

Prostate Cancer

“My positive attitude has helped!”

A black silhouette of a man and a woman embracing, positioned above a blue background. The man is on the left, and the woman is on the right, with her head resting on his shoulder. The silhouette is partially cut off by the top edge of the blue background.

Stories of
Men and Women

Laurence Lepherd
Coralie Graham
Editors

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“My positive attitude has helped!”

Laurence Lepherd and Coralie Graham, Editors

University of Southern Queensland

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Foreword

In this volume Laurence Lephed and Coralie Graham have compiled a valuable resource for those wishing to understand how people find the strength to face the daunting challenges of prostate cancer diagnosis and treatment.

The presentation is striking in four ways.

Firstly, we are given multiple perspectives - stories by men, stories by the women in their lives, and stories that couples tell together. This approach will resonate with anyone who has a special person in their life, as well as those special people.

The second striking feature is that this is a "warts and all" treatment. No one holds back - not the story-tellers, not the editors. The result is that we have uncommonly frank and honest tales of the prostate cancer experience.

The third thing that will strike you is how different are both the prostate cancer experiences and the ways people have for dealing with them. How and when the disease presents itself, interactions with health professionals, and the philosophical and emotional status of the men and women always combine to make each prostate cancer experience unique.

The final striking feature is how Laurie and Coralie have managed to bring out from each person that which keeps them going, building on Laurie's previous efforts in exploring this topic - "Prostate cancer: Climbing above it" and "Prostate cancer: Peace of mind".

Over the past six years of our prostate cancer experience, we (Wendy and Jim) have had hundreds of interactions with others on the journey in our roles as support group leaders. In helping to communicate these experiences to others, we have sanitised these stories - Wendy by her academic approach of generalising the partner's experience, Jim by moderating contributions on a website to comply with an "evidence-

based medicine".

But if you want intimate, honest accounts of prostate cancer experiences, with a focus on what helped the men and their partners get through them, then this book is for you.

Jim Marshall, Convenor

Australian advanced prostate cancer support groups

Wendy Marshall, Convenor (retired)

Partners of men with prostate cancer (Brisbane)

Preface

Prostate cancer is generally regarded as a matter for men. However, where men have partners and families, the partner becomes an integral part of the illness, its treatment and its side-effects.

The experiences for men and women can be very stressful. There are many times during the journey when those affected receive a ‘lift’ from something that is associated with the illness, or they can become depressed when things do not go as they hoped. The editors of this book decided to document the stories of men and women associated with prostate cancer, particularly in relation to the way men and women were able to rise above the illness and its circumstances. Through a general invitation to people to share their experiences, we were able to record both the stressful times and the way in which many were lifted up above the circumstances, and were able to develop a positive approach to coping.

This book contains the prostate cancer stories of 40 people – 10 men, 10 women and 10 couples. An important aspect of these stories is that each person was able to present their own perspective on their journey. The stories reflect both diversity in lifestyle and coping in the participants. Some used quite colourful language in their stories and this was included in the transcription of their interviews to demonstrate the very humanity of their responses.

Traditionally, most concern has been about the men themselves – the stresses associated with diagnosis, decision making about treatments, and the recovery process. Now, more attention is being given to the effect of the illness on their women. Sometimes the men do not wish to acknowledge their difficulties and this can cause problems for the woman and in their relationship.

The participants were asked a simple question – how did they receive lift and hope during their experiences. One of the main responses was that they tried to be very positive during the whole experience. Coming

through the rough, dark tunnel for many of them was achieved through remaining as positive as they could be in the circumstances, but, at the same time, realistic.

We very much appreciate the assistance of the Prostate Cancer Foundation of Australia in providing information about the project to members of support groups.

We are very grateful to all the participants for their frankness in sharing their perspectives with us. In all but two stories the names and places are fictitious. Two participants wished to be identified with their experiences.

Laurence Lepherd and Coralie Graham,
University of Southern Queensland, Toowoomba.

A word of caution

It is vital to recognise when these stories are read that no statement on medical aspects is necessarily accurate. The participants in the research provided their perspectives on some medical issues. They did not claim to be medical experts on the illness and its treatment. Anyone reading these stories who finds something that appears to be relevant should not necessarily accept it as a statement of medical fact but should discuss the matter further with a medical professional or specialist.

Notes and abbreviations

Sexual dysfunction and erectile dysfunction. Sexual dysfunction refers to a the broad array of sexual difficulties that can be experienced by men and women. These can include, loss of libido, inability of the man to achieve an erection and the inability of either a man or woman to achieve an orgasm. Erectile dysfunction refers only to the man's inability to have an erection. Sometimes these terms are used interchangeably in the stories

Radical prostatectomy. a) complete removal of the prostate gland through open surgery; b) laparoscopic keyhole surgery carried out directly by a surgeon; or c) robotically assisted surgery directed by a surgeon operating from a computer console.

Radiation therapies. External beam radiotherapy, or, Brachytherapy – use of radiation pellets in the prostate gland to destroy cancer cells from within.

PSA – prostate specific antigen

DRE – Digital rectal examination

MRI – Magnetic Resonance Imaging

PCFA – Prostate Cancer Foundation of Australia

NSW – State of New South Wales in Australia

WA – State of Western Australia

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Men

Gavin

Mixed circumstances

When I was first diagnosed and had my radical prostatectomy, I decided that anything I could possibly do to help others with similar difficulties, I would. So I volunteered, firstly through the Cancer Council and then through the Prostate Cancer Foundation of Australia, and eventually through Pathfinder. I live in a major city.

I was very pleased that I had tremendous support all the way through my prostate cancer journey. I guess one of the problems I see is that men's cancer does not get the same sort of priority that women's breast cancer gets. I think we are left out in the cold a bit. I would just like to support research and development activities which are going to enable other men to get the same sort of support and backup that I myself have received.

I was diagnosed with horseshoe kidneys back when I was in my late teens. I have been monitored regularly because of that. It was also identified that I had an enlarged prostate back then. So we have been keeping an eye on it. It's been in check and I hadn't had to do anything about it because my PSA had been low. I suffer with urinary tract infections (UTI) quite regularly because I "grew" stones. So having urinary frequency and UTI's was commonplace for me.

Stress and more stress

I was in an extremely stressful job and I was also in an extremely stressful home situation with two teenagers. My wife and I had decided that we were going to separate. I was getting UTI's and my blood pressure was extremely high. I had been diagnosed with sleep apnoea. I also had an elderly mother for whom I was the primary carer. She was in the throes of encroaching senile dementia which in turn put a lot of stress on me.

Over an eight month period my mother passed away, which was a great relief, if you know what I mean. This led to a reduction in my stress levels. I kept on getting UTI's. I thought it was the existing horse shoe kidneys.

The beginning of prostate cancer

I went back to the GP for more antibiotics for a UTI and he told me that he would not give me any more antibiotics until I had my PSA checked. I had the blood test done. The following week I was interstate on business and received a phone call from the GP telling me that we needed to talk. From there on, I knew that there wasn't going to be good news.

I saw him as soon as I returned and, because I had received the earlier phone call, I had prepared myself for the consultation. I had a suspicion that he would tell me that I had prostate cancer, or my kidney was going to be removed. He told me that my PSA had gone up from about 4 to about 12. The GP carried out a digital rectal examination and he said that he could feel lumps in the prostate.

When I returned home I didn't say anything to my wife but booked myself in for a biopsy. This was done a fortnight later. They found that I had fairly extensive prostate cancer that had just gone outside the capsule. So it was a matter of taking dramatic measures.

A fantastic medical team and 'lifting' support

My reaction on receiving the news was to go straight into trying to work out what my options were and what the probable outcome would be. I was fortunate in that the attention I received at this very large medical practice involved highly regarded specialists in the field. The doctors were extremely well connected within the practice. So my GP put me onto another urologist. (My first urologist that I had for the kidney problem was located on the other side of the city). The new urologist had a fantastic team working with him. Even when I went in for an initial consultation with him prior to the biopsies, he provided me with a swag of information, which was fantastic. He put me into contact with the people I needed. I was given a referral to a continence physiotherapist, and the urological practice has its own ED (erectile dysfunction) and continence nurses. So initially I had a feeling of comfort and support because I knew I had a great team behind me. As to whether it lessened my concerns about the future? No, it didn't.

I was also fortunate that my best friend, with whom I grew up, went into nursing. He and I both shared a house together when we were going through university so I was very fortunate in so many ways that many people, including him, were able to help me in the circumstances I now found myself in. When I was diagnosed, the first thing I did was to get into contact with them. I rang a friend of mine who is a professor of immunology. These friends gave me some good advice on where to visit parts of the Internet to gain greater depth of understanding of the issues. This was mind blowing actually. I got a real lift and buzz through the support that I had with so many of these professionals and friends. I was always extremely fortunate because even when I had the downs, I still had these friends and professionals who were able to lift me through their encouragement and their practical advice.

Treatment and side-effects

I had a robotic assisted radical prostatectomy. There were decent surgical margins even though the cancer had gone externally out of the prostate

gland itself. They took further samples from other parts of the body and they all came back negative. The PSA four weeks after the surgery was detectable. We monitored the PSA and it rose fairly steadily so they opted for external beam radiation therapy 12 months later.

In that 12 months, I had the usual issues of erectile dysfunction and regaining continence in which I was very fortunate because of the work I had done prior to the operation and immediately after it. What concerned me most during the period that I was having external beam radiation therapy, was that I met a lot of other guys around the State who were coming in for similar treatment. On comparing our 'journeys', I found these poor blokes received little to no support as I had had with regards to continence and ED nurses. I was in the fortunate position of being able to get support for all the issues, but these fellows coming from so many different places just did not have that facility. There is an urgent need for more nurses and support networks to help a greater number of guys, especially those out in rural areas.

During this period between the radical prostatectomy and radiation therapy, and while most things were getting back to some sort of normality, I struggled with the erectile dysfunction. I went through the normal procedures and I'm afraid I couldn't use penile injections as part of overcoming the ED problem.

Incontinence wasn't a major issue after the prostatectomy. It was more of a problem when I went through external beam radiation. I set myself watersheds throughout, not major ones but just looking at things like getting continence back in a reasonable period of time. These were personal watersheds that I looked to achieve, and I did.

I think the biggest thing of all that needs to be conveyed to those who are first diagnosed is the fact that especially with modern treatment as it stands, it is something you live with and die with, not die from.

Others who had gone through it all

I joined the Prostate Cancer Foundation of Australia (PCFA) support group very early on in the piece. I had my radical done in early December 2009 and I went to the first local PCFA meeting early in March. I found in this group a number of people who had been there and gone through it all. This was a great relief in itself. Admittedly these guys were older. (I was 55 when my treatments had been completed.) I think this is one of the biggest issues in that the support networks meet at night and this enables more people to attend. I do keep in contact with the PCFA support network and I do get involved in some of the activities but I tend to stay away from the meetings, because as my urologist said, “There’s a bunch of pissed off blokes out there”. I was really concerned about this. I found that there is quite a bit of negativity within the support group and that’s why I backed off from it.

Some support lifts

What lifted me was that I get the monthly newsletter from my local group of what’s been happening in the local area. I’ve got to say though that the convener is an inspiration to me. An important issue for me was that when I walked into the local support group and saw guys there who I knew have prostate cancer, there was no visible evidence that they had it. Guys in this situation are always around us, they walk among us, yet we wouldn’t know. The group was a nice, supporting comfort.

The information that the support group puts into their newsletter on the latest developments is fantastic. This, together with the PCFA newsletter, really keeps you up-to-date on what’s happening and is very informative. I get a real lift from the fact that there is this sort of development, and that positive results are coming from the research that is going on.

Hope from a supportive work place

My biggest difficulty of all is that I've got myself going deeper and deeper into a hole going through the separation and on the other things in my life. This included the fact that I fell on my sword when the company I was working came on hard times. They had supported me right through my treatment even though I'd only joined a couple months beforehand. So I thought that if they were prepared to support me so readily, and this gave me a great lift, then I should do the right thing by them and make it easier for them to continue. Immediately I was diagnosed with the cancer, I went into the office of the CEO and said that I had received bad news over the weekend, that I had been diagnosed with prostate cancer and I would have to resign. He said, "Why?" He said that the company would support me. He also said that his father, the owner of the company, had gone through this and that he knew that I could get through it. So that was reassuringly in that, here is me in my 50s and the CEO's father was in his 70s and he had gone through it himself. So this was a case of older people getting through it and showing that getting through it is a possibility for younger people. This gave me great positive hope.

"I'm still alive" – there's hope

What helps me is that yes, I might have some reduced functionality in some areas, but I'm still alive; I'm breathing and I'm functioning; I have a lot. I really don't know where my hope is for the future. I'm on the precipice of 'singledom' again and there's a lot of things I want to do on my bucket list but unfortunately, due to circumstances, I haven't worked in the last 12 months. My telling people that I have prostate cancer possibly affects my ability to become employed. In fact, I know that it does. My long term health looks positive, it's the rest of my life I need to work on.

Part of my hope relates to the advances being made in treatments. There is one trial particularly which is happening in radiation which the radiation oncologist suggested it might be possible for me to be involved

in once my PSA level gets back to one again. I would go through the MRI and have the other scans and see the extent to which I might be eligible. In the meantime I got myself involved in a number of charitable organisations in a drive to get more male nurses and ambassadors to advocate the issues relating to prostate cancer. I want to be a very strong advocate for all men in cancer situations.

Support networks – a lift

I have become very spiritual and philosophical about my journey and all I want to do is make the world a better place. This is my uplifting thing. I was very, very fortunate that I had that support network during my journey. While I look normal, I have prostate cancer. I just want to be treated in a normal way. I don't want the cancer to be a badge of honour. It's a manageable illness. I will live with this thing. I am positive! With the advances in medicine we can have a longer life, but, the saddest thing of all is that it seems that during our journey sometimes, we 'fall through the gaps' once treatments have completed and we again wait to see what the next regime will be.

Frank

I was a 52-year-old man in Western Australia and was diagnosed with prostate cancer. So what they did was to say that they would keep it in check every six months and run a PSA test. About three years later they decided to operate on me and they even got to the stage of putting me in hospital and then sending me home. They said that if we did something about it now that I would have another one by the time I was 60.

I put up with it until I was 62 when I had the options explained to me. Having to face the issues for a decision came as a bit of a shock to me. So my partner and I put our heads together to discuss the matter. She had recovered from bowel cancer. So I decided to have radiation therapy in Perth. So I did the treatment of having sessions from Monday to Friday

and then going home to Geraldton for the weekend and coming back on Monday. I suffered very little inconvenience; there was no pain.

We had a very pleasant time when we were in Perth because we would go down to have the treatment at eight o'clock, finish at nine, and go out swimming, fishing and enjoying ourselves. Everyone else who had the same treatments couldn't leave the building because they had to stay near the toilet. I didn't have that problem. I took some advice there as to whether it could affect me or my bowels, that it wouldn't be great for my sex life and all that sort of thing. But I did not notice one change whatever. My treatment was over a period of six weeks.

So for the next six, seven and eight years I could say, touch wood, "Well they've cured the cancer but they haven't cured the prostate"; I was still getting up at night. After eight years I had cause to go to the hospital again for something and they asked me if they could do anything for me. I asked if there was anything they could do to stop me getting up so often at night to go to the toilet. He suggested that he could put me in to have a Transurethral Resection of the Prostate (TURP). I kept on telling the surgeon that I had a very withered up left testicle and could he look at that see what the problem was; but he didn't.

An annoying catheter

I have worn a catheter every day for the last eight months. It's a bit annoying because it leaks beside it and I have wet clothing at times, so I wear a pad. The Doctor also booked me in for a colonoscopy to look at the back passage. As far as the urethra was concerned, he gave me three options. He said I could have either self-catheterisation, or have a big operation to replace the skin of the urethra – skin from off my arm or backside. The third option was to have a permanent catheter so that the catheter comes out of the body near the navel and it feeds into a colostomy bag. That, in a nutshell, is what was suggested.

In myself I feel pretty good. It's a bit annoying to have a catheter all the time especially with the clothing. (The catheter I have now is in the

urethra.) I go back every six weeks and have it changed. Unfortunately the Doctor who I was working with at the hospital left and currently I am in no man's land and have to go to receive assistance from a stomal nurse at the hospital to change the catheter. However, I received a recent phone call to ask me to go to a major hospital where they would review my case. They don't know what has happened to me and I don't know what they are going to do. That's about my story.

Physical problems – and acceptance

As far as sex life concerned, a man of 74 does not have a very active life but anything at all has been null and void since the catheter went in seven months ago. I did try self-catheterisation for about a week but I just couldn't do it. I now have a LoFric (low friction) catheter. It consists of a catheter with jelly and when you try to insert it, it squeezes the jelly up into the urethra and that reduces the friction as the catheter is inserted. To do this I have to do it once a day every day for the rest of my life. If this works than I don't have to put up with having the catheter in all the time and having to put up with the dribbling. If that doesn't work the other option I would consider would be the permanent catheter coming out near the navel and then into a colostomy bag.

Being a country boy I have the philosophy that 'whatever will be will be'. You accept what you have. You can sit around saying, "Woe is me", but, if I did this, I would probably have been dead by now. I took what I thought to be the best options at that particular time and for nearly eight years it was quite good. I'm getting into the 13th year now.

I haven't had any real problems emotionally. I have a very understanding partner who sympathises with me even though she can't do anything for me. I don't know where I go from here. I've had a second opinion from a doctor and he assures me that the doctor I had first did all the right things. It was no more or less than what he would have done himself.

As far as side-effects are concerned, I accept that I don't have a sex life, I don't like having to get up to go to the toilet two or three times a night.

If I go for a car trip I have to get out occasionally to go to the toilet. I don't wear a bag with the catheter now. I have a flapper switch on the end of the tube so I just drain that into the toilet and I'm right to go again.

"I'm not crying into my beer"

As far as my hope for the future is concerned, at 74 I am not looking for a very active sex life. I will be satisfied as long as I can urinate when I need to, I would hope that I could get to the stage where I don't have to urinate several times a night although I realise that at my age I probably need two visits to the toilet anyway. I'm not crying into my beer; there's nothing much I can do about it; you've got it and that's it. I'm quite accepting of the situation mainly because, in my case, there is nothing much else I can do. Lying on the floor and beating my chest can't do anything for me.

A mutual, caring relationship

I have a partner but we are not de facto or anything like that. We share a house; we have our own bedrooms, our own bank accounts and everything like that. Where it's a little more complicated is that she suffers badly from chronic fatigue and I am her carer. I have to make certain she has a trolley next to her that she can push around for her walking. I drive her wherever she needs to go because she hasn't driven for two years. She is still able to cook meals and she is a very good cook.

She told me the other day that without me she wouldn't be able to do anything; she would have to go into a home. She can't walk very far with her chronic fatigue she tires very easily. Because she cannot exercise very much she puts on extra weight. On top of this she has chronic osteoarthritis in her back.

Rural living – no effect on my prostate cancer journey

I said I was a country boy and my last 40 years I have been a builder. A couple of years ago I had to finish altogether; I had to put all the tools

away and couldn't do any work. I do take little jobs here and there, something like having a door hung and other things like that.

I haven't sought support from other people and haven't been offered any, mainly because we have moved a lot from place to place so there hasn't been any opportunity. However, I wouldn't mind going to a support group more to help other people than to help myself.

I haven't been very much affected by the fact that I have lived in a rural environment over a number of years. I have always been very, very active in fact, after I have finished this interview I will go for a 5 km walk. If it's bad weather I walk 2 km if it's fine I walk 5 km.

I feel I would really like to give something back to other people because I've had a pretty good life since I've had the radiation treatment and if I can fix up this catheter business now I will be very satisfied to be able to continue and help other people where I can.

I forgot to mention one of the other options I was given when I was diagnosed was to do nothing. The idea being that many men do nothing and the cancer continues to develop to the situation where they die with it rather than from it. I should also say that the problems I now have are with the urethra rather than the prostate. This was caused by the radiation. Radiation destroyed some of the good cells which were associated with the urethra. I'm really not keen on having a skin replacement because at 74, I would be putting the public through a lot of cost for very little gain.

A healthy life

I have a pretty healthy outlook on life. I eat well – this is one of the main things. I don't overeat, I don't drink – I haven't had a drink since I had the operation seven months ago.

I don't really get a lot of lift mainly because the situation doesn't worry me that much. The problem of the catheter can be increased sometimes when you realise you've got to be careful the way you sit when you're

sitting in a car, for example, or a flat backed chair, the main problem being the pain because the catheter is there all the time. One of the things I want to avoid is having a permanent catheter. Somebody at the hospital told me the other day that the permanent catheter only lasts eight months.

Talk about it

I'm happy to talk with anybody who has had it or who has been diagnosed with it, if I can help them at all I would be only too happy to. One of the things we have to do is to get men simply to talk about it. If I can help someone I will.

Morris

I was having PSA tests for quite a number of years and eventually the reading started to go up a little bit so we had biopsies done. The first biopsy result came back indicating that it wasn't an aggressive cancer.

Then the PSA went up a little more. We were going on a trip to Western Australia and the urologist thought that we would look at this a little bit more so he did a different type of biopsy. The results showed that there was quite a lot more aggressive compared to the earlier biopsies. The first biopsy showed that I did have cancer but he thought that I might be able to live with it for the rest of my life. The second set of biopsies showed that the cancer had become quite aggressive. I asked him if we could still go to Western Australia and he said that we could go on our trip but that he wanted me back here in about six weeks' time and that he would take the prostate out. So by the time we came back from our trip it was starting to really annoy me as I could feel it large inside. Anyway, he took it out.

