sharing their stories, fears and questions, and being brave enough to stand up at public meetings and share their experiences with others. I learnt a lot.

To John my husband, who I admire greatly, and who remained constant throughout, and by his own amazing strength of mind, inspired in me the previously unexplored emotional and physical strength I needed, to help me help him through. Together - partners in life's journeys - good and bad.

Gail Tingle

Port Macquarie, NSW, January 2007

1 man's body and health

what every woman should know

Like it or not, women are the family health managers and primary care givers. They are the ones responsible for making sure that the first aid cabinet has a supply of band-aids, that children are vaccinated, and that scratched knees and sore tummies get the attention they need. They make medical appointments, pick up prescriptions, and read instructions on the medicine labels. They step in when older family members become ill, or need help to cope with increasing frailty. What's more, more often than not, women seem to know exactly what to do, who to call, and how to manage such demands on their time and energies. For better or worse, family health remains the women's domain but, when it comes to prostate cancer, women are at a distinct disadvantage. They do not have a prostate gland and hence no personal experience as a reference point, and there is still a lack of helpful authoritative information on the topic in the community. In the words of a 56 year old woman whose husband was diagnosed with locally advanced prostate cancer:

“ We all know about breast cancer, and having our Pap smears, but when it comes to men and the prostate, it's a different kettle of fish altogether. We need to **hear** more about it, and **find out** more about it. You know I had to push *[husband]* ... He won't go to the doctor just on his own accord. I'll be honest, we fight about it. ... Until the nagging might wear him down, and off he goes. But **gee whiz**, it takes an **awful lot** ... You only do it because you care about them, and you know there is something wrong. I think probably the wife might pick it up a bit earlier than they do. But **that** *[prostate cancer]* I didn't have a clue about.

Women tend to be much better informed about their own health. As they grow and mature, they learn to attend to their own bodies – weight and size, menstrual periods, wanted and unwanted hair, contraception, pregnancy, giving birth, and breast feeding. And then, there is menopause; smooth sailing for many women, but a prolonged period of hot flushes, night sweats, weight gain and mood swings for others. These are some of the most obvious changes that are part and parcel of being a woman.

Not surprisingly, many of these changes have become subject to medical oversight and intervention, from puberty into old age. Most women accept that staying healthy and looking after themselves means visiting a doctor, discussing health issues and having periodic tests. Pap smears and mammograms have become part of that routine – even if they are not the most pleasant of life’s experiences. As they enter menopause, some women choose hormone replacement therapy or naturopathic supplements to manage discomforts resulting from major hormonal changes. If individual women have not been through all of these experiences personally, they are bound to know women who have. Paying attention and “listening” to one’s body is something women learn to do almost intuitively. And of course, women talk about their health with other women. In the process, they learn from each other; and, in doing so, they learn what questions to ask their doctors if they have concerns or just need to resolve issues in their minds. Women tell each other about their health-related experiences and might be surprised or puzzled to find that men tend to behave rather differently.

Men will talk about cars, sport, or politics, but are not socialised to discuss the inner workings of their bodies, their intimate concerns, or their mates’ experiences of illness. Interest in their own health might be seen as a sign of weakness. Showing interest in other men’s health is likely to raise suspicions; it is not what real Aussie or Kiwi blokes do. A sports or work injury is fine but anything more personal is another matter. Overall, men have much less contact with their GPs than do women. The slogan seems to be “If it ain’t broke, don’t fix it!” Such attitudes are not helpful when it comes to health promotion and medical checkups, especially when the focus is on prostate health and testing for prostate cancer. Waiting until “it’s broke” could be leaving it too late.

It seems that women (as wives, mothers, daughters, and friends) might need to take on another task in relation to their health manager role – helping to reduce the illness and death toll caused by prostate cancer. Ordinary women, in alliance with their doctors, publicists, media, and high profile champions have made a huge impact in the area of early detection and better treatment of breast cancer. They can lead the way in the area of prostate cancer too, by

helping their men become more knowledgeable about the issue and encouraging them to take action. When it comes to prostate cancer (as well as other illnesses), research evidence shows that married men have better outcomes and live longer than men who live alone. The support of an informed and caring partner is an important element in men's survival and recovery from illness.

IN AUSTRALIA (with a population of just over 20 million people), **some 13,500 men are diagnosed with prostate cancer each year**. That's around 52 men each working day. More than 5000 of these men are below 70 years of age – men in their 50s and 60s, the years when they should be enjoying life, and contemplating a long and productive retirement. Whatever the dominant perception in the community, prostate cancer is not a disease affecting only old men. (And however old they are, all men deserve to be informed and assisted to make decisions about their bodies and their health. Recent research indicates that even older men have better outcomes if treated for prostate cancer than if their cancer is left untreated in the expectation that they will die **with** rather than **from** prostate cancer.) Each year, **more than 2,800 Australian men die of prostate cancer** – about 8 each day, many after very invasive and debilitating treatments. Prostate cancer is the second most common cancer in men, after skin cancer, and the second leading cause of cancer-related deaths, after lung cancer.