“Chopping it out and throwing it away”

From the PSA going up I probably expected the results to come back as a positive cancer. When he actually told me it was prostate cancer and that it was aggressive, I never really worried a lot because I thought if I have to have cancer of some kind this is probably the one I would prefer. So all I thought about was chopping it out and throwing it away. I thought this would fix the problem.

That’s what we did and we didn’t have any major problems with the operation or anything. When I got down to the hospital for the operation they fed so much stuff to me I guess that after the first 10 minutes I sort of switched off. I thought to myself, you blokes are doing this, not me, so just go ahead with it. That’s how I thought about it. I don’t think I even thought about the operation because you do that well and truly in advance of the day. I had an open radical prostatectomy. They told me it was one of the largest prostates they had ever seen. So that wasn’t any help!

Stuff left over

The recovery in hospital was all fine. Once I was able to get about and start to do a bit, I had a few problems with bleeding and stuff that caused me a bit of pain and grief, and things didn’t get right. I actually also had back problems and we had to get them fixed. The incontinence problem eventually became fixed up but the bleeding kept on going. When I went back for a check-up and had another ultrasound they picked up some stuff inside the body. It was a clip that had come adrift and had got through to the bladder. It had a stone on the end it and it poked into my bladder every time I did anything a bit rough. The urologist said that it was on the outside of the bladder. He told me that he had three of these happen over some time, and I said, “Thanks very much but I didn’t really want to be one of three lucky ones”! This caused me quite a lot of grief because I do a lot of motor bike riding and that was hell so I gave that away. (This was mostly bike work going round the property for mustering.) How I first noticed the bleeding was that I had a buster off

the bike and the bike ended up on top of me. I had to push it off and I pushed very hard and that's when the bleeding started. I thought I had broken something because it was only about 10 weeks after the operation, but I hadn't. I've since been back and had another procedure that took out the clip that shouldn't have been there. I had a urinary stone in there as well and he took that out; that was almost instantaneous relief. A couple of days after I started to feel good again and it's all good now.

I had a lot of stress at the time of the buster. I was probably at least 15 km from the nearest person because I was out in the middle of the scrub and nobody knew where I was. When I started to bleed I thought, "I'll be dead before I get back to civilisation again", so I thought I just had to stay calm and get myself back to the house and ring somebody up to find out how I would get some treatment.

But by the time I got back to the house it had actually stopped bleeding. So I settled down and went to the doctor and he told me I wasn't too bad. It was very stressful for a few hours. I coped by taking it as though I had to try to survive, and I said to myself that I should do it as calmly and methodically as possible. I knew at the time of the accident that the bleeding had nothing to do with the accident itself but that it was a problem with the prostate. They had warned me about lifting but if you have a motorbike lying on top of you and you are underneath it, you have to push so hard to get it off. You try not to lift with your arms but I just had to. If I didn't, I knew the crows would start circling above ...

Confusing side-effects

Side-effects were a bit confusing because there was the problem of the clips causing me a good lot of grief. Some days I thought I was never going to get better, but on other days I was fine. If I just poked about the house doing light stuff it didn't worry me. It was only when I was lifting and working round the property that the problem became evident. I'd been to the local doctors but I had an infection in there at one stage and they treated me for that, but it just rolled on from there. I had a mixture

of side-effects, one lot from the clip and the other from the prostatectomy itself.

I had some physical side-effects when the clip was poking in. I had no control of anything – bowels or bladder, so that was pretty rugged. But then I only had to rest for a day and things would pick up again. I might go for a week when not doing anything too strenuous and I'm going pretty good then all of a sudden I do something for 10 minutes that is a bit more stressful and I end up becoming worse again. This took a bit of handling for me. I said to myself, at least I am out in the country if a need to have a piddle I can just drop my daks and do it. But this was a worry when I was going to town as I always had to find out where the nearest toilet was.

My living a fair distance away from a major centre where there is readily available medical assistance for prostate cancer didn't affect me at all. There are a hell of a lot of blokes out in this area who have prostate problems. For example, for the next 30 kms along the road where I live there are three guys with the same problem; they live only a few kilometres apart. I have friends who live in different places and the treatment for some has been successful but not for others.

“Part of me is dead”

For me, I think everything has been addressed except the problems affecting me psychologically. In other words, the despondency I felt when I should have been getting better. This is where I feel that I've run adrift. My case might be a bit different to most. I still have some psychological problems, because when we went back for the visit after the operation, that was about six weeks after, we went and saw a doctor to see if we could get our sexual functions back and going. We tried a few ideas that he told us and they didn't work too good. Anyway, my wife has problems with her anatomy as well so we decided we wouldn't pursue that. I think that was probably a silly thing to do; I think we should have persevered on a limited scale. I now keep thinking that I just feel like part of me is dead, you know. I'm not ready to think of it that way.

I guess we made a bad decision there. My wife feels much happier because I'm not terrorising her all the time. How you overcome that I don't know. That's the one I'm grappling with at the moment. I'm currently 68. This is largely unresolved for both of us. I think my wife is probably having more problems with it than I am and this is largely because of her own difficulties. We know why I'm not operating and I guess she knows to a certain extent; it's difficult. She has some physical difficulties of her own that cause the pain – scar tissue and the like, so she is not really interested in it and that's where the problem begins.

I'm hoping that by being frank with you that other people can be helped through being aware of my experiences. I wasn't really ready for this sexual part of it. I was told that it probably wouldn't work properly and all the rest of it, but I never really seriously thought about it. I hope that we will slowly get around the edge of it and hopefully it will improve. My wife and I have thought about it and we realise that we can become closer without necessarily being sexual. We told the doctor that we weren't going to continue pursuing the more active course. I had some injections and there was some action but, anyway, this still hurt my wife so I decided, "Why should I pursue that"? We just have to talk around it until we come up with something. It's only happened recently so we'll see how it ends up.

Positive hope

My hope for the future looks pretty good, except for the financial parts of life. We are very hopeful that our life will return to be very similar to what it was before, and is just a matter of finding something that suits us. I must say that it was my fault that I didn't go back to the specialist earlier to find out why I was still continuing in pain. I guess this was my main worry I had before my first operation; I thought, what happens if something gets left in there? That was my main worry; it wasn't about the operation itself. I thought, they are good fellas that are doing the operation, you'll come out the other side.

What gave me a real lift was that in hospital I was very impressed with the way the nurses knew exactly what I needed and exactly when I needed it. You think to yourself every single dot is put on and you know that nothing is being missed out. I felt when I came back from the operating theatre that everything happened like clockwork for the next 24-36 hours. That really gave me a lift and confidence. They told me, for example, I should do this at such and such a time, and when I get up for walk you can do as much as you like.

Country or city?

We really love the land, otherwise we wouldn't be here. Most of our friends are all really retired and we are silly enough to stay here. We like it; it's not particularly special. I consider it as this is what we have chosen and a good quality of life should come with our choice. I do think it's easier for us to cope with these problems out in the country here than it is in the city. Well I think I'm happy because I can just wander around on my own and there is always something to do to keep my mind on the job. If a bloke is sitting in an office doing stuff there he doesn't really like, his mind could tend to wander. I just find that when I'm doing the job I'm not thinking about the prostate at all. It's only when I come home at night and lie down in bed that some of the thinking will gnaw away at you. So sometimes you get that way that you don't want to come home and go to bed, so you stay working.

Personal support

As far as support is concerned, there is a younger fellow up the road that I spoke to before my operation and he had had a very rough time. He was really good because he told me all the pitfalls to look for and this helped me enormously. The day after I came out of the hospital another friend of ours got diagnosed so I rang him up and we had a good old yarn and we've had good yarns ever since about it. We are both fine now. The personal support of friends was extremely valuable for me, especially for the little practical things that go wrong. A nurse or a doctor wouldn't even think of them as being important; they might be silly things so I

take it upon myself so that any young fellow who is starting to worry about it, I try to have a yarn and tell him there is nothing to worry about because I'm a living example of surviving. Prior to my being diagnosed, I really only knew one fellow that had it. You don't always find out about the prostate cancer problems of others because they just don't want to talk about it. We just have to get the stories out there so that people can cope because you don't really want to have a successful operation then be bugged up mentally. I consider that a lot of my problems come from dry weather and the resulting lack of finance!

Jeff

My story started about the about 35 years ago, not particularly with the prostate. I have looked into prostate cancer quite a lot, and I've seen the reasons why people get prostate cancer, for example, their lack of vitamins and things like this. Overindulgence of alcohol can also be a problem. So 35 years ago I was into a lot of drinking of alcohol and I became a regular drinker, not a drunkard, but a regular drinker which carried on right up to the time of my motor bike accident which was five years ago. That's when my prostate problem really became noticeable.

Major injuries

The accident put me into hospital three months with major leg injuries. I got blood clots and everything else, but I survived. The reason why I had the accident, the doctors reckoned, was that I had a blackout that was possibly due to drinking, not that I was drinking at the time of the accident. I went out on my brand new motorbike and blacked out and went straight into oncoming traffic. That's all I remember until I woke up in hospital. From that time on you are governed by authority, that is, the doctors and nurses, in such things as your food intake. I had a lot of drugs so I didn't feel very much pain. I had some 20 tablets per day. I also had constipation problems and had to try to resolve this. So all this

happened about five years ago. After I came out of hospital, I was in a wheelchair for six months. Unfortunately I got back to drinking again to kill the pain. Thirty-five years of casual drinking with people had got hold of me. It got to the stage where I could not remember what I'd done the night before. My wife didn't like the drinking so I got into the habit of secret drinking, mostly vodka. It became a little game for me so that when the wife went out at night I went to find my little stash.

However, my wife knew I was drinking and it just became worse and worse so, when I was on crutches, I went to Alcoholics Anonymous, a drugs and rehabilitation place. I also went to see a psychologist, but this didn't really help all too much. It was really up to the person, you need to do it yourself. In time, my friends around me helped me and things were looking good.

The start of cancer

Then I got incontinence, getting up three or four times during the night to do a wee. This started about two years later and the doctor said I needed a 'bore out' so I had to go to hospital and get that done. In the meantime I was having x-rays and also getting my PSA checked and it was noticed had it gone up to about 7.5. So the doctor said, "This is not right", so he sent me back to see the specialist oncologist. So he checked me out with tests, scans and biopsies and eventually said that I had prostate cancer. He suggested that I had better come back to talk to him about it. His telling me that I had it didn't really bother me, to be honest. I wasn't perturbed mentally, I just went back home to my wife and told her that I had prostate cancer but at the moment it was not serious; it was localised and confined within the prostate gland. It hadn't got into the bone or into any of the organs. I decided to get the treatment.

So when I spoke to be specialist again he asked me what I wanted to do – did I want to have it out, did I want to have radiation therapy, or did I want to just leave it. There is no way I was going to leave it and do nothing because you go to bed at night just worrying and thinking about it. So what I did was to put myself in the hands of the doctors. I also went

and looked to see what the reason was for prostate cancer – why people get it. There are many reasons such as vitamin deficiency, and obviously alcohol, things like diets, and there is a greater risk of you getting prostate cancer if it has been in your family. So I started looking into it deeply. Particularly, I looked at my diet and started to reduce everything in the diet that I thought might have contributed to it. I also started taking ‘blood-fruit’ capsules that come from America, to see if these might be helpful and I found out that it was good for cancer as well as your skin. So I started taking the capsules. That was good.

Positive action

I had already stopped drinking alcohol. I was clear for a year, but then had a binge one night, then realised how stupid I was and stopped again. It’s now been two years since I’ve drunk any alcohol. I don’t even do it socially any more. Friends came round last night and they had some but I just had some chocolate. I took all these alternative medicines and felt that that was good. I took these while I also had the 40 sessions of radiation.

I went every day on the cancer bus for radiation. At the end of this they checked and found that the PSA had come right down to 1.5. Then I went again and again and it came down to below that. This was great. I attributed this to the radiation and also my lifestyle. I had altered the lifestyle – the drink had gone out, all the fatty stuff had gone, a lot of the dairy went out and this helped me so much. While this was going on I was still taking painkillers for my leg. The leg was a mess and it still is. They were almost at the point of taking my foot off; but they didn’t.

Unfortunately, with all this I got hooked on codeine. I can tell you now that I took over 40 codeine tablets within a couple of weeks and I kept wanting more; they gave me a lift. This might have seemed a good thing at the time but it can be a bad thing at any time, as much for the prostate as well. It’s so easy to become addicted. Now I’ve cut my tablets right down. Just every now and again I need some tablets for the pain. You have to be careful that you don’t just go to the chemist to get some tablets

just for the buzz. I have some other variations in my life – I live by the sea, I love my family, I fish and tomorrow we're going away for a few days and that's all good.

The good, and the not-so-good

My PSA has now come down to .55 and I go to see the specialist every six months for a check. He is really, really good. He is interested in me and has asked for example how I am sexually. I've been married 47 years to my wife. We have four children although we lost one, and we have six grandchildren – everything is going fine. We were married when we were 16 and 17 and we've been sexually good all our lives, just what a couple needs, but all that went after the prostate. I will let the specialist know anything, I have no skeletons in the cupboard and I told him I have problems with erections and just everything is gone out of the sexual life. Now that I'm older I don't have the needs of a younger person, but sex does help your marriage. To me as a man, that's a major thing. I've always been highly sexually active since I was very young, and now what I find it is that with the leg and the prostate, sexually things have gone a bit crazy. I have a lovely wife who is very active and obviously she has needs as well, so this has been a major thing.

Of all the prostate problems I've had, it is the sexual thing that has let me down at the age of 65. You see, I am the sort of person who needs a hug. I'm a warm person, just like my mother but my wife is not, she is just the opposite but she still has needs, you know, so this has been a major problem. My specialist said to me, "Well you're 65, what do you expect"? But I said, "I didn't expect this". I have a terrible time with this in the head. I see lovely women going by, I look at legs ... but I never go any further. I have a terrible time in my head. I pray about it; I ask God to clean my heart and my mind continually.

"My beliefs help"

The positive attitude that I have, and my lift, is basically through my beliefs, and my faith. I can talk to you now easily, but I know I can talk

to God always and in a way that He listens. He is never far from us. There is no doubt about it; my beliefs help me a lot. I also have a very good family. One of the three children lives not far from me. We are very, very close and even the things we are talking about now I can talk over with them. We are a very open family as well. I don't hold anything back. I know that the world system that we live in now is going to deteriorate, but my hope is that there will be a kingdom in heaven that will rule over the earth and there will be a resurrection. That's when I will see my daughter again.

A lift kicking a problem

My drink was a massive thing that brought my prostate on. I really think this. I really felt the lift when I was able to kick the drinking problem; it was fantastic. When I really think about it, I know I can lift my arm and really pat myself on the back because I am happy. There is a real sense of achievement in kicking the habit. I am 65 now and I have a lot of back pain, the trauma of the leg is still there and is affecting me still, all of the nerves are gone in the leg – I have no feeling there.

I get depressed some days, and I am under a psychologist at the moment, and also a psychiatrist. (I was on antidepressants.) I can't always focus on one thing; I can be thinking of three or four things at once but that's no good; I have to be more focused on one thing. Since I have had the prostate problem it seems to have got worse. This makes me feel very frustrated. Talking to my wife helps me to get out of the frustration, and also talking to friends.

Constant action

Being busy is another thing I do; for example, I do the leukaemia collections. That's great. I really enjoy that because I am doing something worthwhile. I come home, finalise the money and I think about all that could be achieved through that. I'm really excited about that. I am better being busy.

Idle hands are no good for me; I need to be busy because I have worked all my life eight hours and ten hours a day. I've worked, worked, worked, worked and worked. It is a problem that when I had my motorbike accident, then when I had the prostate problem, then the sexual malfunction, pain, all these things have meant that much of my life has had to be put to one side to try to cope with these other things. I just cannot accept these things. I always find it really difficult.

As well as the prostate cancer I also have skin cancers and I go every three months to the doctors to try to have some of these resolved. I just hope that that I can stay cancer clear.

Gareth

Changed plans

It started early in May 1996 when I went home from work. My wife and I were going to go out to the Club and I asked her to phone through for a taxi and I went to the toilet. I started urinating pure blood. So I told my wife that she should cancel the cab and we went to the doctor instead.

We were then referred to a specialist in a hospital. It took a week but they eventually found that I had a large cancer on the whole of the left kidney. They operated on me immediately; I was 8 to 9 hours on the operating table they told me. The surgeons said it was like scuba-diving working underwater because I was bleeding so much. They removed the kidney and, after a long time in intensive care I said to the doctor, "What happens now? Do I have radiation?" He told me that that wasn't going to take place because with kidney cancer they either get it or they don't. He said that there could be a cell floating around that could activate itself later on.

I got over the operation and it was actually eight years to the day that my right lung showed up with a black spot. (I was getting tests done every

six months. This involved chest x-rays and physical examinations.) They took a biopsy on the black spot and found that it was secondary kidney cancer. I was sent to a capital city immediately and the surgeons took quite a lot of the lung out. They sent me home again and I haven't had any recurrence since. It was very stressful all that time waiting for it to recur, particularly as I had another friend who had a similar operation and they didn't get it all and he died within about 9 months of the original operation. They told me that they didn't know whether there were any more cells there and it could reactivate but, touchwood, that hasn't happened.

Further tests

In September 2005, I was getting further tests done by the urologist who put the glove on and found in a digital rectal examination that I had a number of lumps in the prostate. I went for biopsies and the doctors took seven samples, five of which came back positive. They did further tests and they maintained that the PSA reading was 9.2 and the prostate was the size of an orange. It was too large to do anything with it straight away so they had to shrink it and they put me onto a tablet called Androcur which I had for three months. It was the worst three months of my life. The side-effects were absolutely horrendous. They told me what would happen that the body stops making testosterone which the cancer feeds on and I would go through what women go through at menopause. They weren't wrong!

Radiation

However, it worked and it shrunk the prostate to the size of a walnut and then in January 2006 I started radiation therapy in a capital city. I think we had to go there every afternoon from Monday to Friday in one week and then Monday to Thursday in the next week. I had 37 treatments that took nearly 2 months. I went through the radiation pretty well. There were over 100 blokes per day going through and I got to know a lot of them and I wouldn't see some of them for a week. They said that they were suffering bad burns around the crutch and the anus. I went right

through it without any trouble. However, within a fortnight after I had finished it hit me. I had blisters on burns around the crutch and the anus. It was bad enough until we cleared it up with ointments. I still have the prostate; they wouldn't take it out. I get PSA done every six months and I have the physical examinations. Currently my reading is 0.5. It did come up to about 1.5 at one point and I asked the doctors what happens and they said that they wouldn't do anything but if it got to 2, they would know that the radiation hadn't worked and they would see what could be done after that, if anything. Fortunately it has not got to 2 and I'm still sitting around with 0.5.

Being positive

As far as my attitude was concerned, when I had my diagnosis I had to think positive; "I'm going to beat the bastard," as they say. This is the attitude I take if I'm going to be able to cope with it every day. On top of that, I was told at that time in 2006 about a herbal tea called Sir Jason Winters Products which is a mixture of various herbs. His books and products are very interesting. I've been taking this.

Possible cause?

Talking about stress and that, I was living in a small country town for a number of years and came to the larger city centre a few years ago. In the country town they started growing cotton. I was also a heavy smoker but I still blame the cotton spray for a lot of my problems. I am 71 now. My wife, who is the same age as me, has also had problems with cancer.

I got out of the house!

I've had some very difficult times and I had considered retiring about eight or nine years ago. I stopped work for a while but really, all I was doing was sitting around thinking and moping about it all the time. So I made a decision to get out of the house and I went back to work again. I will retire when I drop. If I went home I would be doing nothing. I can't play any sport because of the previous surgery associated with kidney

cancer – it still hurts, even when I get in and out of the car. I am active in the garden; I make sure I keep myself active to get my mind off it all. The only other things I do beside work is to have a couple of drinks at night but if I retired, I think I'd be starting to drink too early in the day. That's another reason I have continued to work.

My family – all the support I need

The only support I have is my family, but that is all I need. I see my GP and I see the other specialists, and I see the urologist every six months. I'm a bloody crock, but about three years ago I was having trouble walking with breathing and pains in the chest so I went to the doctor, then went to the hospital and had an angiogram. They found I had three blockages in the heart. The surgeon was able to put stents in three arteries but he couldn't get to the one at the back of the heart. He told me to comeback if it annoyed me but I haven't been back because it doesn't really annoy me. From the time they put the stents in, my pain went.

Get on with life

I have three sons; if I need anything done they will come home and do it. I don't talk to them about the illness. They knew what happened. I don't bring it up or talk about it to anyone really. Why talk about it when you're only going to get bloody concerned about yourself? Think positively – that's the attitude I take. You've got a get on with life. I have a little spot in the middle of forehead just above the eyes and if problems occur I just press that and say, "Get on with life, you mad bugger".

My wife has been very supportive; she has always been concerned. I am really more concerned about her than I am about myself because she's had both breasts removed. At the same time, she seems to be more concerned about me than she is about herself! That's human nature.

Vernon

Frequent checks – then the shock

I have been fortunate that I have had to go to the Doctor very frequently since I was 22 because of high blood pressure. I recall that I commenced having PSA tests at about the age 50 and they appeared to be normal until November 2011 when I had my regular PSA test. I did not even ring up to get the result but I received an advice from my doctor saying, “You'd better come back and see me”. My GP indicated that there had been a concerning change in my PSA since my last blood test. It actually went from 4.4 to 5.6 and this was considered a high velocity change so I was referred to a specialist and I saw him also in November. I ended up having a biopsy in February 2012. When I went back to the specialist accompanied by my wife, I was told that I had localised prostate cancer, a Gleason score of 6, Stage T1c. I remember the day fairly well. We were shocked by the news. We came home and my brother had just arrived and I told him, and I also had phone calls from each of my children. I told them that I had been diagnosed with cancer.

Once the initial shock had subsided, I don't believe I had great anxiety. It was only localised so we looked at it as though we had time on our side. I joined the local prostate support group. The first meeting I went to was in March. I was fortunate that as soon as I walked in the door I saw sitting at a table a gentleman and his wife that I knew. Until then I did not know that he had prostate cancer and that he had been through treatment. So I felt very comfortable joining the group. That allayed some of my anxiety I guess. I've been a member of the group ever since. In March, as a result of the Cancer diagnosis, I submitted a claim and received proceeds from a trauma insurance that I had in place.

Exploring the treatment options

I explored the options that I could take, and realised that I could have surgery. I was probably influenced by discussions I had within that

group, where I considered that the best place for this cancer was out of my body, otherwise it was only going to get worse. I decided that I wanted to have robotic assisted surgery. I had some problems with my health fund in that it didn't support entirely what I wanted, and after some heated email exchanges I changed to a new health fund. I ended up having the surgery in October 2012. It was not intolerable financial stress, even though the surgery was costly. I was covered by health-insurance generally but, in addition, I had some funds from the trauma insurance payment.

Pre-surgery I had a telephone consultation with the surgeon and he indicated that I would probably be in the hospital for about two nights. (This was going to be in a capital city at some distance from my home.) So I told him I wanted to stay an extra night as the surgery was scheduled for early afternoon. It was a Wednesday. I had a couple of small problems in the hospital after the surgery. One of these was that I was probably taking too much morphine for the pain and ended up getting a racing heartbeat. I had a bit of an anxious time there. While the nursing staff came into address this issue, the cannula came out of my arm and I had to get them to fix that up. This also caused me some anxiety. Post-surgery, on the Friday I had severe pain in the ribs and I had trouble breathing. I ended up having an x-ray but nothing untoward showed up. This all happened in the extra night I had asked the doctor to give me in hospital. I'm pleased I had this otherwise the problems would have occurred whilst I was at home.

On the Saturday morning my surgeon phoned and advised me of the post-operative pathology results. He said "his gut churned" when he read that the Gleason Score was 9, Stage, pT2c. (The cancer was more aggressive than originally diagnosed). This eventual different diagnosis occurred because the more aggressive cancer was located in a part of the prostate that wasn't able to be accessed during the biopsy.

Difficulties, but lifts

During this time of difficulty, I had a real lift from my children, all of whom had studied a health science. One of my children returned to further study and was able to give me some additional support in interpretation of pathology reports and any further treatments.

I had to have the surgery in a capital city and stayed in some accommodation for the night before. I had a good night's sleep as I had little anxiety about having surgery. I realise that I was doing the right thing because I was addressing the problem.

I stayed in the accommodation for a week after the surgery while I had the catheter in. The catheter, of course, was uncomfortable. My family, including the grandchildren, visited me shortly after I had left the hospital. That, of course, gave me a great lift.

Side-effects

Side-effects virtually started straight away because as soon as you remove the catheter you realise you haven't got very much control of your bladder functions. When I left the capital city to make my way home, I was 'all dressed up' with disposable undies etc. But this didn't stop me from having the occasional leakage. When you look back at it now, you realise that was just part of it. I coped with the incontinence fairly well. Prior to my surgery I had some prostatitis, and in some ways the urgency associated with this was worse than the incontinence after the surgery. It was really uncomfortable to have to rush off to find a toilet sometimes.

I also had erectile dysfunction. Sometimes when we are considering prostate cancer and we realise that our prime concern is to get rid of the cancer, we neglect, subconsciously at least, that there are other problems associated with it. In my own mind this didn't worry me, but as men, we know we are not functioning as normal men do.

Wide-spread support

What helped me most in confronting these issues was the help and support of my wife, family and friends, and the support group has been beneficial. You hear the different stories and when you think of it you realise that you might have had a particular difficulty but there are others who are obviously worse off than you are.

I believe I am coping with life fairly well at present. I left the workforce in February 2011 due to stress in the workplace and a close family member being unwell. I made the decision to leave so I resigned. My wife and I decided that we would go on an extended vacation straightaway because if I went back into the workforce again I wouldn't have leave for some time. It was the month after we came back that I had a blood test and the chain of events started my prostate cancer journey.

Keeping active

I haven't been in the workforce since, so I have been able to focus on coping with the prostate cancer.

When I finished work I made a list of about 40 things I wanted to do and a couple of years later I'm working my way through that list and getting well down it. I've been able to do things like assisting to care for our grandchildren while our daughter works a couple of shifts each week. I enjoy this; there is no pressure associated with it.

"Around a bit longer!"

I hope to be around for quite a bit longer. Having said that, I'm still having my PSA tested and it has risen from about 0.02 in February 2013 to about 0.06 in February 2014. After discussion with my urologist it was decided that I would have radiation therapy. I had around about 33 treatments of this. I have another blood test in the next month and that will be an indicating factor of where I am at the moment. The side-effects from my radiation therapy were minimal. There was just a minor bladder

and bowel irritation. The hardest thing with the radiation therapy was to get the bladder fluid about the same every day.

Another thing that happened post radiation which I discussed with the radiation oncologist was that I did get the sensation of a 'prickly itch'. I explain to people that it was like the burst of sky rocket, or the skin of a pineapple. My GP said that this was probably because of reduced testosterone.

The other aspect of our journey is this that we have a religious faith and I get support from this, particularly through the patron saint for cancer, St Peregrine. (This is really a spiritual lift.)

Another lift

My involvement in the local prostate cancer support group is uplifting in that what little I know about prostate cancer still enables me to tell my own story to others which may help someone. Even if it's only one in a hundred who gets some benefit from what we say, it is worthwhile. I spoke last week to TOMNET and some questions came up that were very interesting. We make certain they know we're not medical people but they have often simple questions like, "What is the function of the prostate?"

As far as my relationship with my wife is concerned, I find I tend to get a little tense at times. She has been very understanding and supportive.

My wife and I have talked about the treatment process along the way but certainly have not at this stage dwelt on our feelings should the next blood test not be what we had hoped for. Every now and then I ponder about the ageing process with the added burden of prostate cancer and its treatments. Recently I found out that my physical strength for age is not what it should be so I need to commence an exercise program. This may help me cope with the side effects of any further treatment.

Ian

Cold turkey

In June 2002 I was diagnosed with prostate cancer. It was called a ‘cold turkey’ biopsy because there was no anaesthetic. It wasn’t really bad; all I got was a little bit of pain pressure. Nine places in the prostate were tested. I didn’t mind having it without anaesthetic but quite a few people said there is no way they would do theirs without it! There was evidence of the cancer but the doctor told me he thought he would get it.

A shock

Going back to the beginning, when it first started I didn’t have any real symptoms but I noticed the waterworks were getting a bit strange. I saw the family doctor and he did a few digital rectal things because I was chronically constipated. So over the years I’d had a few DRE’s for constipation and compacting and stuff like that, but I had no PSA testing. I went to a men’s tune-up at the RSL one time. They were talking about PSA at this tune-up so I went to a doctor and ask him if I could have a PSA test. He said that he didn’t think there was a reason not to have one because I was having cholesterol problems and stuff like that. So he did the DRE and he said that feels fine and also sent me for a PSA test along with the cholesterol and all the others. It came back that the PSA was 10.9. At that time I was 67. He said he had seen higher readings and it had been nothing, and that he had found lower that had been something so he said he would send me to a urologist.

So I went to see the urologist for the biopsy and it came up with the Gleason score of 7, 4+3. He rang me up that night at about 6:30 and told me that I had cancer. He was a lovely doctor who I trust a lot; he’s got a good bedside manner and he would do anything for you. So he said, “You’ve got cancer,” and that he would like to see me to talk over the options. That shocked me. But I said to myself, “What can you do; if you got it, you’ve got it!” So I went to him and he told me I had four choices

and he gave me the phone number of a prostate cancer support group coordinator in a nearby town because I wanted someone to talk to about it. There was not one in the town in which I lived and I was a bit shocked about that.

I found there was a cancer support group in my town, it was mainly for leukaemia and breast cancer and there was only mainly women there. One of the ladies there had a father who had prostate cancer but that's as close as I got to someone who could talk to me about it. So I rang the prostate cancer support group coordinator in another town. He settled me down quite a bit. What he did was to put me onto some of the back numbers of the Prostate Cancer Newsletter so I read all of that.

Open surgery

I had my diagnosis in June 2002 and I was operated on in August that year. I got out the night before my 68th birthday. I had open surgery. There was no nerve sparing because of the closeness of things. I wanted it out. I did all the bone scans as well because the urologist said that if it got to the bones than it was no point in operating. They found something on the bones but they were not sure. They said it was most likely Paget's disease but they were not sure at all. So he wanted an MRI. So I went and had the MRI but they lost the other x-rays that I had taken down to them so when the MRI came back they said there are no other x-rays to compare it with. They said it is probably Paget's. I think the prostate cancer is pretty well controlled now because all of the tests are coming back good; the PSA is staying pretty level now.

Considerable stress

When they discharged me from hospital, they discharged me with the paper hospital pants I had on. They had taken the catheter out because the doctor wanted this to happen before they let me out of hospital. With only the paper pants on I really flooded and my wife had to pull up on the way home and get some pads from the chemist. Next morning I rang the HACCs nurse and she came around and put me on the list for pads. I

was going through five pads a day and wetting everything besides. She gave me some pads to try out and then went on holidays for a fortnight. When she came back I had to try to find out from her where I was on the list because nothing had come yet. It was around about 15 months before I got onto the pad list!

I had bad stress with this; I still have a little bit of incontinence but I'm handling it. It is just that you get a wet pad and it stinks. I cope with that by saying it could have been worse; I would have had the operation again if I had to go back. I'm not sorry that I had it.

Stress – with satisfaction

A lot of my stress now is because I tried to set up a prostate cancer support group. This has been my life for 10 years now; that's what keeps me going. I want to give service to the region in which I live to the other guys that are here. I'm getting pretty close to that, I hope. That is the hope that is driving me but my wife is thoroughly sick of it because, "You're over it," she said, and I should just get on with life; but I can't. While I'm doing this it drags me away from home a lot and I'm letting other things float. There is no sex at all; there's nothing there; I've tried a few times and I've been to specialists, the erectile dysfunction doctor and things like that, but it doesn't seem to make much difference. My wife really wouldn't care if I never have sex. But it is a big thing for me because I really miss it. That's probably most of the problem; I used to have 'it' but I don't have 'it' now. It's a common story and I am trying to get something done about this for the guys in our local area. You've got to go to a major city for just about everything. Where I live is not too far away – it's classed as semi-rural, but just not close enough for people to go and get support when they need it.

This local area support group received a grant to get the group going and I only hope it continues to grow. It keeps me going because I don't want it to collapse. It's a sore point with my wife but, at the same time, she helps with the distribution of newsletters and things. I'm not computer

literate I have big fights with it (the computer). It won't do what I want it to do!

Hope for continuation of local support

My hope for the future is that more services will come into this region. We now have access to an advanced prostate cancer support group in the area. My goal is that if we can get around the incontinence and the erectile dysfunction problems it could well be that we can get younger blokes to come along and get diagnosed before it gets away from them. I have three sons too so I would like the group to be there for their support if they need it. That's my goal. I had a problem with benign prostate enlargement about 15 years prior to my prostatectomy and because I had the TURP 'rebore' for that there was a problem with reconnecting of the urethra to the bladder neck. The surgeon had to repair the 'funnelling out' of the bladder neck before reconnecting the urethra. That's what I blame for my incontinence being so severe.

A real lift

Once I'm working with the prostate cancer support group I get a real lift when things go well but mainly when people say, "Thank you for the work you're doing". When they have indicated that they have been helped by what I have been doing, that gives you a real lift. When things go well during my life relating to the prostate cancer, that gives me a lift as well. We have good meetings of the prostate cancer group and things like that. I do a lot of mechanical work at home now on cars and, if it works, it works, if it doesn't it doesn't. I can't do much about it. This has been my attitude over my life. I'm 80 in a couple of months' time.

I was incontinent for six years. A speaker came to address the incontinence support and reference group with which I had become involved soon after my operation. So after six years I had a sling fitted. It took me a while to make this decision because I didn't want to go under the anaesthetic again because the anaesthetic before played up a lot with me. But, I had the surgery and coming out of hospital and getting

over the main hurdle of incontinence was a real lift. Getting more services in the regional town will be getting my goal fulfilled.

Being useful

One of my greatest problems is probably my wife and her attitude. Put it this way, there is no feedback between us. She said, “You’ve done all that that with the support group just let them do it for themselves now”. The worst part is like trying to juggle between her and the work I do. We’ve been married for over 50 years and I just can’t make her see that this is really what’s keeping me going. Being useful is the thing that makes me happiest most. It is so important that men speak up about what they’re doing and what they are going through so they can be mutually supportive.

Tim

I’m not feeling too bad at the moment. I’m still working but am going to retire in December. I’ve had more than enough so I have to draw the line somewhere. I’ve worked for nearly 50 years – more than enough, I think. You’ve got to stay in touch with reality and I think that these days a lot of people just look at the dollars, or whatever, and forget about their own health situation and, at the end of the day, they can end up worse off than if they retired.

How did it start?

My story started with a dose of shingles which I had never had before in my life. That knocked me about quite a lot. It was very close to my eye and the doctors told me to get straight to the emergency department of the hospital. This rattled my cage and caused considerable stress. After several weeks of tablets, I was able to get the shingles under control. Once that was cleared up, the doctor told me that I was due for a PSA test. So I had that done and it had gone from 3 to 6. On reflection, I could

be wrong, but I always seemed to think that my immune system took a dive when I got shingles and knocked me around. That might have been a trigger for the prostate to become active. I might be surmising here but I felt that was my best shot that what I think happened.

Once the doctor had determined that the PSA had risen quite a lot, he didn't give me a choice but told me to go to see the specialist. A lot of guys I've spoken to had many choices before they went any further. They've had the chance to go to support groups before they took any action and find out all about it. I didn't have anything; I was just told by the local doctor – prostate cancer, which is a hell of a shock when they write that on your referral, to say the least. In May 2009 I had a radical open prostatectomy by a specialist. I was off work for four weeks; that's all the leave I had.

Stress and no support at work

My work at that stage was probably pretty stressful, and I didn't get much support from the people at work at all. This really didn't help matters. So I had the surgery and the specialist, being as specialists are, was very careful in what he said. All he said was that the cancer had been contained.

He did mention the word 'nerve-sparing' but I don't know how much of this went on. I am improving now; this is been for five years since I had it done. I am 66 now.

Once I had gone back to work, I had periods of stress and depression. I was working in a job assembling photocopiers where the management were far from friendly in terms of understanding or providing any support. I did not get any support from the company whatsoever and this was a disappointment to me. However, I battled through the periods of depression. For about 6 to 12 months after my surgery, when I was back at work, there were a lot of times that little things would upset me very easily. A young guy I worked with would often say to me, "What's the matter"? He didn't understand that this was something that was part and

parcel of having prostate cancer. I've had no further treatment since my surgery.

The PSA went down to .01, or something like that, and after five years it has gone up to .07. It had gone up slowly over five years. The local doctor said that if I needed to have any further treatment it would be hormone therapy that he would suggest. I'm getting the PSA level checked every six months now for my own benefit.

"An absolute saviour!"

I have to say that while I was in my depression, my wife was an absolute saviour. She has helped me a lot; I would be lost without her. I just had to work my way through things as they came along. I am now through the worst of the depression. I try to keep busy and do what I can. I found a lot of times that after a week at work, I would go home absolutely bugged through the pressure of work that was dumped on me, and the fact that I'm not getting any younger, and summer time gets pretty hot. All these things make some weeks very tiring and exhausting. Sometimes I would get home to my wife and she would ask me how I was and I would say, "I'm bugged". Then I spent the weekend recovering and getting ready to go back to work on Monday!

Anyway that's in the past. I seem to be coming through the other side now. I keep myself busy and I have volunteered to coordinate one of the prostate cancer support groups in our State. It's only a very small group but it has been going now for two years. It gives an opportunity for people to come along and talk about their own issues, and whether they need to have treatment and things like the side-effects.

Side-effect

As far as side-effects are concerned, I had the usual erectile dysfunction but I didn't go for penile injections. When the specialist mentioned that this would be a possibility I said, "No, no, forget that". I couldn't handle the thought of having an injection. So I didn't go down that road. He gave me one or two tablets such as Viagra or Cialis. He suggested I try

these but when I found out how expensive they were, I wasn't in a position to spend hundreds of dollars willy-nilly on something that may not work. So I was a little bit apprehensive and probably slow in getting things moving that way. Eventually I ventured into purchasing a couple of vacuum pumps which I have used on and off over the years and I found them to be of some benefit in getting the blood flowing. Basically, it's an exercise regime and this seems to have been some benefit. I don't use them as much as is recommended, which is one a day or once every couple of days to get things working properly. I used to use them couple of times a week so I did feel there was some purpose and benefit in using the vacuum pump. It's really a case of feeling in the mood, and how fit you are. I'm probably a little bit overweight due to natural causes and my fitness is probably right down even though I'm doing a physical job at work. Once I retire in December, I have planned to start using my pushbike and do some regular things.

I did not have any problems with incontinence. The specialist told me to see a physiotherapist and I had one session with him. He gave me things to do which I practised and they worked. I realise some people have significant problems but I really didn't have any, except for 2, 3, 4 weeks maximum when, for example, I sneezed badly or did some sudden movement like getting up out of a chair quickly, or something like that. In the early days it might have caused a leak, but nothing major. The only other problems I had were the headaches associated with Viagra. I do have some Cialis tablets, low dose, but I need to get into a routine and monitor how things go.

Strong support

Having a partner-wife, or having somebody who understands and supports you, can help quite a lot during the journey. This is worth about \$1 million. I was lucky that my wife was with me every step of the way. She goes to the support groups with me; she helps me endlessly. I would say this is the biggest lift that I could have ever had. If I had been on my own it would have been 100 times harder because I would not have had

someone to prompt me, push me and point me in the right direction. It can be very easy to fall into deep depression if you haven't got anyone who can understand you, or understand what you've been going through. I was very lucky to have someone who gave me a lot of support.

The future

I have a good plan for the future when I retire. I'm going to tell the company what to do with their job – good and proper! I got no support from them whatsoever. We are going to do some extensive travel before I get old and decrepit. I have some hobbies I will do. My wife is from the northern hemisphere, and were going to go and visit there sometime next year and have a holiday. For me, the whole purpose of working is so that you can have some enjoyment in your retirement. That's what I want to do. I don't want to keep working as a lot of people do. They see the dollar signs and they get a fixation with 'the more money the merrier'. But if your health takes a dive, the money is not going to do you any good at all. The thing to do is to pull the pin at the right time so that you have time to have some enjoyment and have some life after you have been working all your life. My wife and I both enjoy each other very much; I've got two sons and they are both financially well-off in terms of their lifestyle and good jobs. So what little money I managed to save all my life is for us to use, and we will use it for our enjoyment.

Giving something back

I will keep on doing the support group work for the Prostate Cancer Foundation of Australia (PCFA) as long as I can. That's my way of giving something back for something I have gained from my going to support group meetings. I see this as a positive return for the help I received. I went to another prostate support group for three years, and I listened and learned a lot from that, and met a lot of people. When the opportunity came for me to work with the support group closer to where I live, it meant I could still stay in touch with PCFA and not have to travel 40 km every month that I went to a support group meeting. This

is my way of contributing a little to help those who may have to go through the same sort of journey I have gone through.

One other thing which is worth noting is that not a lot of information is given about what happens to the size of the penis after a radical prostatectomy. It ends up being considerably shorter and this can be something which causes concern for men. This happens because the removal of the prostate can shorten the shaft. It is not something that doctors want to talk about too much because they are more concerned with getting rid of the cancer. It is something men may find worthwhile talking to their doctor about in some detail if they can.

Talk about it!

The more you can talk about these kinds of situations and the more information you can receive, the more it can make your living a little bit more bearable during the stressful times. Sometimes men don't want to talk about the issues but it can certainly help them if they do.

Trevor

I was diagnosed in August 2012 as a consequence of my PSA being at a level it shouldn't be. I then went through the usual routine of a biopsy which proved positive and then, on Melbourne Cup Day in November 2012, I had the prostate removed. This was carried out by robotic assisted surgery.

Coping with the side-effects

I realise that the two most important side-effects that most people experience are incontinence and erectile dysfunction. I was more worried about the incontinence than the other. Fortunately with this I had no leakage at all, except in the most minor sense for a few months. I did a fair amount of pelvic floor exercises in the month between the

diagnosis and the surgery, and I think this helped me a lot. I continued with this after the operation and then got a bit bored with it after a while and thought, “I’m not doing any more of this”, but it all sorted itself out soon after anyway.