IN NSW alone (in a population of just over 6 million people), in 2004, **5477 men were diagnosed** with prostate cancer and **905 died** from the disease.

IN NEW ZEALAND (in a population of 4 million people), in 2002, **2656 men were diagnosed** with prostate cancer and **591 died** from it. The figures for Maori men are of particular concern since Maori men are 16% less likely than non-Maori men to be diagnosed with prostate cancer but are more than twice as likely to die from it as non-Maori New Zealand men. The figures for men of Pacific Island background in New Zealand are similar to those for Maori men.

It is relevant to note that these numbers are very similar to the numbers of Australian and New Zealand women who develop breast cancer each year, and who die from it. If anything, the statistics for the incidence of prostate cancer are worse. For example, in NSW, in 2004, 4,085 women were diagnosed with breast cancer and 928 died from it. In 2002, in New Zealand, 2364 women were diagnosed with breast cancer and 625 died from the disease.

According to the latest NSW statistics, the chances of a woman being diagnosed with breast cancer are 1 in 11 by the age of 75 years, and 1 in 8 by the age of 85 years. The chances of a man being diagnosed with prostate cancer are 1 in 8 by the time he is 75 years old and 1 in 5 by the age of 85 years.

Despite these almost mirror-image numbers, prostate cancer has been shrouded in silence; community attitudes and perceptions are very different, and most importantly, public health education and clinical services for men are lagging seriously behind. To begin to make a difference, at least for the individual men in their families, women need to be informed. So here are some basic facts:

Genes

We inherit much more than our looks from our parents and grandparents. The genes they pass on to us carry predispositions to many diseases, including heart disease and some cancers, including prostate cancer. A man who has first-degree blood relatives (father or brother) with prostate cancer has a much higher chance of developing the disease than a man without such family history. The risks are higher if the relative is diagnosed with prostate cancer before the age of 60. While we cannot choose our ancestors, we can be informed about any disease risks we have inherited and act on that information by being tested and, if this becomes necessary, being treated while the disease is still in its early stage.

Lifestyle

Apart from genes and ageing, our health depends most on our lifestyle and approach to life (good diet, regular exercise, and a positive outlook go a long

way to ensuring good health and healthy ageing). In that, men and women have much in common.

- We need a healthy diet.
- We need regular exercise (even if it is only walking the dog each day).
- We need a sense of purpose and optimism about life overall (supportive relationships, a sense of belonging, religious faith, meaningful work or other activities...).
- We need to avoid exposure to harmful substances (tobacco, pesticides, industrial and other pollutants, excessive use of alcohol and other drugs) and chronic stress.

Healthy living can do wonders for our sense of wellbeing and reduce the risk or delay the onset of some illnesses, including prostate cancer. In the end, however, we have to accept that human bodies are not designed to last for ever and, sooner or later, normal ageing and disease processes will set in. For this reason it is important that women and men take action to ensure that, if they are to be diagnosed with a treatable disease – be that diabetes, high blood pressure, heart disease, or some kind of cancer – they are diagnosed early, before the disease has done too much damage and while it can be treated more effectively and with less impact on the person. Prostate cancer is such a disease. If detected early, it can be treated much more successfully than if detected after it has spread beyond the prostate gland and into surrounding tissues and other parts of the body.

Age

Our bodies age and degenerate. As cells and tissues change and die, joints tend to become stiffer, kidneys less efficient, muscles and bones weaker, and blood vessels less elastic. Unfortunately, the older we get, the more likely we are to also get some form of cancer. Like breast cancer in women, prostate cancer is more common in older than younger men. However, in some cases prostate cancer can appear in younger men, before the age of 50 years, especially (but not only) those with a family history of the disease. Even when prostate cancer is diagnosed in men who are in their 60s or 70s it is very likely that the cancer first appeared some 10 or 15 years earlier and grew very slowly over those years.

Because early prostate cancer might not cause any symptoms, unless a man is tested, the cancer might not be diagnosed until it has had time to spread. Earlier detection of prostate cancer gives men more options for treatment, and a better chance of being cured.

A word about testosterone

Testosterone is a male hormone produced mainly by the testes and responsible for male sex characteristics such as deep voice, strong muscles and bones, aggression, libido (sex drive), potency, production of sperm, and growth of the prostate gland. Testosterone is also known to increase energy levels, sharpen memory, mental focus and spatial ability – and contribute to baldness.