With respect to impotence, I came back to more or less where I was before the surgery after about 18 months. This was about 10% of where I was when I was 18, but I thought, “What the heck; this is probably just old age anyway”. (I’m 64 now.) To help with the impotence problem, I have worked with a men’s health doctor and he met me every couple of months or so from the first year and he checked to see that things seemed to be working okay. I was encouraged to have two strong erections a week and as long as I was doing that all was well. That was more less it.

‘A day at a time’

Apart from the initial shock, I think I moved through the downtime fairly quickly. The diagnosis indicated that the likelihood of the cancer spreading elsewhere at the time was very low and this was confirmed after the tests and surgery. My PSA tests since have all been zero; so this was all pretty good. What was important to me was that by nature I am a ‘cup half-full’ person. Initially, after diagnosis, I was a bit freaked out. However, I moved fairly quickly into a two-step process which was really, “I’ll just take this as a day at a time”, and the second thing was the practice of acceptance. I just said to myself, “Well I’m just going to accept this, work through it a day at a time and take it as it comes”. The consequence of that kind of practice of acceptance, together with taking things a day at time, was that I was able to keep myself emotionally pretty level.

I think the other thing was, I refused to have any of the rhetoric, except in an ironical sense, where my friends were trying to take the Mickey to me. I refused to get into the, “I’m battling with cancer,” or, “I am fighting cancer,” rhetoric. Before I was even diagnosed with cancer I refused to have anything to do with any of the “I’m fighting cancer” rhetoric which others used to say. I almost adopted a kind of Buddhist approach to the

whole thing which was simply ‘a day at a time’ acceptance. I was trying to distance myself away from it in the sense that “this is not me battling cancer”, but, “this is just me”, with something going on in my body which is not very nice and which none of us want. So it wasn’t me just fighting this alien creature that had come from outside to invade me; it was just me.

I mentioned the Buddhist approach because of my background. My area of expertise is in comparative religions so I’ve done a lot of work in Buddhism and mysticism. I have a lot of background in spirituality generally, but I’m not a religious believer. So I have a lot of background in this area of spirituality and associated notions of acceptance and a day at a time.

I kept my hope level too, in the sense that I am a glass half-full optimist, so I think I was more dominated by the necessity of taking it as it comes, rather than driving myself through the context of hope. Although when you are an optimistic person it is ‘hope’ with a small ‘h’.

I do tend to take life generally a day at a time but, of course, I recognise that none of us can just do this absolutely, we do have to plan two years ahead in some ways. I try to spin off that Biblical saying that ‘today’s own troubles are sufficient to themselves’; I don’t get too anxious about the future. For example, when things start coming up that I could get anxious about, I tend to ignore them until the very last minute and then deal with them as they come. I think this happened at the start of my prostate cancer journey and it has worked pretty well.

Moving on

As far as tests are concerned, I have my six monthly PSA tests. After 12 months the men’s health doctor said, “You’re okay; off you go”. In a sense, when I come up to the six monthly checks and tests, I guess I do get anxious for a day or so beforehand, but when it comes I just say, “Okay, blood test, go to your doctor, hope its zero, thus far so good; move on”.

My managing prostate issues ‘spiritually’ takes place in an atheist context. That is, I am not a believer in God (nor in any transcendent realities, for that matter). Comfort to the believer who wonders why God has allowed this to happen to him, may be provided by ‘It’s the will of God’. That is, it’s a form of theistic acceptance. Comfort to the non-believer who wonders why this has happened to him, may be provided by ‘well, why shouldn’t it?’ That is, it’s a form of atheistic acceptance. The emotional mode of acceptance is probably much the same in either case.

I’m very fortunate to have a very sympathetic partner; she’s been really good. I tend not to be a great communicator with other people about things at a deep level. I always tended to tuck most stuff away a fair bit. I tend to find that the more I talk about something the more worried I get about it. To be perfectly frank, I haven’t had a drink for 15 years; I had a drinking problem in the 1990s. I used to drink to manage stress but now I’ve managed to find other ways to managing stress without resorting to alcohol. Drink just did not work.

I try to do life without big swings in emotions; without big highs and lows. I try to manage life with just the ripples of ups and downs. I think this is coming out of a commitment to some kind of emotional equanimity.

Emotions

I didn’t feel the need for a great deal of support. This goes really to my general way of doing life which is to do it on your own. This probably goes back to the way I was brought up. I was brought up as an only child with significantly older parents than most kids, so I tended to do life without needing to rely too much on other people. If I have a self-criticism I can say that I probably tend to be too cold, and not sufficiently emotional.

My partner has been really supportive of me, and I think she knows me well enough to know that this is the way I do business and she is more

than happy with that. We have some gender nuance discussions; when I'm in extreme mode I say that emotions lead you away from the truth whereas she can tend to be more emotional in her reaction to things. This is just gender rhetoric! On balance I tend to think that, at a deeper level, emotions are things that aren't helpful to 'getting on'. Sometimes it can make you a sympathetic person where you really wouldn't want to be. Sometimes I can be driven by my emotions too much. However, controlled emotions can make you appear to be a little unfeeling.

Ben

No symptoms

I was first diagnosed six years ago when I was 56. Initially, I didn't have any symptoms. When I think about it now, down the track a bit, I was healthy and had a pretty normal life and I hadn't actually considered that I had prostate cancer; I had no pain or anything. I took the plunge like a lot of men do. I saw my GP one day and I said, "I am a bit of squib, but do you think that I should get a blood test for the PSA; I've never had one." So he said, "While you're here I'll do a physical examination." As a bloke you don't like that sort of thing but ... The doctor said that there didn't seem to be any swelling in the prostate. So I thought that's good, but I'll do blood tests. About a week later I did the blood tests and this was in 2008. He rang me up when he got the results back and he said that I'd better come back and see him.

So I went and saw him and he said that my PSA was high. But, I had no idea what that meant. He said that for somebody at my age it should be zero point something but nine was pretty high. So there were a few alarm bells there. So I felt, "Okay, great, okay"! I didn't panic but fortunately, I have some pretty good contacts, and my father is a retired cardiologist specialist, so we made an appointment fairly quickly to see a specialist urologist. We had a consultation with him and he gave me a physical at

the time as well. He said, “Yes, your prostate is swollen and I can feel that.” He was obviously a little bit more experienced than my GP at that sort of thing. He said he thought we should do some biopsies; so I went down that track.

I had to have some bone scans as well but these didn’t prove anything specifically, but I have a lot of white deposits on my ribs and various places which were concerning because they could be some signs of prostate cancer. They could have been old injuries too, because I’ve been around the bush for most of life and I’ve had a lot of falls off horses and bikes.

“Not particularly nice ...”

So I had a biopsy (this was all over the period of a month) and I think he took about 15 biopsies in the prostate. This was a pretty painless affair. You are sort of sedated, but the results came back pretty grim. Thirteen of the 15 biopsies were cancerous with the Gleason score being 9/10. So this is pretty nasty cancer. We went back to the specialist later for another consultation and he said that this was a cranky cancer version, not a particularly nice one, and that doing nothing was not an option. He told me this was one that could kill me.

We discussed the options of radiotherapy, various drugs and brachytherapy but in the end my specialist said that the best way to proceed was surgery. He was reasonably confident that the cancer had been encapsulated, that it hadn’t spread, but he told me that I was young and that this would be a good way to go; this was his recommendation.

Constant support

Gay was with me all the time. She had been with me at every appointment and this gave me a tremendous lift. This gives you a lift because, when one of you gets down, the other picks you up. You both don’t like to be there sobbing away, not that there was a lot of sobbing, but it was a rollercoaster ride. You can’t have the surgery for about six weeks after the biopsy to allow time for the prostate to settle down. There

was a fair amount of inflammation of course. I went in for the radical prostatectomy in mid-September 2008. There was no robotic surgery at that stage so I had the full Monty. I maintain that they gut you like a kangaroo. At least, it felt like it!

Anyway, the surgery went well. I did a lot of preparation for it. I had quite a few visits to professional nurses who specialise in men having prostatectomies. I never knew the importance of doing pelvic floor exercises before this. But I was very fit in those days, and I still am. I concentrate on my fitness and health and try not to be overweight but I said to Gay at the time that my one of my biggest fears with the surgery was that I might leak like the Titanic for the rest of my life. If I never have another erection I can live with that, but I don't want to be bloody peeing myself for the rest of my life. This was one of my biggest fears actually.

Some complications – two weeks in hospital

Anyway, the surgery went well. I was catheterised. Even though I was pretty fit, it knocked me around a bit. Day three wasn't a great day because the surgeon came back and informed me that he had to remove a few lymph glands at the time and that the cancer had spread. (I should say here that I'd asked him to tell me directly anything he had to rather than keep it from me.) It had moved out to some nerve bundles on the side of the prostate so we had to remove one whole nerve bundle from one side and a part nerve bundle from the other side. One of the lymph glands came back showing that it had cancer cells. I always knew that after day three of the surgery it was going to come back and revisit me at some stage. I ended up having two weeks in hospital. I'd had a pretty crook back after I'd fallen off a horse and broken the back when I was much younger so this didn't help the recovery process. So with this, and the lymph glands etc, it meant that I had more time in hospital that I had anticipated.

A slow recovery – and a lift

After surgery I came home and this was probably the lowest point. The surgery knocked me around much more than I thought actually. I did some exercises while I was in hospital but I was pretty ginger about it. I used to get very tired and it took me three months to fully recover. I had the catheter out before I left hospital and when I came home, I started my pelvic floor exercises straightaway. I was very lucky in that, probably for a month, I only had a little bit of leakage here and there. I thought that having such a small amount was pretty good.

It was probably on a couple of occasions that I woke up in the night after having gone to bed and felt rather damp. When you're a grown man and you haven't peed yourself since you were a baby, it makes you feel pretty bad. It was one of the worst times. I could put up with the pain but not that. This was pretty depressing. Gay was there always and this helped so much. She said, "I don't care if you pee yourself every night, I'll be there to help you". Having someone there to love and support you and accept what you are going through is just so good. I don't know how someone would go through all of this by themselves. It would be very tough. I got through the rehabilitation; it took about three months to get back to pretty good health but I was very ginger for a long time. If you weren't very fit I reckon it would knock you around quite a bit. The robotic surgery available now doesn't seem to cause so much trouble.

It's nearly six years since I've had the surgery. I've been having regular, sometimes two times a year, bone scans, CT scans and PSA tests. After the surgery my PSA went down from 11 to 0.04. That was pretty low. It was great. Unfortunately, my PSA started to rise again not long after the surgery.

Within 12 months it was nearly one and it has sort of been doubling over the last six years. Twelve months ago it was six. Currently is just over nine. It has gone from six to 9.2 in 12 months. My specialist said it was probably to be expected that was going to happen. He said that you just have to keep on keeping fit and doing as well as you can. He has always

said that when your PSA gets up to around 10, that's when your alarm bells go off, that's when we have to start discussing further treatment with an oncologist.

Secondary cancer

The other thing was that my last bone scan came up with the identification of a site that wasn't on the previous scan. So it was definitely identified as a secondary cancer in my pelvic bone. So this is a bit of a worry. He suggested I go and see a specialist oncologist, which I have done, and he confirmed that the site that was identified in the scan on my pelvic bone was definitely a secondary from the prostate cancer. He said he didn't think that specific site would be producing a PSA at 9.2.

He said that there were new MRI scans out with better technology and that I ought to get one done. I did this about a month ago and the MRI proved that there was another site as well so I have a couple of sites now that have been identified. So these confirm that there has been metastasis. They also picked up a mass, a tumour about the size of a matchbox (26 mm long, 36 mm high). It was in the vicinity of where my prostate was so both specialists have clearly identified that it was a secondary of the prostate cancer.

An emotional ride – and real lifts

I've been pretty good emotionally since I've been told that the cancer has come back again. I did go through a tough couple of two weeks, but Gay and I are very close; we've been married 28 years.

When the Doctor told us that I had a tumour as well as the other sites, I took that pretty hard. I didn't burst into tears; Gay did, she was pretty emotional about it. We went and had a coffee and I looked at her and asked her if I could say it! I just used the f... word to her, and I said we have a few problems. It was pretty emotional. It was emotional just knowing that I had the cancer in the bones. I suppose I expected that, but to have a tumour as well that was growing that wasn't picked up until

two or three months ago... The doctors said it was probably there but tumours can grow pretty quickly.

So about a month ago we started talking to friends on the phone and I got to stage where I couldn't talk, I got pretty emotional and had to say, "Hang on a minute mate, I'm having a girly moment here," and just had to hold my breath, get myself together after two or three seconds, and move on. That happened quite regularly for about two weeks.

What helped me through this and gave me a lift frequently, was the support I was getting, particularly from Gay and my friends. All of them said, "Look mate, if it was me I'd be a bloody gibbering mess. I don't know how you are keeping so positive". (I've had friends crying with me.) I'm a very positive person. I've probably got that from my father who was a survivor of Changi. He had a tough life there during World War II. He is a very tough cookie. I just don't lie down and do nothing. I think I'm a good patient to. When I'm crook I don't whinge and carry on and fuss around. I suppose it is just a mental attitude. I had friends and people like Gay saying, "If you want to cry, that's fine; you've got every right to." Others said, "If it were me, I would be worse and would be blubbing for a week or two". But I haven't had that because so many friends have come up and wished me well. I even had a boss ring me up the other day and said, "I'm coming up to see you. Maybe we can have lunch and sit down and have a chat". I'm pretty lucky as I have some really good, genuine friends. I classify a genuine friend as someone who I can trust with my life, my wife and my money. I've got at least a list of 10 people like that who have been in regular contact with me over the last month.

I have two brothers and a sister. One of my brothers is older and he's had prostate cancer as well. He still has a few ongoing issues but he hasn't had the issues like I've had. He went through radiotherapy for seven weeks so it's been good to be able to bounce stuff off him. But he hasn't had any sites identified like me with respect to the bone and the tumour. I've had nephews ring me up as well; they've been extremely supportive and have also given a space when I needed space. I show my emotions

whereas Gay bottles it up. She says, “I just really want to cry about something but I just can’t”. I can’t say that I cry at the drop of a hat or for whatever reason, but I get emotional and I can get teary in a movie but, what the heck, it’s a good movie.

Reality

But in this situation I was looking at death straight in the face. I asked the oncologist, “Look mate, what’s the forecast if I do nothing,” because I’ve often discussed this with Gay. That’s another big thing; I’m always talking about stuff with Gay. We don’t talk about it every day. We’ve been talking about this a lot in the last few weeks because it is ‘now’. I used to get pretty depressed 24 hours after a visit to the doctor because the doctor would tell me to come back in another 6 or 12 months but that I should keep on with what I am doing. That would get me down a bit but then you’d move on. But this time there was no moving on. This was real. The oncologist said, “I would give you two years if you don’t do anything”. Even so, it’s not like saying I will have a good quality of life over the next two years if I do nothing. With the tumour the way it is I could have all sorts of problems within one or two months.

Surgery wasn’t an option. I explored every option before I formalised the decision of how I would handle the situation. I was fortunate in that both the oncologist and the surgeon urologist made the same recommendations. So I started on the series of treatments with a new hormone drug. This is designed to reduce the size of the tumour for a start and then in about two months’ time I’ll be having more tests – blood tests and probably more MRI scans to identify how much the tumour has shrunk. Then I’ll probably start a course of six and seven weeks of further treatment. That’s to be decided by the oncologist here after discussions with his colleagues.

Sexual activity

Sex has been an extremely important part of my life. I’m a pretty virile male and, up until I had my prostate cancer surgery, it still was and, it

still is. I've been very lucky, even though half of my nerve bundles were damaged in the prostatectomy. It was probably six months before I was able to get aroused again, at least six months and possibly even 12, but I've found help through Viagra. I've tried Cialis but I find it makes me feel pretty bloody rotten for 24 hours; it works OK. The doctor said it was a matter of you picking which one might suit you best. I never did try the penile injections which Gay said we probably should, and from various descriptions, it's not as bad as it sounds.

Gay and I are able to talk about it very easily. She has been my biggest asset with helping me to rehabilitate that way. It's not secret squirrel business. Overall, any progress is a bonus; it's better than death. I'm very lucky. I haven't got full function back but I have enough. I read quite a lot about this before I had surgery and have spoken to a number of people about it. I have a good mate who I didn't even know he had prostate cancer but when I found out, and he knew I was having surgery, he rang me up and said, "Look you can have a yarn about it with me at any time". So I said, "Tell me all about it", so we had three or four phone conversations prior to my surgery.

It's all about communication and information and being able to talk about it. Having had the surgery, I'm absolutely comfortable about talking about it now. I was probably more reserved and shy talking about prior to my diagnosis, but now I've had the surgery ... I know with the drug I am now on I was told I would lose my libido I would be unable to maintain an erection. So you ask, how long am I going to be on this for? Well, for the rest of their life. You think, well whoops ... But then you think of the alternatives.

An active life

There are many things in my life that I still do such as watching the football, for example. It has only been for two weeks that I have started the chemo injections and so far nothing has changed, which is good.

I have a bit of nausea, which is a bit annoying, and I find if I drink alcohol, even if it's not much, I can feel pretty terrible with the head getting very hot. The nurse told me the other day when she was giving me the injections that I would probably want to cut out drinking tea, coffee and alcohol and I thought, with sex going as well, "Oh great!"

I'm going to survive

I'm looking at the short-term future at the moment. I know I'm going to survive; I'm very positive. If I wasn't going to have any treatment I know I would not survive. At the moment I am not going back to work. I have an extremely good relationship with work so I could have taken a voluntary redundancy now because of my ill health. When I say ill-health, I don't feel ill even though I'm getting side-effects. I've been in a very stressful job for quite a while because it takes me away for 10 days and back for four. I've been doing this for 5½ years. It is one of those jobs you've got to do. You take a lot home, you've got the phone with you all the time and you always get emails coming in. You can't do that job at 75% of your capacity. You've got to be full-on. As it is now, I am on six months' leave.

I've had two really big decisions. The first one was to decide what sort of treatment I was going to have. The second decision was what I was going to do with my job. Fortunately, I am 62 and we are in a reasonable financial position. Work is the least of my worries. I'm sure I will get back to work eventually.

One thing at a time

I am looking long-term but I'm putting all my focus at the moment on the next six months. We are doing one thing at a time. I know I am going to be here in six months. Once I get my health sorted out I'll be looking at the job again. I had to consciously review my job and consider taking the redundancy because I couldn't go away for 10 days in a stressful job and manage my treatment and recovery of the same time. My work colleagues gave me a lift to cope with the second decision. They gave

me great support. They told me even though I felt that by not going to work with them I was letting the side down, they told me to take the time off because I did not need the stress. When one of the senior managers came to see me last week, he said that he was sorry that I was crook but at the same time, even though he would have great trouble filling my position, he said that I had to take the time off and that if things work out, well, he would take me back to work in a heartbeat. This gave me a big lift.

I've been getting on with life

My story started about six years ago and I have been very much on an emotional rollercoaster ride.

It hasn't stopped me from getting on with life. I started a completely new job and career since I had been diagnosed with prostate cancer. I came from a rural background and I had a sheep and cattle property. I had a very varied career in many aspects of the rural and land work. So the diagnosis came, the treatment came and I got over the hump and started working again. Just because I had the surgery, and even had ongoing issues in my situation, it didn't mean that I could not get on with my life. I certainly plan to do the same. The difference this time is that I honestly want to spend more time with family and do a few trips. I'm not going to put off anything. I'm planning on living for a long time. However, because of the enormity of what I've been through the last two or three weeks or months, particularly with the tumour which was inoperable because of the location, it makes you think about it your mortality quite a bit.

A bit of humour

I'd like to treat the situation with some humour even though it's very serious. I'm always good for a joke with people, and I often use my mortality in a joking way and say to people, "Don't think I'm going to die or anything; it's better than being covered with dirt"! That's just the way I am. Even though I don't mind a bit of humour I'm the first to say

that I've been through a bit of depression but not over a long term. The most important thing is having a network and in my case having a loving wife. (Now I'm getting emotional!)

Women

Betty

I am 76 and I live in Western Australia (W.A.) in the southwest. I come from England and have been out here in Australia for over 50 years. My husband, Rick, was born in Western Australia and I met him over here. We are Anglo-Saxon middle-class, and my husband has been a management consultant. We are very involved in environmental issues. We've been living with solar power for over 15 years now. We harvest our own water and we grow our own vegetables as far as possible. We nurture and love the community; our son and daughter-in-law and granddaughters are very close by.

Treatment changes

Rick was diagnosed with prostate cancer in 2005. He had been having regular PSA tests along with his usual health checks. His PSA was high and he had biopsies and all the rest of it, and he had a radical prostatectomy within 3 weeks. About three or four years ago, his PSA started to climb again. He then had radiotherapy in a city which is fairly close to us. He had two or three lots of this; his PSA was just contained. He then had hormone therapy. His PSA went up again and then he had a scan and they found some hotspots in his bones – that was at the beginning of this year – so he started chemo. This seemed to be doing

relatively well but it was not containing the PSA as much as we would have liked. So he went on to further chemo and hormone therapy.

He was on that for three months and his PSA went right up. He had another scan and it was found that he had a lot of hotspots in his bones. It's in his ribs, spine, pelvis and shoulders. So he started on another sort chemo. But while we hoped that the PSA would go down, it has actually gone up. This really shook me up. He is a very pragmatic strong sort of person. So we've had a little bit of a rethink.

Great support

I have a nursing background so I think I can cope with a whole lot of stuff like diet and whatever he needs, so I can provide nursing care for him. We have tremendous support from family and friends, and the local prostate cancer support group. In fact, at the last meeting, we had the prostate cancer nurse, which is a whole new role for care down here. She was absolutely marvellous. Our GP is absolutely on board and is the pain management coordinator for the program Rick is on. He and the oncologists complement each other well. We know we are being looked after. We have a good team of people supporting us.

Being positive

My husband seeks out information. When we went to the oncologist last week we said, "Well, what?" She said that Rick could continue with chemo but there was nothing else she could do. Rick was a W.A. representative for the PCFA and had been to a conference on the Gold Coast where he had heard a talk on Nano Particles. So he is looking in to that. He is right in there as far as part of the management team. This gives him strength and also gives me strength. He is a very positive person and I think I am too. We are not in a situation where we are wondering, "What the hell is going on"?

We are looking into things and seeing what we can do. We know we have a healthy lifestyle and all those sorts of things so ... I don't know how people get on who do not know what questions to ask, and who

maybe can't understand some of the medical terms; they must be way behind.

Bucket list?

When Rick was first diagnosed it was a shock. We had thought about it and talked about it so we could totally agree about getting it taken out. He had the surgery within three or four weeks of diagnosis, but we did not think about our future in terms of compiling a bucket list and things like that. At that earlier time we saw the situation as being just something different. I think a bucket list is coming now, but before we didn't think about it at all. We just thought of conquering this thing and getting on with life.

Even now with all the armoury of medical inventions, the PSA is going up; it's not working. So we have got to think, not of death, but of a limited time; but we talk about things.

Talking...

Rick asked once, "Do they think I'm dying"? We talk about all these things. We plan things together. We talk with the prostate cancer people and hear what another person is going through and know we are able to communicate effectively with each other. We have found it very useful to talk with other people as well.

My brother said, "You're strong – you and Rick can cope with this and will do the best for each other". I think I am strong – I have thought about it, and I think my mother had it – a kind of detached resilience. Not that I'm not emotionally involved, but there is a healthy inner strength there which was like my mum had. I have it as well. I guess that's strength acknowledged.

... and being positive

I think my positive attitude has helped me absolutely, and Rick has a similar attitude. We don't have an, "Oh, gosh!" attitude. However, we

know that it is very serious when it has gone into his bones. He could be in a wheelchair and all sorts of things. We do know that. We are not the sort of people who curl up and get overly depressed about things. We make decisions and solve problems together, and that gives us strength.

Erectile dysfunction was a problem at first but Rick has never had incontinence. He was absolutely fine with that. Whereas a lot of people have this difficulty, Rick didn't. But, the erectile dysfunction was something I felt quite awkward about. We did try injections and other things but they didn't work very well. Between the two of us, we decided that we would not continue with injections because they seem to be so clinical. That decision was okay; it was a bit hard on Rick. Again, this was something that we were able to talk about as a couple.

Discussing problems

While there doesn't always seem to be a lot of support in coping with erectile dysfunction, the prostate cancer support group where we live does a lot of important things. I think knowledgeable staff also helps. The other thing is that the wives in our support group get-together every now and again, and on one occasion this sexual dysfunction issue came up and our discussion was really, really good.

When we are there with the guys, it does come up a little bit. It seems to be a very important issue with a lot of people. One of the group said that they reckoned that prostate cancer caused divorce because there were so many hardships including the sexual side of things. When there is a bit of fragility in the relationship anyway, other issues in prostate cancer would not help.

Louise

Alan was first diagnosed with prostate cancer about 2001 – it was before I knew him. At the time, he worked as a natural therapist and when he

was told he had to have his prostate removed he didn't want to do that so he asked for some time to treat it himself. He made some modifications to his life-style and when he had another biopsy, there was no cancer. He went through ten years of surveillance before there was a rediscovery of cancer in 2011. Probably, in some way, his background made it a little harder for him because he felt convinced that he hadn't done enough.

He had his prostate removed with robotic surgery. The cancer was still contained within the prostate capsule – nothing had escaped. He didn't need to have any other therapy, so that was great. He continues to have his PSA checked and a digital once a year, and so far everything's tracking fine and there have been no problems with the medical side of things. He is having no treatment except what he is following up himself. We met in 2007 and were married in 2008. I am 53 now.

Creeping up

When we went to see the urologist in 2011, this was just a follow up because Alan had kept track of his PSA level, which was a very good thing, because the doctors didn't. The PSA readings were very, very low which is why the doctors didn't pay much attention to them, but the levels were creeping up gradually. He realised there was something going on. So he went back to the urologist who did a digital examination, but he didn't tell Alan at the time that the gland was firm. He said that Alan should have a biopsy because it had been a while since he had one. After he had the tests, we went in to see the urologist to get the results. We were both convinced that everything was fine and that we would see him in another couple of years, but when he said that the cancer was back again, we were both in considerable shock.

Alan wanted time again to treat it, but I was just terrified. The urologist was wanting to book him in immediately – and I would have gone with that! But Alan said that he wanted to think about this. Because he has been involved in healthcare work for so long, was involved in active surveillance and also with the Prostate Cancer Foundation, he had done

a great deal of research into what treatments were available. He didn't want to automatically go down the route of having surgery. He was looking at having brachytherapy and other options.

A dark time

When we went back a week later, the urologist effectively convinced him that brachytherapy was not the best option for him, and booked him in to have the surgery. Within a very short period of time he had the surgery, and we've been dealing with the consequences ever since.

After the surgery, Alan spent a lot of time crying and that was very difficult. I knew I had to take a back seat to a certain extent because this was his body and his decision, so it really did involve me in a lot of listening, a lot of support, and from time-to-time redirecting him when he got into a reflection of, "if only I'd done X, or if only if only I'd done Y", so there was that side of it. I'm not quite sure if there was any lift or hope involved. I think it was really a very dark time and I think it was very frightening for both of us. I think I was probably more afraid than Alan was because I didn't want to lose him, and I was really afraid that I would. He was trying to grapple with what was going to happen after the surgery because he knew what the consequences would or could be. It was one of those things that helped bond us together, but it didn't feel particularly joyful at the time.

"Ready, aim ..."

The initial consequence of his surgery was that he came home with a catheter that was strapped to his leg and, because of the cuts from the surgery, he couldn't bend very well. So, in the middle of the night if he needed to get up and go to the toilet, we had to both squeeze in there together. Basically, we had to do a lot of joking, and we would say, "OK, ready, aim, fire", or "point and shoot" and all this sort of thing, to make it less gruesome! Then we took a lot of photographs of him to show exactly what it looked like. Then of course, he was terrified at the prospect of having the catheter removed because he had a procedure

done some years previously that required a catheter, and the removal was absolutely horrific. This time, luckily, it wasn't.

The prostate cancer nurse suggested that Alan have an injection to help himself get an erection in order to get the blood flowing back to the penis. So we went to see her demonstrate this. She used a product that caused his penis to become so painfully engorged that he was in a great deal of discomfort and we were really worried that we would have to take him to hospital. That was a very full-on experience. Immediately after the surgery he had erectile dysfunction. The idea of the injection was that he really needed to get a blood supply back into the penis to keep it healthy. We actually worked out on our own that he could have an orgasm without having an erection – which was something we didn't know.

Some baggage

He had significant incontinence after the surgery and had to wear big, bulky pads to start off with, which really upset him. He had been going to incontinence physiotherapy beforehand – as soon as he was diagnosed he went there. So he has been going to that ever since. He is now pretty OK with the incontinence but it has taken a long time. There are still days when he leaks for no apparent reason. The erectile side of things is still problematic, so, there is that side of it. There is also the psychological side in that the penis is shorter as a result of the surgery and that means a lot to a man. So there is quite a significant amount of psychological baggage that has gone with the surgery.

As for me, it has changed the intimacy of our relationship quite significantly. We were very happy with our sex life prior to the operation but we couldn't really say that we are now. We do our best, but very rarely do we have anything spontaneous. We do what we can, given that it is very difficult for Alan to have an erection and maintain one. Even when he does have one, the penis is engorged but not really rigid. It is a completely different sensation for him and for me. He has lost a lot of feeling in it – there's that side of it as well. Fortunately, we did have a

great relationship beforehand and we were also closely communicative and affectionate with each other and I think this has now probably increased. From my perspective I thought this was very important because I did not want him to feel any less of a man because of what happened, and that he always felt wanted.

It was a very emotional time, and in many ways, still is. Sometimes he goes back into the “Tape-loop” where he says, “If only I’d done this, or if only I’d done that”. I have to stop him when he does that. He beats himself up about it still. However, he has increased his involvement in the Prostate Cancer Foundation through the local support group. He has written a book about his experience. It hasn’t been published yet but it has been written. It contains a lot of humour because we think it’s important to use as much humour as we possibly can.

I think I’ve become evangelical to a certain extent about the importance of men really looking after their own health and not necessarily relying on doctors, because doctors are very busy and they may not necessarily pick everything up.

Shared strength

I think we have gained a lot of strength from each other. The journey has probably strengthened our relationship and this is the great positive that has come out of it. It has caused us to find the very best we can out of adverse circumstances. That’s the positive. It has also given us the opportunity to interact with a lot of men and their partners who have been going through a similar process. It is always heartening when you can talk to somebody and help them with their process because so many men do not have very much information.

There is not a lot of information available for women either. The most helpful thing I think that I have come across at all is a book written by Bettina Arndt called ‘What men want – in bed’. That book made me cry, but it strengthened my belief that it is so important for partners to maintain a really close relationships with their men, and to show them a

great deal of affection. With things deteriorating sexually, I think that becomes even more important. I think that's what really meant a great deal to me because, being one of the younger women, given that a lot of the men in prostate cancer support groups tend to be older, the wives are often older. It is sometimes confronting when you come across a wife who says something when her husband's out of earshot, "Oh he wants to get a penile implant but I don't want him to", so I think, OK, but, they're happy because there is no sex! I think how very sad that there is an imbalance in what they want. They don't have that sorted. I think this is one of the areas that is really critical to mental health in going forward. There certainly isn't a lot of information for women about post-treatment, as far as I can see.

Alan has been involved for a couple of years with the Peter MacCallum Cancer Centre, who are putting together a decision aid booklet, for men who have localised, low risk prostate cancer, to help them provide the best choice for them. As part of that, they have been putting together a DVD that people can access through the Prostate Cancer Foundation website, and Alan and I have been interviewed for that DVD. There was only one other partner interviewed and that was a gay male. I was the only female partner that volunteered. So there is definitely not very much out there at the moment.

When we went back to our urologist for our second visit after our week off, we started to ask him questions about what would be happening afterwards in terms of his incontinence and sexuality. The urologist said, (bless him), "Look, that's not important at the moment. I'm here to save his life"!

More and more younger men in their fifties are being diagnosed with aggressive prostate cancer. Alan regularly provides support and information to other men now. One fellow came to Alan recently and told him that his prostate cancer had not been picked up until it had moved into his bones. He is now on hormone treatment, going through hot flushes. His partner is having difficulty with that as well, so for the younger the men who are being diagnosed, there seems to be a bigger

impact on younger partners because, I suppose, the younger partners are perhaps more interested in participating sexually.

Felicity

My partner is Gary and he has been diagnosed with prostate cancer. He was diagnosed in September 2008 just after we had come back from an overseas trip. He saw a specialist who then suggested a biopsy but there was a delay of about four months before this happened because the specialist was on holidays. Then within six weeks Gary had a robotic prostatectomy. The biopsy had indicated that the cancer was not confined, which was unfortunate; it had escaped the capsule.

Incontinence

Within 12 months of the prostatectomy the cancer started to come back because his PSA began to rise. This meant that he had to have seven weeks of radiation treatment and since then he has become quite tired. In the last seven or eight months he has started to become incontinent, not badly, but enough to trouble him to carry spare clothes and things like that. One of the problems was that men's incontinence pads are so huge but we have now found some streamlined pads and he is quite happy to wear them. It's mainly when he is standing up, or getting out of a car, that the incontinence happens. But it's not too bad, it's just enough to be a pain. Anyway, we have worked our way round that and we are moving 'onwards, ever onwards'. This affects me by the way I watch what it is doing to him. He finds it quite demeaning because of the smell and other things, but we've worked out how to manage it so that it won't happen.

Taking the problems on the chin

The circumstances are emotional for me because, for example, sex is just no longer existent. But then this doesn't bother me because I'm 65 in

another month; but it did bother him. It's coming up to six years now. It was either a matter of him not being here at all, or being here and, pretty much, taking the problems on the chin and looking at what we have to do. Gary was not able to obtain an erection and he was put onto Viagra. He had to have a huge dose of this but, with headaches and all, we decided that it just wasn't worth it. So he actually saw the nurse that he had been to before the operation and he started penile injections. However, we pretty well found that we just had to make a date, there was no spontaneity there. Then we had the problem that if we put too much in the injection, then the erection would not go away at all so then he would be in pain. So this didn't solve the problem. Then Gary started talking to someone about a penile implant. But I hope he changes his mind because we have enough problems when we look at the incontinence difficulty as well. Gary also suffers badly from gout but, he is 64, so what do you do?

Our lack of sexual intimacy affected me about five years ago but not now. When we realised that Gary has this problem we understood that we both had to deal with it, not just him. Now that I'm 65 next birthday, the sexual issue doesn't bother me at all.

The initial problem

Going back a bit, in the very difficult time around the original diagnosis and the delay we had while the specialist was on holiday, we went together to our GP and he said that Gary had a problem because his PSA reading was nine. So he told Gary to get up and he did a digital test and the doctor said that there was something there that shouldn't be and this is why he wanted us to see the specialist. Gary and I didn't really discuss it together very much. We knew nothing and while this was the case we decided that we would not fret; and it was Christmas. So when we did see the specialist, and Gary was put in to have a biopsy, the specialist called us both in to see him and, on the way in, because he had been asked to bring in his wife, we knew what we were going to be told.

However, neither of us got ‘knocked down’. I just said to Gary, “Okay its cancer; it’s got to come out, let’s just get it out”.

Also at that time, because you know it’s cancer, you don’t think that much further. The sexual side and the incontinence side never entered our heads. Even when you talk to the nurse before you have the operation, it doesn’t register. It didn’t with me and I know it didn’t with Gary. We didn’t think of the huge change that we were about to have. We know of men who have passed away because of prostate cancer, and we just think that we are lucky. I know we both think that. Our life hasn’t ended. What do they say? “As you get older it’s a privilege. Don’t look at a birthday and say, ‘Oh, my God’. Just look at it as a privilege because not many get there.” That’s the way we both feel. Cancer diagnosis can be horrendous, but neither one of us felt knocked over by Gary’s diagnosis. We just felt, “Let’s get on with it”!

Relationships

There has been a definite growth in our relationship mainly because we have talked about it, and he tells me what he was feeling. In the support groups, a lot of men do talk about their physical issues but the women are left floundering. I talk to some partners who come to our support group and the husbands won’t even open up to them about the intimacy issues in private! I just feel that Gary and I are fortunate that we have been able to talk about it and discuss it. In a lot of relationships that doesn’t happen.

There is not a lot of information for women ‘out there’. My advice to women is to go along to a support group. That is when you do find other women who understand where you are coming from. I have friends but, if their husbands do not have prostate cancer, they have no idea. You can’t talk with friends too openly about the sexual side of things. They are still having a sex life, but they don’t understand that somebody is unable to have one. If you talk to a woman who is going through the same thing, sometimes you could learn a bit from them, and vice versa. I have found this very helpful.

Support

We had a woman who came a few months ago whose husband had just been diagnosed, and she was only 52. She couldn't get her husband to come, so she came on her own. By the time the evening had finished, before she left, she came over to me and threw her arms around me and said "I'm so glad I came". If you can help one or two people, you just feel good about that. If you are trying to cope with this alone, it is very difficult, but if you are able to talk to someone about it, there is your hope right there.

As far as our current situation is concerned, while we have no sex life, everything else is normal. We go on holidays, we bought an old car and go on trips with this. We go out with friends, go out to dinners together. We go out all the time. We just get about together. We realise we are getting older and thought that we might as well do it while we can. If we don't leave the kids anything, they won't care!

Learning to laugh

There has been some personal growth for us; and we have learnt to laugh, especially through all the different stages. On the sexual side of it, we just sit and laugh! You either sit there and cry, or sit and laugh. I know which I prefer. Crying is not going to get you anywhere. You just learn from it. Sometimes you think, "Well I won't try that again"! You have to do the whole journey together. I must admit that I haven't really had a down time, but Gary has had a few. I am actually his carer now what with the prostate cancer, his gout and a few other things. I don't like doom and gloom so we try not to let that happen.

"One of those things"

We still go to the specialists and have regular checks. Those are becoming once a year now but we don't know how long that's going to continue. It has been five years now but we've had to add the extra year to the general 'return' period because of the radiation. There have been

examples of people who have had the prostate cancer treatment and the cancer has come back after a period of years. You just don't know. It's just one of those things.

Sandy

I grew up in Italy and have been in Australia for 50 years. I grew up as a Catholic, but not committed Catholic – then agnostic – I have a spiritual background that is both ancient modern – Eckankar (Experience the Light and Sound of God), and I have embraced this for about 28 years. It has been one of the keys factors in helping us during this challenging time.

My husband was diagnosed officially in 2013 and he went into a watch and wait mode. He had a high PSA for four years prior to this but was symptom free. The results were sent to a urologist in Brisbane – the year before last. The urologist said he thought my husband had cancer. Now my husband is in palliative care stage. It is now six weeks since he stopped chemo. He feels much better now, not as totally tired. My husband is still working one day a week at 81 years but he lost most of his hair. He has a very positive attitude in life and is still pain free. Cancer has spread to his lymph nodes, bones, liver, appendix (size of banana). My husband chose not to have surgery to remove his appendix. Removal would have meant removal of both the appendix and part of the colon, so we decided not to go ahead with the surgery. A colonoscopy was the most invasive process he has had.

A spiritual path

My husband follows the same spiritual philosophy as I do. Not so much a belief – it is an experiential spiritual path. Ultimately, any experience you have is your own and nobody can take that away. If you are ready for it – and allow yourself to be open to it, you will be able to prove its veracity to yourself, otherwise you will walk away and say it is poppy-

cock. And that's fine. It's a belief that accepts that where everyone is at, is the right place at the right time, it's accepting and supportive of everyone on any spiritual journey they may be on. We aim to support others to grow spiritually in whichever path they choose.

Our interesting experience – my husband and I have been together for 39 years this year. We had both been married before. We moved together from South Australia to Queensland. My relationship with him has been really interesting. The weird thing was that I felt I was being 're-parented' by a nurturing and loving adult. That particular word is the only way I can describe what it felt like. It would make sense many years later, after we had been in Eckankar for a few years.

Part of the spiritual disciplines that we follow, involve a systematic daily practice of spiritual exercises (like spiritual gymnastics) which, by degrees, can enable a person to grow into the understanding that we are Souls inhabiting a physical body and that we are here to learn spiritual lessons and work out outstanding karma. During these years of contemplation, we visit (sometimes consciously) different inner planes to expand our understanding and purpose of life. Past lives recalls are sometimes needed to make sense of some of the challenges we encounter in our daily life. They can happen spontaneously, or during contemplative practice, and/or sometimes in dreams. These recalls are never willy-nilly, but they are very specific in being pertinent in some way to our current needs. Amongst other past lives recalls I came across a previous life where my husband had given me a solemn promise to do something for me which he was unable to do at that time. It was in the late 1700's. My husband was a navy officer in a British ship – I was not a woman then, I was a young lad of about 13, an orphan who had been living on the streets and who had been somehow brought on a ship. The officer (my husband) took a liking to me because I was smart and witty and he thought I had potential. He promised he would help me to have a better life, but he wasn't able to. I was just a boy and he was an above the deck officer and he couldn't protect me. I died before he could fulfil his promise. This particular memory – my experience of this past life,

was particularly vivid. I was 100% sure I was there. It came up to address personal issues existing at that time. Memory of some past lives is incredibly vivid – in this case I could smell the tar on the deck and the stench of unwashed bodies below deck. I was there. I was 100% sure I was there. Apart from that particular one, I have had several past life memories which have surfaced and have been particularly relevant to the present. They come up to help me resolve specific emotional issues which I endeavour to explore in the present.

“Dying is not a problem”

Of course one of the huge benefits is that in the process of reliving the past, I also remember several deaths. Therefore the process of dying is not a threat. Some deaths have been unpleasant and some have been actually quite nice. The whole idea of dying is not a problem. I see it as a passage to the next stage of my never-ending journey.

My husband has had similar experiences, but not exactly the same as mine. But between the two of us what we put together confirms that they are aligned. It has been a fascinating journey. Our doctor is a bit puzzled, we believe, about our reaction towards death which is quite uncommon. It's OK.

All this hasn't actually provided us with hope necessarily. We work with an inner spiritual master and this entity has said to my husband, “You've got cancer and you'll be OK”. My husband is very grateful every day. We are excellent support for each other. He has received love from so many people. Love support is all around us – it's very tangible. It makes the whole thing different; I am a super realistic. I actually look for literature about the cancer progression to give me information about what to expect. A lot of stuff that is given in literature and on the internet, is all focussed on expending energy fighting this – let's win this battle. The cancer journey focusses on the cancer rather than living. There is a risk with people who have a particular condition that they become that condition. So we live life every day; every day is the focus, and the cancer is incidental. We live totally in the present, except for when we

have planned practical stuff such as what to do with the physical body once we have moved on, and how to be sensitive in this respect to our children's emotional needs at that future time. (We share six children from our previous marriages.)