Testosterone levels are highest in adolescence and decline after that, more so from about the age of 40 years. Despite their gradual decline, testosterone levels in most older men remain within a normal range and have no significant effects on their overall health. In a minority of men testosterone production can drop to very low levels (condition known as male hypogonadism) and can contribute to reduced muscle strength, decreased energy levels, decreased sexual interest and potency, poor concentration and depressed mood. (Low testosterone levels are not always the reason for such changes. They can also be due to depression, effects of some medications, liver disease, or other hormonal changes associated with ageing, so it is important to seek appropriate medical help and establish the cause of these or any other symptoms.) When testosterone replacement is used in men with very low levels of natural testosterone it can have positive effects on their health and sense of wellbeing.

But is testosterone replacement a cure for ageing or an elixir of youth? Should healthy older men use testosterone supplements to boost their testosterone levels, energy, mood, and sex drive? Use of anabolic steroids (testosterone supplements) in sport has shown that long-term exposure to high testosterone levels can lead to serious mental and physical health problems, including liver damage, infertility, and prostate cancer. Testosterone is not a tonic and its use in healthy older men – those with testosterone levels normal for their age – carries considerable risk, including increased chances of developing prostate

cancer. (Because prostate cancer 'feeds' on testosterone, boosting blood levels of testosterone with supplements could contribute to faster and more aggressive growth of prostate cancer that might otherwise have stayed dormant.) The risks, particularly the long term effects of testosterone supplementation in older men who do not suffer from hypogonadism, are not fully understood. The best current advice is that testosterone supplements should not be used to prevent or relieve the physical or psychological effects of normal male ageing.



The role of testosterone in the management of prostate cancer is discussed later.

Screening and early detection of cancer

Most women are aware of the importance of regular Pap smears and, as they get into middle age, the importance of mammography screening. These are designed for healthy women to make sure that, if they are in the small minority who will develop cervical or breast cancer, any signs of cancer are detected early and managed appropriately. The acceptance of such tests by women themselves, and the provision of these services for women across the country has taken time. What we have learned from women's experience is that regular screening and early diagnosis saves women's lives. Similar achievements are yet to be realised in relation to prostate cancer, but things are beginning to change. Men are starting to realise that they can learn from women's experience and change their attitudes:

“ My friend died of prostate cancer, my age, sixty seven. Why aren't men being screened?... The GP never once offered a blood test. That's partly my fault. I should have insisted myself. I'm supposed to be educated. I should have insisted on the blood test. I didn't have a blood test for five years and I am going to the doctor regularly. But women are regularly screened for breast cancer, well, why not men? Am I missing something here? What is it? Why cause all this unnecessary suffering if an early diagnosis can cure the cancer while it is still in the gland?

Friends of mine, I say, “have you had a blood test?” And I tell them about my experience and their response is, “Oh, I’ll be right mate”. This old Aussie, “I’ll be right mate”. ... “No, it’s serious”, I say. “Get in and have a simple blood test”. *(67 year old man, 12 months after diagnosis of locally advanced prostate cancer)*

The reasons why testing is important is that prostate cancer often begins to grow while men are still in their 40s or 50s, or even earlier. Unless tested, men are likely to remain unaware of this fact for a number of years. In some cases it can take 20 or more years before a single symptom of prostate cancer appears, but by that stage the cancer is likely to have taken a firm hold and spread beyond the prostate gland. Waiting for symptoms to appear first is unwise, since early prostate cancer, when it is most treatable, is usually asymptomatic (there is no bleeding, no pain, no visible lumps, and no urinary or sexual performance problems). Also, it is not yet widely appreciated that an increase in the blood level of PSA (prostate specific antigen) occurs many years before prostate cancer becomes large enough to cause symptoms. So the PSA test provides a means by which prostate cancer can be detected in its early stages. (We will return to the topics of the PSA test and early detection later.)

Women who care for their men want them to be healthy, to age well, and to be able to enjoy life into their later years. After all, we are constantly reminded that 50 is the “new 40” and 70 is the “new 60”. As today’s generation ages, we are staying more active and enjoying better health than previous generations have done. Living longer is much better if it also means staying healthier. As the family health managers, women can make sure that men do their part in looking after their own health, including having periodic tests – not because something is “broke”, but because it is important to ensure that we get to it before it is. After all, few men would buy a new car and then completely fail to check tyre pressures, oil levels, or other servicing requirements. Yet, many men need encouragement, and more, from women who care for them, to visit a GP, or to have a simple blood test. (One woman’s solution to the problem – sending her husband a brief email, reminding him that his blood tests were due.

What several verbal reminders failed to achieve, the email did. He made the appointment to get the blood tests the following day!) Men, just like all of us, hate to be nagged. Your man might be the responsible type who is informed and proactive about his own health. He might need no more than an occasional gentle nudge. But if you are going to nag him, pick your issues and your time, and learn to nag wisely.