A man of action

I found it frustrating that I couldn't find more practical stuff on the internet or in the books I read. They all focus on, "Let's win; let's hope; let's do". All I want to know is what I can expect when my husband dies. We need to be realistic. We have put things into place. We have organised things like funerals, all of this stuff. My husband has taken care of that because he didn't want me to have to deal with that kind of stuff when he knows I will be upset and stressed. As much as I have been partly involved in that process, this is something he took upon himself to deal with. He has started giving away things that would be a problem for me to dispose of while he is still alive, like guns, and his boat; it's really practical stuff. Some say he is courageous – it is, but it isn't. What would I do with a heap of guns? They are things that he has loved dearly; things that I have bought him, so there certainly is an element of attachment to them. It is interesting how the universe puts things in our way for an opportunity to do good things with them. My husband came across an article of someone who was accepting donations of guns for Aboriginal people who wanted to go hunting with them on Cape York, so he contacted the guy and they came and picked them up yesterday. The boat too is now gone; he sold it and they came and took it away yesterday. It was one of his great loves. My husband went and bought a canoe a couple of weeks ago so he can return to fishing as soon as he is able to. I fully support him as much as I can. He is a man of action and adventure and cannot fathom how I can spend so much time at my computer.

Differences

About five years ago my husband started having problems maintaining an erection. He thought it was simply part of the aging process. After a

while he tried Viagra – it made him feel really weird and he didn't like it. He is 10 years older than me so I really expected that as we aged he might have problems later on. We simply talked about it. This is just life. What surprised me most is that we both are really touch-feely people – and my husband actually found any sexual touching really frustrating – he would get all stirred up and then couldn't do anything about it. I have got myself a vibrator and I got myself a teddy bear – two to be precise. We have had separate bedrooms with a nice queen size water bed each. We have done that for many years. When I went through menopause, our temperatures were completely opposite. He couldn't cope with my tossing and turning when I got too hot. We went to double beds at that time – one each, and we actually came to really like having our own room. We contemplate every day in our own space and we have different time clocks. I stay up late and listen to the radio until midnight, while my husband is awake at 5 o'clock in the morning so having a separate place is really important for us. We don't like living in each other's pocket – as much as we dearly love each other, we both are very much individuals. It is a very special relationship; it will be missed, very much. I feel incredible blessed that I found him. We are very happy; we have been very blessed – very lucky to find each other.

I found the support groups a bit "wishy washy", maybe because we both have some background in psychology. We also both worked in welfare and as counsellors for Lifeline for a long time and helped run groups. Both of us have a good deal of self-awareness. We went to some of the blokes' support groups but found them very boring. They really are information sessions and 'proper' meetings. I go to the women's support group meetings occasionally which are somewhat different. The groups are helpful on the practical side and if you want to ask a question or want booklets or that kind of thing that's fine, but support groups to me are not quite like that. At least not the ones I have attended or run.

Changes

It has been interesting for me to discover that most of the other partners are intimately steeped in their partner's cancer process. They were astounded that I didn't always go with my husband to the medical appointments or ask more questions. Basically, if my husband said, "Don't fuss," I would back off and that's fine – it's his body, it's his process. It's not a drama. If I wanted to have any more information, I have had to wait for my husband to pass the information on to me. Over time that has changed; I am probably more involved now than I was in the beginning. I know that my husband found the guys' support group very boring. Everyone is talking about themselves and what they might be doing. In truth, most information these days is available on the internet, books – latest and greatest news and stuff. I always associate support as more of an emotional nature; that's not what we found especially in the men's group.

We are very lucky because we have each other. Our spiritual path gives us all the support we need. We are very blessed in that respect. My husband really hates the term 'cancer journey' – I am alive now! I understand, however, that's what people are used to hearing and that's OK.

Yvonne

We were brought up as Australians, I suppose. I have European background – English-Irish. I probably believe in Christian ethics and their ways, but I don't believe I need to go to Church to follow that regime. I am 72 and George, my husband, is 73. We live in a rural New South Wales town.

Effects on the partner

George was diagnosed with prostate cancer about a year ago. He's not doing very well at the present time. He's well physically in himself, and well mentally, but, he has neuro incontinence and that is quite depressing for him. He has always been extremely fit, and he is a reasonably thin person and has been very active, but the incontinence is limiting our lifestyle. This affects me in that we can't do things together like leaving to go away anywhere or have a holiday at the moment. I can still continue in my activities but together as a couple we are quite limited in where we can go.

Last year, George had a TURPS procedure and there were indications then that there was some cancer present. He had biopsies taken of the prostate, and one of these confirmed that there was cancer present. After a lot of discussion, George decided that he really wanted to have the prostate removed. We tried to find a very good specialist but the one that was recommended he would have had a very long wait. He didn't want to wait, which he should have, so he asked his GP to refer him to another specialist. So George went to see him and he felt fairly comfortable with him.

This specialist went through all the pros and cons of having a radical prostatectomy, open or robotically assisted. He also went to a radiation therapy specialist but, because George had had the TURPS procedure, he wasn't eligible for brachytherapy. So, after toing and froing, and after having decided to have a holiday, he decided to have the robotically assisted surgery.

Not a lot of lift and hope

Following this, he didn't really recover. He just has no control over his bladder whatsoever. So it's been quite depressing for him, really. He does all his exercises, and they still keep saying it could come good, so, we live in hope. So, there's not even a whisper of solution at the moment. There's not a lot of lift and hope in his journey at all at the moment.

He has changed specialists now and has gone to the original urologist that he should have gone to in the first place. He said that, because of his age, he would never have operated on him at all, because George probably would not have died of the cancer. But, anyway, it's all over with and done, and he goes back to see the new urologist next week. He has cancelled going back to see the urologist that performed the operation.

Challenging for man and partner

It's very challenging for both of us because we walk every day and go to the markets three times a week. He was a very, very good and keen bowler, and now he can't go bowling at all; it's just too difficult. When we walk, we have to walk along the same tracks where we know where all the toilets are.

The sexual difficulties we experience are probably worse for George than they are for me. I think males think about it a lot more than females do. All of the procedures he has to go through to keep the blood flow into the penis don't affect me, but he has to have injections. He has no spontaneous erectile function at all. It is very difficult, but he is very patient. He has always been a patient person and when he does get down, I really notice it.

The difficulties affect me, I suppose, in that he doesn't feel very affectionate any more. Most of the time we are happy but there is just no spontaneity about life any more. With the injections, George hasn't mentioned that there is any discomfort at all. He usually works on this while I have gone out, or something like that.

Personal space needed

One of the issues that I find that affects my life is that George is always here at home. I know I don't have as much space as I would like. It is just that he can't go to bowls or do the things he used to do. He still does the garden and that sort of thing but he doesn't have much time out. I quite like having time in the house on my own. He probably likes his

time as well, but he has more of it now. This will probably continue for the moment. I know there are things that can be done down the track that will help George.

He is in the support group which is very helpful, for both of us really. We both go. It is usually an evening meeting and they have a guest speaker, and we have a meal at the pub where we meet. We sit around and talk about how things are affecting the men. We talk and get new ideas. People say, "Well, I've tried this," or, "I've tried that," or, "I've just had a sling inserted". We've only been going for a year but it has been quite helpful. We found out about this research through the newsletter that came to all the members of the support group.

We definitely have a positive attitude and this has helped us as a couple, except that it is a bit hard for George to be positive.

Bonita

I am of European, British origin. My spiritual background started with an aboriginal community in the district when I was a kid. We were farming people. I went to Sunday School sometimes and then I went to an Anglican a girls' school. That was the formal side of it. Spiritually, I have been involved in meditation, Buddhism, personal revelation and near death experience.

Different emotions

My partner, Bon, was first diagnosed with prostate cancer in 2011. Now, his health is currently good. He is not having any treatment at the present time. When we first had the formal diagnosis, we had a house full of people and my clear memory is of holding Bon and crying, and nobody else knowing what we were up to because they were all looking forward to a wonderful holiday. I was hanging onto him and crying and thinking that we would distract ourselves by all these people around. We always

had faith that it would all be OK. We always had faith and we didn't think about it much. It would be fine! Our faith helped us immensely. We never asked, "Why us"? That wasn't a particularly important question because life's a lottery. We were just us.

When he was diagnosed and started to consider treatment, Bon didn't have emotion, just a very calm approach to life. We were introduced by our surgeon to the different forms of treatment. Bon never had any doubt that surgery was the best form of treatment and I felt right about that too. I always trust my gut reaction. If that was wrong, we would have known. Surgery was correct for us although I am aware that very close friends and neighbours chose something different. We never had any doubts about it. Bon just assumed that surgery would be good.

I think that the surgery started to become emotionally very difficult when Bon related it to the definite effect the anaesthetic would have on him. (In previous surgery, Bon had very bad reactions to the anaesthetic, to the point that the nursing staff called me to ask if that was 'normal'.) There was also the isolation in hospital because Bon was some distance from me. I had not at that stage appreciated just how much he needs me to be close to him physically.

Indifferent hospital treatment

The general treatment by the hospital was not helpful because they sent us away after the surgery without any preparation whatsoever, not even incontinence pads. They didn't even tell us that we would need pads. So we were rather taken amidstips with that. It was a very big, hard learning journey to find out what would make him comfortable, and what had to be done. These were sheer practicalities. We were given no written information about what to do afterwards. It was appalling; appalling. There were no directions, no discussion – and you need them! Bon is a very big person and had a big problem with that particular aspect. Bon was emotionally affected immensely.

Emotional cost

I was affected emotionally after the surgery in that initially, I could not understand why he was not joyful about what to me was a totally satisfactory outcome of the surgery ... all the cancer was removed. The surgeon was brilliant and the surgery very successful. So I was troubled for a long time until I realised that there's got to be an emotional cost as well. I think this is insufficiently understood, and I think that many people find there is a general downturn in a person's mentality, or something; there is an inward turning.

What about testosterone?

At our age, the sexual thing is not that exciting but that is certainly part of the emotional aspects of the illness. I really don't think there is nearly enough understood about testosterone and what goes on in the body if you don't have your glands anymore. What is actually happening? What needs to be done? How is all this impacting with the individual? I feel this very much needs to be looked at.

For example, what connection is there between loss of testosterone and the onset of dementia? From having now lived with it, I think it is very significant. But the post-operative care, information and warnings are quite badly dealt with, or, in our case, were not dealt with at all.

Therapy

Bon joined a post-operative physical therapy group where the sexual issues have been quite well spoken of, and there have been plenty of talks given to us by experts in the field. I did notice that not many people turn up to the group and my theory is that because of the age of most people, sexual activity may not have been the biggest thing in their lives. I think that at our age they are more like friends than hot-sex lovers! So maybe they are not that keen. The sexual issue has not affected me at all. But I did feel very sad for Bon, and this impacted on me as a partner.

A lift in the country

Thinking about what gave us lift is a bit complicated. Surprisingly, we have always taken great strength in that we were living in the country and walking in the bush and realising that after the surgery we could do that again. This has helped us to be connected back to nature. This provides us with very spiritual input. We leaned very heavily on that. The daily walks we did up and down the area we lived were very important to us and helped us, not only physically, but emotionally. We used to stop and hug, and breathe the air. It was lovely. It's very important to us. This positive attitude has definitely helped us cope with Bon's illness.

A greater role in decision-making

Without a doubt, his illness has changed the way we make decisions in that I now have to take a role in a lot more decision making. Bon is now not as strong physically or emotionally. I had to make a decision about moving from the country to the city, and consider what sort of circumstances we could move into and handle together. I felt mostly in charge of that but I was always conscious of making sure Bon was on-side and being part of that whole process. I had to step up to that role while he was unwell.

Cancer treatment and Alzheimer's – a connection?

There is a huge emotional loss associated with the illness. I spoke earlier about the early onset of Alzheimer's. In Bon's case it was in the family but it is not necessarily hereditary. I really felt that the surgery and the anaesthetic, acted as a trigger. The cancer and the treatment puts you between the devil and the deep blue sea. You really don't have an option. If you have cancer it must be dealt with. It is the primary thing. However, the inescapable feeling that dementia was precipitated needs serious examination. One or two other girls we have met at dementia information gatherings have confirmed that they also noticed this

connection. We should be listened to. I would really like to think that in particular becomes an area of serious academic and medical research.

I would also like to promote the development of a post-prostate treatment kit, with simple practical suggestions, like, you will need pads when you leave hospital, to being alert to serious emotional difficulties.

Suzi

I am 43 years old of Christian background, but non-practising. I work in a number of different Catholic organisations. I've had quite interesting experiences giving support. In terms of my beliefs, I have had two or three very dark periods where I've had some traumas in my life and have felt protected. I've had the ebbs and flows of adulthood and this was sometimes challenging.

John, my partner, was diagnosed with prostate cancer in December 2013. He had an open radical prostatectomy and has now been cured. This was his second bout with cancer and it was a major operation. The recovery period was probably more challenging than we expected. So, at the moment, he is cured of the cancer but living with the consequences of the surgery. I guess this was a lot more significant in his life than expected.

A strain on our relationship

In terms of continence, he has done very well and recovered very quickly, but in terms of sexual function he has had a lot of slip-ups so this has probably been the major part of our journey. This is very difficult for us at the moment. Both of us are currently in therapy; we've been getting some assistance from a psychologist to work out some things that have arisen as a result of some of the dysfunction. We've found it very challenging at times. It places strain on our relationship. Many people underestimate how difficult it can be. It's the unspoken stuff. Many

doctors treat the cancer, but it becomes a greater problem when so many life changes take place as a result of a prostatectomy. John is only still very young; we'd only been married for a couple of years when this occurred so this has been rather a blow, and having to live with the difficulties has been quite difficult, a lot harder than he expected. For me, I have felt a lot of pressure at times, to try to be more understanding, especially when I was nursing him through his recovery, and now at later times.

It has been less than a year since diagnosis. In many ways, the medical side has been dealt with quite quickly and very effectively. The surgeon did a great job. John had bowel cancer earlier and we knew there would be a lot of scar tissue from his previous surgery, but we were underprepared for how much the prostate surgery was going to knock him around. Certainly, the emotional side of being sexually dysfunctional has been a surprise for both of us. It's not like you can recover in your own time. There are other things happening.

A challenging mix

We are going to the psychologist, and I hope this will work. It's not a very comfortable conversation at the moment between John and me. What happens is that when everything's fine in a relationship there is no problem, but if you throw age, major surgery and recovery into the mix, it becomes difficult to have a normal, loving physical relationship. Some things that may not have normally been a major problem become amplified, and this amplification is partly due to, for me, the worry of health issues and trying to avoid the strain.

Society is not very patient with people who are diminished in any way, so some of my husband's work experiences through colleagues and friends have demonstrated a lack of understanding as well as a lack of kindness, whereas I've had quite a different experience. I've had very supportive and kind colleagues and friends and that's possibly because I work in a Catholic organisation, I'm not sure, but certainly, people are aware that I am going through some difficulties and they are very kind,

concerned and considerate. My experience is very different to John's, and you very much want to protect your partner from the kind of difficulties he is facing.

Different reactions

At the time of diagnosis and the decision about treatment, we were particularly reliant on the expertise of the surgeon. I found a lot of comfort by doing research and finding out as much of the facts as I could know. Both John and I found this very reassuring. I would say that the hope for both of us came from the sense that it was not quite as frightening as we thought. It was just something we had to go through. I'm not sure that I felt particularly lifted in any way; that was nowhere to be found. I guess when John was given the 'all clear', that was to me a lift, more in a sense of relief – the pressure was off. I looked to my partner to see what his response was, and his attitude was "that was only ever what was going to happen". Perhaps that was a male thing, rationalising and thinking, that was the best possible outcome and that was the way it was going to run. But for me, I wanted someone to say to me, "Now you can be relieved," pat me on the shoulder and say "OK". I always was a kind of optimistic person but, what you hope to be was cancer free, I guess that grinds down a little bit in the face of some experiences.

It was in the recovery period following the surgery that different things started to arise that were completely unexpected. I think that a lot of attention is given to the man throughout the surgery and recovery. It's about all the things that might happen but, in all of that, the partner tends to be a bit neglected. Whatever kind of hope, lift and optimism you may have had when you are told "everything is going to be fine; everything is going to be fine", does actually get ground out of you because your partner has these other kind of symptoms. There's recovery in one sense – the cancer had gone, and then there is incomplete recovery – there are still problems.

Unprepared for some challenges

Erectile dysfunction seems to be quite a common fate for any kind of prostate cancer treatment and we were just unprepared for how much that was going to affect us. I think a lot of people would have to be completely unprepared for that. They would be very challenged by the idea of talking about it, confronting it and dealing with it. I was never particularly challenged by that but my husband certainly was. I found that particularly hard because I'm a talker, a copier and a problem solver, and a thinker and a doer. John wasn't necessarily facing the facts which were that his sexual function was probably not going to come back straightaway, but you are going to have to work at it a little and with some other strategies. These strategies may be uncomfortable; hence we are getting some psychological help.

Counsellor help – and further challenges

This was a battle in itself on my part to get my husband to the point that he realised he needed help. We are only in the early stages of discussions at the moment. We had an initial consultation together and now we're seeing him separately. The psychologist was recommended by the urologist. Unfortunately, he is not my cup of tea, but ... he's a bloke! The way he describes and explains things work quite well for John, but for me it lacks that feminine kind of thinking – that there is a kind of higher power, or that we can just alter the way things occur by our manner, our attitude, our belief or our positivity.

It is quite an interesting experience to be talking to him about these issues. Our situation is probably not particularly black and white and we haven't quite arrived at that stage of dissipation of the stresses as the result of John having prostate cancer. In terms of lift and hope, we are waiting for that to happen! We are a bit more hopeful from going to see the psychologist because he has recommended to John some very concrete things to do. This has been great because I could not be all those things to John. I couldn't be the nurse, the housewife or the goddess! I couldn't be the sex goddess in the bedroom as well as the nurse, as well

as the sexual recovery person. It is just too much for one individual to be in someone else's life. I can imagine that marriages break down through this kind of stress. The counselling experience generally has been quite positive and the psychologist, and my husband, are hopeful that things will get back on track.

Frustration and stress

John is hard wired (virile). He's very calm but his sexual appetite is quite important to him and when that outlet was no longer available, he became extremely stressed very quickly. It was a bit scary for a few weeks there. He has improved hugely. Stress was a big problem for him; his blood pressure was up but he has managed to get that down. John has realised that the sexual health aspects are too important to neglect.

Dark sky, then blue sky ...

There was a phase, particularly earlier this year, when we were just wondering what we'd done to deserve all of this hardship. There were a few things that happened that were extremely stressful in a very narrow period of time. In many ways, John's illness was only one aspect. I guess this gives you an idea of how bad things were. I did wonder why we had such a terrible series of events in our short life together. I am beginning to feel that there is a shift and that things are now more positive – blue sky – and that we actually had to start to spend time exclusively with one another and push other people away and focus on ourselves, which is at odds with both of us because we are both very giving and very generous people. This meant that we also ended up seeing more of the people we loved and cared about. So that was important.

... the right direction

Today, I feel as though we are heading in the right direction. We've certainly been able to get over a hump whereas we had been concerned that we may not ever; but I feel more confident that we will. I have felt very isolated during this process. I think John is disinclined to join with

a prostate cancer support group, and I thought that was crazy. I think joining a group would be the best way to do things. If you do this, you find people who have been through something similar and try to get advice from others, or share stories and be supportive to other people, but that's not my husband's way. So, when necessary, I send him fishing with his mates! We both deal with things very differently.

A typical story?

I feel that our story is very typical and I would hazard a guess that there are more than 50% of couples who are going through this are not talking to anyone and are dealing with problems in isolation. I know of some friends of other couples where the fellow will just not discuss it and will not seek any help or assistance and the wife is at her wits' end. I really feel for those couples because what they are going through can happen incredibly easily. They can slip into denial, and there can be ambivalence: "Oh, you'll be all right; don't worry about it; don't think about it". I think that's very naïve – very Pollyanna. It's a very grown up disease and you have to start thinking like a grown up. It is the prostate gland; it's trivialised by the surgeons in some ways.

A problem not to be minimised

My husband and I were having fertility treatment before he had prostate cancer, so it has been very frustrating for me to hear a surgeon minimise the seriousness of the problem. Any part of your body is important. This was the end of an important chapter in our life and we had to make a decision about whether we would proceed further with the treatment. But that was just too much to think about. This was very, very painful actually. In another way, it was probably a relief because the decision was kind of made for us. You think, well, you can relax on that one; you don't have to worry about it any longer. I was tending to think that I was getting a bit too old to have a newborn anyway, or even a small child. The decision was ultimately made for us. But, of course, this was an extra upset for us.

“Very medical”

You go through the very medical cancer type of treatment, and a medical approach where the urologist talks about the issues, margins and eventually says things have gone well and the surgeon’s ‘high-fiving’ himself. Really, that’s what they are like. “You are cured. I’ve cured you!” I was very grateful for this, but, then I think, “Yes, John is cured of cancer but what about the rest of it? Now what? What happens next?”? You get sent home and then you have to try to cobble together your life again.

But, in many ways, things are better now. The urologist referred us to an excellent physiotherapist. She was absolutely outstanding and she really helped John with his recovery of continence. But John was incredibly lucky that that was not an issue for him. He has not had any ‘accidents’, and I think that must be horrific for some men. That would be a good reason not to leave the house, if that was a complicating factor. The sexual function probably comes way, way, way down the line in terms of priorities. Yet, for me, a younger woman, it’s quite high in terms of the important things in the quality of life. I’d like to advocate a little bit more the validating of this experience as an important one.

Some assistants

Thank God, I say, for the drugs, basically. Viagra, Cavaject, and all those sorts of medications that were not around 20 years ago. Without these our marriage could have possibly been over because of the amount of stress and tension for my husband. It was in the palpable range; it was pretty ugly and I didn’t ever expect to see that ending. The drugs are the hope! We can talk about it until the cows come home, but if there is no practical solution somewhere in there, it is extremely difficult to manage.

Having a relaxed and positive attitude is so very important as well because one of the problems that John had was that he was 100% reliant on the drugs and 0% reliant on his own fortitude, and resilience. He had trouble remembering what it was like to be a loving partner and a good

person; it's not just about being able to have an erection. I think for a lot of men it's really a matter of, "Look, mine's bigger than yours"; it's just hardwired in there. A lot of men struggle with that because all of a sudden they are unable to win in the 'arm-wrestle'.

Self-care priority, and a work in process

In some ways I do wish I had more of a faith journey and a bit more support in that regard, but there was not just room for that. There was too much crowding and in some ways my own practice was to find my own spiritual centre. I had to look after Number 1, I guess. I had to look after my own soul, my own sanity and my own safety and connect with my own sense of higher purpose. I think I have developed some spiritual fortitude and some strengthening, perhaps. I'm now less inclined to be distracted by unimportant things but more a sense of purpose, and focus on things that are more important.

I'm a work in progress at the moment – spending time together with John and being kind to one another is really important. We just have to remember that we have to do that.

Lauren

I come from a background where I am a Christian; I attend church, but not as much as I used to. I originally came from overseas but I am now Australian and my cultural background has fitted in very well here. I'm 67 now and live in NSW.

Gleaning information

Edward was first diagnosed with prostate cancer in August 2013. He has had brachytherapy. He has just passed the three month mark after treatment with very good results so we feel quite positive at this stage. The initial diagnosis was fairly traumatic, for both of us. But he

straightaway called me in to the doctor's surgery so I was part of it from the very beginning. The cancer word was a big shock. Edward was quite flabbergasted so I probably started to ask a few more questions than he did.

The first specialist Edward saw suggested that he should watch and wait because it was in the early stages. I didn't find him very caring; it was: go away and think about it, here's a book and come back in six months' time. I was very unhappy about that. I have very good friends who are part of the nursing community so I questioned one of them who does voluntary work for the Cancer Council. She gave me a lot of information, and together with the Web, we started to ask a lot of questions. This particularly included friends who have had prostate cancer. We then chose to get a second opinion. The second specialist that saw Edward was fantastic. He was just brilliant and there was no watchful waiting so we went forward from there and Edward had brachytherapy in June of 2014.

We were actually planning an overseas trip and I thought we were going to have to cancel it. But the doctor said, "No, continue with it". The oncologist we had was absolutely wonderful.

We also joined the prostate support group. This was very good and informative. They had some fantastic guest speakers. I think we have both weathered it pretty well, actually. Edwards had a bit of trouble at the beginning of the holiday because it was only about six weeks after his treatment. Because we were away, and because he was doing all right, he coped with it. We both had distractions, and I honestly think we went from strength to strength.

Issues

There were a few urinary issues that he had to deal with and he was on medication for that but he had to manage it. There were things we were going to do but we actually cancelled because toilets were of high importance; this is improving now. He is reducing the medication he is

on, and the effects of the treatment on him are slowly improving week by week.

Erectile dysfunction was a real concern for him at first; a great concern. I think this was one of the main reasons he decided not to have the surgery. He was also told that he was a prime candidate for the brachytherapy because he was not overweight and his prostate wasn't enlarged. There was a healing period where there were 6 to 8 weeks where he really just had to give himself time – which I was happy with. Then we both started to experiment – both of us, and his erectile function became pretty good, and that is improving too.

The early diagnosis was so important for us, and I think we have to thank our very good GP who was insistent all along that, when he had his 12 monthly medical check-up (Edward also had high blood pressure), he had a PSA test as well and this is what picked it up. I tell everybody I know to have the PSA test!

Lift through prayer

I did a lot of praying during the various stages of the journey and that lifted me. Also, for both of us, it was getting knowledge and information on what we were dealing with and what could happen. That empowered me, and both of us, enormously; not just medical information but wide ranging, relevant information. A lot of information from the Cancer Council was just like that. It was easy to read and understand. For me, knowledge gave me hope. Being a Christian and praying – that all helped too.

My spirituality helped me in that there was someone I could talk to other than friends. (Edward is not a very spiritual person.) During the treatment phase it was the doctors who helped – the urological specialist and the oncologist. They gave us so much faith. They were so organised and provided so much information about what was happening and how it was done. That was definitely the doctors who helped us. They were

very positive and very sure in themselves and knowing what they were doing. I really appreciated that.

“Watchful waiting would have been difficult”

We’ve been very, very lucky because I know that in the support group we go to, there are a few people who are not in as good a position as we are. They are still struggling a bit with things so I feel very fortunate. I think Edward feels this way too. We are so pleased that we didn’t do watchful waiting. We would have both found that very difficult knowing that there was something in your body that nobody was wanting to do anything about. There have been people who have accepted this position and have monitored themselves, but I don’t think either of us would have dealt with that very well.

During my personal journey as a whole, my Christian-based spirituality helped me to realise that through my prayers, God put me on a path that gave me the facility, or the people who came my way, that provided me with the information that helped me cope. I did pray about that, that we would make the right decision. When you find the right doctor, there is somebody ‘up there’ helping you. There are a lot of doctors out there like our first one. It’s a bit of a worry. This spirituality has always been a part of us, but, more for me.

A shared experience

Edward and I have always discussed everything about the illness together. I went to all the appointments with him. Sometimes he gets a bit frustrated because things have changed yet he had no symptoms. He had nothing prior to being diagnosed. But then he came out of the treatment not being what he was before he went in. He found that a bit frustrating. Sometimes he gets a bit meditative about that and then we discuss it. There can be arguments as to why he is feeling despondent, and why he is not feeling positive when his diagnosis is not good. However, he does lift himself up because he does know that things have turned out, at this point, very positively. So then we have to get past the

things that irritate him, like having to get up to go to the toilet a few times a night, which he never had to do before. His sexual function is vastly different to what it was before, but it's still there. He has had to come to terms with all this and it hasn't been easy, but he has his life, and his prognosis is really very good. We try to focus on the positive things. He still works part time so he keeps himself very busy. We both have a busy life so we don't sit around and dwell on things all the time. If he was not a well man as some men are, it would be much more difficult to cope with.

The right time

There is still a slight fear in the back of my mind because I've been associated with cancer a few times. My dad had prostate cancer and my mother had breast cancer, but you have to be positive about it, and I have to be positive for Edward's sake. But, nevertheless, there is always a niggling fear at the back of your mind that it could rare its head down the track. But, I put it to the back of my mind and that's very often when I pray to God. I don't necessarily kneel down, but I might just be busy doing the housework and I'll talk to God and hope that He gives you the strength to cope with what comes your way. I liken this experience to the one we had when we were changing countries. There were a lot of obstacles that came in our way but eventually everything happened in the best time-frame. This has happened in our cancer journey. We have been able to see the right person at the right time. It doesn't always happen in your life, but you are very grateful when it does.

Fiona

Jumping PSA

Frank was diagnosed with prostate cancer some seven years ago. He had been having health checks for years because he is one of those who does

look after his body. He had his PSA readings taken at those checks but all of a sudden he decided to have his PSA tests done more frequently. His father was diagnosed with prostate cancer and I think that pushed Frank to have his checks more frequently than he would have done. His father had radiotherapy.

When Frank had a biopsy the cancer turned out to be quite strong. The PSA had jumped a long way from the previous time. The biopsy showed he had a Gleason score of 7, (3 + 4). He had radiotherapy; they wouldn't operate on him because of his age (almost 80). We said we would not have the surgery. But, when we look back on it now, we would rather have had something different. When he heard about it, he would have fancied having the seeds (brachytherapy). One of our friends had these put in and he functions better. Frank had a lot of trouble with radiotherapy with bowel bleeding and all sorts of things like that. Since then he has had several goes at hormone therapy. That's not the best in the world either.

“Stop the drama queen stuff!”

In himself, I think he is almost afraid. About three years ago there was a spot on the base of his spine. They didn't know whether it was arthritis, or whether it could be a secondary cancer. But at this stage, it hasn't altered. He is a bit of a panic merchant and he says to people, “It has gone into my spine now”. I told him to stop the drama queen stuff, because that hadn't been proven! It is exactly the same as it was three years ago. So the medics do feel that it is arthritis.

He takes his health seriously. He will be 80 next birthday and he doesn't take any extraordinary medications. He does take quite a great deal of complementary medicines. He is under a naturopath. He believes in that, but I don't quite. If he goes into that, that's OK by me.

A changed relationship

We have never lived in the same house. We spend quite a lot of time together – we go on holidays and things like that. We contact each other

a couple of times a day to make sure we are OK. We do the family things together but we don't live together. He just lives down the road from me so we are in close contact.

I personally felt OK at the time of Frank's diagnosis because I had been down the cancer path myself. He tended to see himself dead already. This seems to be fairly normal with cancer. When a lot of people are diagnosed – they are getting along very nicely and then here's this rotten thing (cancer). I think he was more afraid of it than I was.

Frank's diagnosis affected me because there was an alteration in our relationship. We had been having lots of fun together. It's great to have someone to do this with, but then he became cautious all the time so it made a lot of difference to me. For example, if I cooked him something he would say, "It's got such and such in it". He also tends to get a lot of misinformation such as, "The seeds of capsicums are poisonous"; then he finds out it isn't quite right. That made a big difference to the ways I did things for him. He became more, how shall I say it, more babyish? You get empathy from me – you don't get sympathy.

"You live with cancer, you don't fight it"

When things changed I thought, "Oh no, here we were having a nice life together ...", but, I know what happened with me and I know what happened with other people. You live with cancer; you don't fight it. It is a part of your life. It doesn't have to overwhelm everything. I was more optimistic, but I really did feel bad about it. I seemed to have been free of it all of this time and I'm feeling good about that and, lo and behold, Frank gets it.

I had planned to go on an overseas trip with a friend but I cancelled that because I wanted to stay home and be part of him. I didn't feel that I could go away. I didn't want to do that. I did later on and I'm going on another one shortly because he is OK. But I think that sickness can be a tyranny, that you can revolve around it. Initially, I gave Frank every bit of attention I could because you have to have someone to say, "Come

on, we'll go here now and we'll go there now". It's not quite so frightening if you are going with someone. With the tests that happen, it's a whole new world. I know how frightening it can be because I was overseas when I found a lump in my breast and came back to Australia as I couldn't handle it by myself. I was understanding of that in Frank's situation.

"I feel a bit cheated"

I might say that I felt a bit cheated that part of my life has been truncated. I don't feel like that now, although I do feel sad. But, then again, we are both getting older so probably half the stuff would happen anyway. But, maybe not. I can't go on holidays with him now because he gets too nervous when he is away. It has made a great deal of difference to our lives.

His hormone therapy treatment did affect us as a couple. He threw temper tantrums – not so much around me but when he was outside. I think he felt pretty rotten most of the time. I know how I felt when I had menopause when things would irritate me. I could see where he was coming from. He would kind of say, "I'm allowed to do that because I am having this hormone therapy".

Messed up

Frank did have a little incontinence, but when he had radiotherapy, sex stopped. He had no interest in it and I don't think he could have had an erection if he wanted to. Up until then we had quite a regular sex life and I was enjoying that, and then it was turned off because of this. I felt a certain amount of frustration about that because when you have something regularly and then it doesn't happen ... Then he came good for a while, but it was never quite the same. It wasn't so much dysfunction; he couldn't hold it as much. Then he went on the hormone therapy and it messed it all up again. When he came off the therapy he wanted the sex back again but I said, "I'm sorry, I can't do that. It's not fair to me". He understood that. Because he had been on the hormone

therapy and had quite a long time of it, and then wanted to start sex again, I said that I couldn't do that because it would be too hard coming off it again. Enough was enough for me. It was really good too. It helps keep you young, you know. It makes the body function better. So that means the women suffer from prostate cancer as well, don't we? I imagine it happens in other places as well.

We still hold hands

But, we still sit and hold hands. This might seem funny, but I think in a way he is a bit relieved. He has had this Methodist outlook. Mine was a bit different because I was a Presbyterian. But we still hold hands while we are walking down the street, and while we are watching television. Or, we might snuggle up on the couch and listen to music. We still have that companionship. He chooses not to sleep in the same bed as me in case he wets himself. He doesn't do it all the time; it's only some times. That's mainly him. He gets up and down all night going to the toilet and disturbing me. He doesn't want to do that. I talk to other women in the carer's group and different ones have said, that they just stopped having sex altogether. Some people just couldn't be bothered. There's a bit of age in there as well!

Being around positive people

I have found that exercise and meditation, and being around positive people, has helped me cope immensely. Getting with positive people is important. Some people with cancer have a lot of negatives. One of the reasons I still go to my cancer support group is to be around positive people. If they whinge and moan I just get up quietly and leave. One woman came to me one time and whinged a lot and I asked her not to tell me anymore. She was quite shocked!

I've had many difficulties in my life and I got rid of those. I have had to face and stand up to those, but Frank doesn't look at things straight. That's one thing I wish for him. I learnt at my cancer support group that cancer does not have a chance to take a hold unless I become helpless

and hopeless. Frank has had experiences in his life that have caused him to become very stressed. I just wish for him that there can be something positive. Cancer does not have to be all bad.

Differences in attitude

My spirituality was confirmed by the cancer experience. I think I was wafting in and out of it a bit and not being positive with myself about it. Spirituality was something I wanted but I didn't seem to be able to give myself full permission to do that. I had breast cancer and, standing in front of the mirror and seeing that I had my breasts removed, (and having had a hysterectomy, that isn't obvious because it is out of sight, out of mind), I was faced with a lot of things from my own experience. It has taken a while but I am much more able to make positive decisions in an easy manner. On the other hand, Frank seems to fly by the seat of his pants. For example, he will read something and decide that he would have to do that right now! He will have sudden passions about things. We both have different attitudes about life – he is the pessimist and I am the optimist.

Making decisions

We do talk about a lot of stuff. I think we have shared quite a bit together. This has made us close in a lot of ways. We didn't pull apart and go in entirely different directions. No, Frank's prostate cancer didn't change the way we did things as a couple. We have been together for nine years. I was almost at the end of my working life, and he was too, so we were going into the next stage anyway. Frank intends to hang on. I am not unkind but I think it is necessary to think straight, and I do. But Frank doesn't want to hear so he gets angry. He's starting to not know where places are in our city – which says to me he might be following his sister's path and might have the start of Alzheimer's so it's a matter of me having to have a certain amount of patience. He stays in a flat of his own and is not eating properly, he expects me to come and feed him. There are other things like this. I said to him recently, "Do you think it is time for you to make a decision about where you want to go before

your kids have to make the decision for you”)? He surprised me by making a decision within a day that he would sell his flat and move. My goodness me, that was quick!

We are slightly different to people who are married. Because we don't live in the same house, we can come and go with each other as we will. We frequently visit each other and have time with each other's children. I always look after myself in Frank's interest. My cancer experience has helped me cope with the difficulties we have faced together.

Jean

I was born in Australia and in a little country town. I am 62 now. I don't really have a religious background but I am a Christian and my family is Church of England.

Nothing to worry about?

We went to our local surgery and the normal doctor we see was not available on the day we went. All we wanted to do was to get some more scripts. The female doctor wanted to do some blood tests before she handed out scripts to check his cholesterol level etc. She asked if Max had ever had a PSA and as he said that he had not, she said that she would include that test as well.

About a week later we went back for the results she was not available but our normal GP was. He started by saying the test results were fine but wanted to know why Max had a PSA test. I explained the reason why and then I asked him what the results of the PSA test were. He told us that his level was 11. I asked him if this was good or bad news. He said that there was nothing to worry but that when it was a 100 we should then start to worry about it. In the meantime he suggested that we come back in another three months for another test. We did this and the next test PSA result was 12. Again he said that we had nothing to worry about.

Three months later again we had another test and the results came back that it was 13. We were concerned that it was climbing but again he indicated that until it reached 100 we had nothing to fear. In the meantime, while we were waiting to go back in another 12 months for our regular check-up, we came across a friend who had been diagnosed with prostate cancer and his level was seven. This immediately set the alarm bells ringing for us, so we went back to the GP and asked him when we could have another test.

So we went and had another test and this time the results came back 17 and he said there was still nothing to fret about. I objected to this and started to explain about our friend. He put his hand up in my face and said, "I don't want to talk about it anymore". We said that we wanted another opinion so he gave us a referral to a specialist and sent us on our way. I actually rang the specialist rooms myself and I said that I would like to make an appointment for my husband to come and see the specialist. The receptionist said that they normally only do this on the basis of emergency. I asked her, "How much more urgent could it be?" and I explained about my husband's levels. She indicated that she hadn't received the result at that stage but I told her that I had a printed copy with me. She booked him in for Monday.

Action

So we saw the specialist and I had the results with me and the specialist immediately put him up on the table to carry out a digital, sent him in for the biopsies and, lo and behold, found that he had cancer! He actually wrote to the GP a week or so later and told him that this gentleman should have been referred immediately after the first PSA test, not now. Anyway the surgeon operated almost immediately. He had to take quite a lot of nerves out because the cancer had spread, not to the outside of the prostate, but pretty close to it. Max was extremely, extremely lucky.

An amazing urologist

The urologist followed up with us quite a bit and he was really an amazing man. We had every faith in him. So in the follow-up testing it was found that my husband's PSA had not come down to zero where we like it; it was still up around two so he said that there was obviously a little bit hanging around. He wanted to do some radiation therapy as well. This happened 12 months after the operation. So my husband had 33 radiation sessions.

In the meantime, while Max and I were going in and out every day for treatment, I became very sick with shingles ... through stress. My husband had to go for the treatment himself for the last two weeks without me. He then had a PSA test that indicated that the PSA had been brought down to zero which, hopefully, it still is. He has another blood test tomorrow to find out if it is still down there. Luckily for us, he was probably one of the lucky ones, but, no thanks to the GP.

Issues

There have been a number of issues associated with his surgery. Most of these relate to the nerve damage which was done when the open surgery was carried out. He still has incontinence now, which we are going to raise with the specialist when we see him in a couple of weeks. We would like to see if we can have something done about that for my husband.

The incontinence is difficult for me as well as for him because when he gets up and down, so do I. I have now had to leave work because when I had shingles as the result of my stress, it was most difficult for me to work. It was also discovered that I have a severe degenerative spinal condition where my discs are bulging. After about 12 months of perseverance I have had to leave work. I was a carer in the community. Now my husband has just retired and so we are now just spending as much time together as we can and doing the things that we just want to

do. We are actually going away in a couple of weeks just to catch our breath.

Despair – and hope

We actually left our GP immediately. He was a bit shocked but he should have referred us to a specialist much earlier. Once you have a higher PSA value you just need to have it checked. I was completely despaired when Max was diagnosed. I could see in his face the impact it had on him. In trying to help him I found that when he went to work, I would just fall apart. Luckily for us, we have some really amazing friends who were lifting us up by phone calls and keeping in touch. Then when we had the specialist and the new doctor now, it wasn't all doom. They gave us that element of hope that the illness does not have to be a death sentence. But we still, every now and again, have our down days. I lost my mother not quite 12 months ago and I was looking after her for about 12 years. Her death knocked me around for a good three months just because of the sheer business with some of the other siblings.

“My husband is my rock”

I'm lucky that my husband is such a positive person and he is my rock, and I suppose I am his rock as well. We have lived together for a very long time and we are just there for each other, and living each day for each other. We have decided that life is too short to dwell on what could have been, and now we just live each day as best we can. It's not easy just at the moment because he has this test coming up. It is always a bit of a worry as to what the results are going to be but we are staying positive that everything is going to be fine.

“I am grateful he is alive!”

One side effect of the treatment has been that my husband can no longer have an erection. This affected us for a little while but we spoke about it because we talk about everything. Then we said well, if that is all we have in our marriage then we have nothing. It worries him more than it

worries me. I'm just so grateful that he is alive and he is with me because so many of my friends I see when I go to support meetings are not so lucky. Some have husbands whose cancer is very advanced. So when you put it all together the sexual difficulty is the least of our worries. He now has injections. So there is still a little bit of intimacy and it has taken us just a lot of time in developing this in our relationship. But I help him draw the needles up now and we make a bit of a game of it – what else can you do? If you want that intimacy back you need to work together and make it happen.

I was talking to a lady yesterday who had lost all of that. Her husband has come out the other side of his treatment but she is still dragging her feet behind him. However, she went to one of the big prostate cancer seminars, and for her it was as if the light had been switched on. So when we go to seminars or to the support group meetings, they are a huge support for some of the ladies. But there are so many women out there who will just not reach out and ask for help. This is a big thing. I am not too scared or proud to ask for help. I think one of the major reasons is that some women do not want to talk about the intimacy aspect of the illness and the problems this can cause in the marriage. We know of one man whose wife left him because she could not cope with his lack of intimacy. This is real sadness.

I think that because my husband and I are both from the country, our thought processes are a little bit different to city people. I guess this is generalising a bit, but in the country I think you can tend to appreciate things a little bit more than what you do in the city. You're living in the fast lane more when you are in the city, but in the country you are not. You can make every day count more in the country because there are so many beautiful things to see. We both come from families with very old-fashioned values, so I suppose our background of parents having long marriages and things like that do help us a lot in our thinking.

Being positive

My positive attitude has been of great assistance in my being able to cope with my partner's illness. The most important thing for me is him, his well-being, his happiness and his health. I would never ever know what to do if I'd lost him and he thinks the same sort of thing of me. I think if you can help your partner by trying to stay positive and try to make things a little lighter, even though it is a serious situation, it does help you to get through it a little bit easier. Also, talking to other people who are in the same position, men and women, helps. My husband talks to men and I talk to the women, together with the specialist and doctors, they all help you a lot. They give you some degree of hope when you come out the other side. We are very comfortable with our specialist; you can ask him anything and he will be very honest with us about it. I think it's a huge step for anyone to have that amount of trust in your doctor.

I am not allowed to do any vacuuming or something like that because of my back condition. My husband bought me a little stick vacuum so I can do a little bit, but he still does the bulk of the vacuuming with the big machine on the weekend. Now that he's retired, he'll be able to do that more often. I still do whatever I can – I do the washing and the ironing, but he is a great help in the house. Because of this, I can now get out into the garden with him. It's a two-way street with some give and take. This can be with everything, with your health and also your whole outlook in life. If you want a strong relationship with anybody it is give and take.

Incontinence

We went to a seminar recently to try to help us understand more about my husband's incontinence problem. We had a doctor who indicated the possibilities of using a sling that can make you dry. We are going to see our own specialist first and talk about surgery but we are also looking at the possibility of talking to the other doctor about the sling.

Max has some excellent days but then there are the odd days where he has a very bad one, and after four years, I think it is his right to be able to stay dry. While this doesn't affect me personally, I feel very sad. I get upset because it is upsetting him so much. It's hard to watch him getting so frustrated. He gets embarrassed, and I try not to say anything. I know that if I was incontinent, I would be embarrassed as well. I try to make light of this. To help, I have three or four flannels that I always put beside the bed at night time in case he needs one. If we go away then I pack these into the luggage, or I take pads with me in case he needs one. I try to make it as easy for him as possible so that he does not get stressed or embarrassed.

We are a support for each other and you do what you can for the one you love. We've known each other since childhood. We've been together a very long time and we will have been married 40 years next year. It's a give-and-take situation in our relationship and I think that if you give as much as you take or, give more than you take, you are going to be a lot happier for it anyway.

A stronger relationship

I think that the difficulties that we have faced have strengthened our relationship. It has made us more aware; it has made us more appreciative, and it has made us think about each other a little bit more and not take each other for granted. Now we do things that make us happy and not what makes other people happy. Everyone has children who ask, "Can I have, can I have ..." We have children who sometimes ask this as well, but while we listen, we are more aware now of trying to help each other. We know that we still have quite a fair journey to go through because my husband's Gleason score was quite high. So it is still not a clear road ahead for us just yet. The road itself has made us appreciate the time that we have together and I think we just want to grasp every single moment we can and enjoy. That's the guts of it really, just enjoy.

I think it's really sad that there are still doctors out there who think that a PSA score of seven is no big deal. It is a huge deal because once it gets out of the capsule that's it! The other thing is that if there is cancer in the family genes, it doesn't matter whether you 35 or older, you have to check the cancer possibilities. I know I have advised my daughters to be checked for breast cancer.

More support needed

I don't think there is a lot of support from the government for prostate cancer to help men. They are the ones who are suffering equally to women with breast cancer. There is a lot of promotional and research activity for breast cancer but there is nowhere near the amount of this for men and prostate cancer. There is plenty of support for men if they go out there and to ask for it, but there is not a lot of money being provided to carry out research to eliminate prostate cancer for men. I think that's pretty sad.

I don't think there is a lot of information out there for men when they have treatment. I have a brother who had absolutely no idea that when my husband had his prostate removed, he also lost his sexual function. There are so many men out there who do not understand the impact it has on a person who had the operation, or their partners for that matter.

Helping others

My husband and I are very heavily involved with the prostate care group. We go to the group for men and partners and I go to the group that is just for partners. Once a month I share responsibility with another lady to have a meeting just for the women in our local area who need help. The ladies can reach out for help if they need it but they don't like talking about some of the intimate parts of it. Some of their husbands don't like talking about it to other men either. If people want to ask for help, it is there. But if they don't want to ask, there is only so much people can do if you are not prepared to ask.

I get very frustrated sometimes. My husband and I have a very good relationship but you don't like saying too much about the issues sometimes because it must be equally frustrating for them, if not more so, because it is 'their fault', if you know what I mean. Other than that, I am extremely happy to have Max with me and to share the rest of his life with me.

Couples

Bill and Sue

Bill. I guess it all started off when my GP gave me a blood test for the PSA . When the results came back they showed that it was a little bit high so he indicated that we should watch this. Six months later it was up a bit more so we cut back to a three-month interval. It again went up further and earlier this year it had gone up to nine and he decided that I should do something about it. So he sent me across the road to work with a young urologist. He did the physical examination and told me that I really should have a biopsy. So the biopsy results came back fairly high and he said he thought we should get it out in a hurry. This happened only a month or so later. I had a robotic prostatectomy. So that's how it happened. The bloke in the hospital rang me and said that he was quite confident that we got it all. I had a blood test two months afterwards and it showed a PSA value of .025. I thought this is quite okay but the surgeon wasn't happy with that so I'll be fronting for up another blood test at the end of this week.

Being prepared – both of us

When I was told of the diagnosis I had already mentally prepared myself because I was watching the PSA go up, and I had been talking to people. I know years ago it was a taboo subject but more and more people are

now starting to talk about it. My next door neighbour had his done last year and the bloke two doors up from us had his done last year as well. So it is a matter of just talking about it and I was prepared. I was hoping that there would be no problem originally but when the PSA started going up all the time I knew something was there. I didn't ever get shocked with a confirmed diagnosis. So I thought, well, this is just one of those things that life throws up at you; we'll go with the flow.

Sue. I felt much the same about the diagnosis. It wasn't a surprise for me. We are both pretty positive people most of the time and we just got on with it. The technology, information and expertise that is now available is good. We had a very supportive journey, and the time before the surgery was very short; it just needed to come out straight away – so we didn't delay. We had medical, family and friends' support, and it was our decision together to have the prostatectomy but there was never any real doubt about what needed to happen. We availed ourselves of all the information that was around at the time.

Everybody else was straight down the line and very positive, including the urologist. You realise just how common it is for people of a certain age and so we just decided to get it done and get on with the rest of our lives. Certainly it is not what we would have chosen.

Bill. I took the surgery very well. The fact that it was done on Wednesday afternoon and I was home on Friday lunchtime – it was just absolutely amazing to me. Everybody talks about it being a major operation, which it is. But nowadays, with the expertise and the robots, it's much easier. The recovery was quick. There was one bloke in the paper who said he was out mowing his grass within a week, but I decided I wouldn't do those sorts of things, just give myself a chance to recover properly. I did play on it a bit and said that I was in the convalescent mode and hanging in there!

Side-effect: only one

The only side effect really was the erectile dysfunction that comes with it but we were warned on that. We had 46 years of a pretty good relationship, and with all things are available now at some stage we will resume some sort of physical relationship.

I didn't have much trouble with incontinence. I went to a physio before surgery and he gave me exercises to do. Of course I had the catheter in for the first week which was a bit tough, but once it came out everyone asked if I was wearing pads, but I wasn't. I saw the surgeon after two months and he asked how everything was going. I told him that I had only one 'accident' in the whole recovery period in those two months. He was very pleased with the way it worked out. So that side of it was not a problem at all. I probably go to the toilet a bit more than I used to but I can sleep through all night now.

A positive hope

Sue. Bill is very patient, very laid back and I was very impressed with him. I'm very grateful. You hear the good stories but you also hear the ghastly ones. Bill was playing golf and doing whatever – gardening, travelling, exercise and all that sort of stuff. For some people it is not an easy journey but we were grateful that it was for us. The first week was not too flash but after the catheter was out he was a new man, which was great.

We have a very positive hope for the future. We just plan to get on with life. We are Christians and we know everything will be fine, whatever it is, and we will get through it. We are not seeing 'pie-in-the-sky'. You face the reality of what may, or what may not happen, but is not much point spending the rest of your life dwelling on that; we just think positive. We have a sound relationship and good family and good friends and we don't need absolutely anything more than that.

As far as our health is concerned we would much rather have Bill well for the next however many years than not. There was no doubt in our

minds at all about the outcome of this surgery and treatment. We have great hope; we just get on with things. We've had all these years together and of course stuff has happened in our lives but this is just another issue and we will deal with it as we need to in the future. I am aware that Bill talked about the manhood thing and how important that is in a marriage; so Bill and I have talked about that. Thankfully we can talk about it and sometimes joke about it in some sort of sense but it does not define who you are and that's really important I believe.

Bill. As far as my hope is concerned, when I first went to the surgeon he said he could give me an extra 20 years. So I thought, okay, I'm 71 that wouldn't be too bad if I can get there. That is why I hope next Wednesday the PSA will show up zero and remain that way. We will find whichever works best for us on overcoming the erectile dysfunction problem and just carry on with life as we are. We'll continue to travel.

Mutual support

We haven't had much to do with support groups. It is just that we have talked with our neighbours when the opportunities arise and we encourage one another. They have had the same problem and we support each other where we can. I know there are support groups around and very helpful especially for men reluctant to share. I'm a dyed-in-the-wool ex-farmer and work on the principle that we have been able to work through this together. As a farmer you cope with things yourself; you get stuck into it and away you go again.

Sue. I think the only other thing I want to say is that it helps to have a support network. We have Christian friends and family friends. We don't talk to people about it every five minutes, but if somebody brings it up when you meet them and they ask how things going, we are happy to talk about it. This is so much better than it was during in previous generations, or previous years even. Many people do a fabulous job of just getting on, and making the most of it and look for the positives. That's not 'airy-fairy'. The reality is that getting on with it is okay.

I've never really felt the need for a partner support group because we have very good spiritual and emotional support networks in our church and in our family group. I'm not averse to it but I just haven't had the need for it. The women who do not have such good communication with their partner would find things much more difficult particularly with the subject that she just couldn't talk about; I think this would be very difficult.

Choosing hope

Also we have sought and been given clinical information just to give a few more handles to hang things on and to realise that this is not the end of the world. We have very positive friends who have gone down the same track as Bill, so that's really encouraging for us. We are encouraged by other people's journeys and we are encouraged by Bill's journey because it could have been so much worse, I know. I wouldn't like to paint this story as 'everything is rosy in the garden' and that we have an unrealistic hope. It is hope because we have hope in our lives and this is just another aspect of life for you to choose to have hope, or you choose to have despair. The way we look at it is to choose to have hope.

Barry and Rosemary

Tests

Barry. In my particular case I had been having regular PSA testing and the results were all about the level of four. I then had a colonoscopy and the doctor reported that one side of the prostate appeared to be more enlarged than the other. I went back to my GP who had PSA tests done and it had leapt up to 7. He then referred to me to a urologist in town who said that the only real way to get a solution to this was to do a biopsy. That proved to be positive. He then referred me to a urologist in a capital city who comes through to town here and, as a result of that, he

basically said to me that there is only one option and that is to do something about it rather than just monitor it for the time being. As a result of that, both he and the other original urologist determined that my medical condition probably didn't justify having surgery. So that was followed by my going to a major hospital.

Just taking it back a step, first of all I had an MRI of the complete body and also a chest x-ray. From that I then went to the major hospital where he performed an examination of the bladder and a flow test, to see that there was nothing in the bladder. I was then referred to an oncologist at another major hospital. He broadly told me that these were the options: I could have brachytherapy or external beam radiation. I wasn't happy about external radiation because I did have a relative who had external radiation and they ended up burning his bladder. He ended up with major complications as the result of that. So for me the only option was to have brachytherapy. So I asked, "How long do I have with my options open?" and he said, (if I remember rightly), "Six to nine months". We proceeded with that almost straight away, and it was about 12 months ago I had the brachytherapy which was the insertion of the uranium pellets. I had considerable discomfort with this.

The other thing of course is that they emphasise that I had to use a condom if I wanted to have any sexual intercourse. So from thereon, during the journey you know that about every month there is some significant change in the level of discomfort and that sort of thing. This is just naturally part of the healing process.

Side-effect discomfort

The other thing I suppose I noticed was that my incontinence became a problem, and also I was having some difficulty with a bowel motions. I talked to the oncologist again and he gave me some tablets to improve the urine flow. I actually went and saw him again to try to minimise the constipation that was occurring at the same time. This seemed to work reasonably well. I'm certainly not having any trouble passing water now. The biggest problem was controlling it, and after the various readings

and discussions I had, this seemed to be really stress incontinence. This has certainly persisted and, of course, the only real answer to that is that that you really need to wear an incontinence pad. That in itself is not a complication it is just that I do have to comment on the fact that they give you a rash and that can be quite disturbing at times when you try to overcome that with creams. Probably the one that I most success with was Sorbolene cream. This eased the discomfort and I tried as much as possible not to use the pads. I guess in fairness, I have to say that I only use them as a precaution because very rarely do I have problems. The biggest difficulty I face is that you can be sitting down and then you stand up so that the urgency became quite pronounced so you had to get yourself to a toilet very quickly. Sometimes of course you end up with a bit of the dribble. I never recall ever actually having a complete loss of bladder control.

Que sera, sera ...

When I received the diagnosis I felt like a dead man walking! I know what this means because I had been involved with a lot of Vietnam veterans and the process just moved on and on. I had heard of prostate problems, then testicle problems and then it went to secondaries and so on, so it really was a case of “your number’s up”. The only difference is that you don’t really know when and how. You just have additional stress thrust upon you and this was difficult at the time. Once I’d been to see the oncologist and we had made a decision about what to do, I reached the stage where I was thinking well ‘whatever will be will be’. Of course, at the same time we were highly supported by our church group and by family and so on, and I think that from my perspective, everyone was taking a positive approach that the treatment would be successful. I did have some negatives because I immediately looked at the statistics of some of the people who’ve been in this situation and had been affected by Agent Orange. Their statistics weren’t very heartening.

Being positive helps, ... and helps

Rosemary. Barry's diagnosis did affect us all but we kept a positive attitude and tried to keep him positive as well because of the support of the family. I also had support because I went to a cardiac group and they were very supportive. I could talk to doctors and nurses at the hospital who were associated with the cardiac group as well and this probably helped my attitude to help keep Barry going.

Barry. I think we were all positive, which helped me quite a lot. Any kind of support you get is going to be helpful in dealing with the problem, and certainly I guess my comment was that Rosemary and I went along the journey together and, of course, the family was being positive about it all also. No one was saying, "How long have you got to go, boy?" Everyone was really saying, "Well, they'll fix it"!

Rosemary. As far as my lift and hope is concerned, I've been through a fair few shocks with Barry's health over the years. I just made myself think positive and I kept that positive attitude up for him and the children. I did get despondent sometimes but I just brought myself back out of it. I did this through prayer and reading different things about it and discussing it. I have a daughter who is also a nurse and I discussed it with her. I also admit that I tried to keep myself busy and keep that positive attitude towards everything.

Barry. I accepted that things were taking the path they should be taking. I did go back and talk to the oncologist to ask how things were going. I had done a PSA test and found that this had come down to three, which was obviously in a good range. I'm 72 now and I am due to have another one in a few weeks' time before I go back to the specialist. Provided things are still running along these lines, then we are meeting the objectives of the brachytherapy implants.

Living with brachytherapy

One of the problems associated with brachytherapy is that you cannot nurse your grandchildren. You just cannot have close proximity to the

implants. This, of course, goes even further because you have to declare yourself to the medical professionals. I didn't have any emotional problem when I was explaining this to the grandchildren. You have a little card that you can take along that you give to them. I have to say that there are probably very few in the medical profession who know what it is all about anyway. Even when I went to have an MRI, the person doing the scan had said, "Well what's this brachytherapy (sic) anyway?" I said in my blunt way, "It's like having a uranium mine in your bum"!

Hope

Rosemary. My hope for the future is that when Barry goes back to the doctor this time and has his medical, that things have worked for him. If they haven't, we just have to keep building our hopes up that the PSA will be diminish quite considerably.

Barry. If the seeds haven't worked, I presume my only other option will be to have surgery, despite the fact that they declined to operate the first time. On a positive note, the fact that the cancer was contained wholly within the prostate, and that there was no evidence of any patches anywhere else, if the seeds do the job then the cancer cells will be killed anyway. All I can say is, I'm positive.

Support groups help both

I did go to one of the support groups and think they are beneficial. To talk to people is very helpful. I believe they are very beneficial because they tell you about what the latest developments are in the field. More importantly, you don't generally run across too many people who want to talk about it except in those sort of venues. The other thing is that the people freely discuss how they are travelling during the journey and what the other options are.

Rosemary. I think it's a good idea to have a support group for prostate cancer for both the man and woman to go along because your partner speaks about things there that he may not speak at home. I think it's a wonderful idea.

Barry. The Vietnam veterans also have a lady's support group. They just invite the boys along occasionally and that's been very helpful as well.

Rosemary. The Vietnam veteran's partner group are a very good group as well. I've been very lucky because I've had lots of support. The groups help because, if you bottle all these things up, it doesn't help at all; it's no good for your nervous system or anything. I think any support group, if you can go along and talk to them, can help people out. It's the exchange of ideas and just generally talking about it to a group that know something about it.

Barry. It's a really good opportunity for Rosemary to get out of the house otherwise you are living in each other's hip pocket all the time. Rosemary goes to cardiac support group and I go to hydrotherapy as well. I go to a group called *The Roosters* which is an all men's group. It forces you to go out if you don't want to go out. If you don't attend, you feel as if you're letting the side down, and also you are not interacting with the people you should be interacting with.

Rosemary. While the Vietnam veterans group simply call themselves *The Roosters* ... (*Barry* – and of course, the girl's call themselves *The Hens*.) One deals with men's business and the other deals with women's business!

Rosemary. There is a very good book on brachytherapy which we give to our grandchildren to read. Ours then understood what was happening to their grandfather. We explained to the younger ones, but we gave the book to the older ones who were 12 and up to 20. It has demonstrations in it and it did help them a lot. They weren't frightened to kiss their grandfather and they knew exactly how to treat him. It is a very valuable book.

Phillip and Sara

Phillip. This narrative begins eight years ago. I had been having regular PSA blood tests that had remained low but the last couple, over a six month period, had doubled. I went to the urologist who performed a biopsy. This showed multiple areas of prostate cancer. The MRI scan and CT scans were clear. I was 64 years old. I was given the options of brachytherapy or surgery. Radical surgery was suggested because once you got the prostate out that's the end of it. So I said, "Go for it," without any question. So I haven't gone through all those hoo haahs such as needles or things like that; it was straight down the line open surgery.

Open, radical

Going back a bit, I went to a surgeon in a major city who specialises in radical prostatectomy. He said that the results had come back that I had a really very aggressive form of cancer and the sooner the prostate gland came out, the better. For me, the number one thing was to get it out as soon as I could. We should not think that it might go away because it won't. I had no problems facing this. As far as recovery was concerned, I had quite a significant problem in the first operation with my urethra which resulted in a blood transfusion. This resulted in my being sent home again before the surgery was completed and then coming back for the surgery about six or eight weeks later.

This solved another problem. Passing urine had become a bit sluggish; my age seemed to be starting to catch up with me, but it turned out that the surgeon asked me whether I'd had an injury in the area of the urethra at some stage. I'd then remembered that once I had been kicked by a cow when I was doing some herd testing and this had caused a hardening of some arteries and, lastly, blockage of the urethra as the surgeon was trying to go into the prostate gland. The second surgery cleared the obstruction and everything's been fine ever since.

Surgery was performed on a Monday and I came home on the Thursday and went back to work again virtually straight away. The full recovery took about 12 months, maximum. Going back to work didn't worry me because I was a physically healthy 64 at that stage. Hopefully this will continue. I had some difficulties for the first month, and afterwards just a little bit of incontinence occasionally, but I find I can manage it, so now it's not an issue. Sara came down with me and stayed close by.

Hope – a product of background

As far as hope is concerned, I didn't ever have any doubts about the outcomes of the treatment that I was having; not one. My background helped me in this. My father was a dentist so a medical atmosphere prevailed in the house that I was brought up in. I became very independent at an early age; I did my own thing. This independence has helped me to always look on the positive side of things. I have never had the issue of, "Oh, oh, oh, what could go wrong" type of thing. My positive attitude gives me a lift; I'm a realistic person.

Accelerated process

The operation certainly decreased my libido but then again I look at it from the point of view of my age. I was just starting to accelerate a process that was going to happen anyway. That's the positive side I see of it. In this regard, I didn't hold back discussing this with the urologist at my annual check-ups with him. So he suggested I just go to a health clinic and see what they can do. I did that and took the clinician's advice and went back to a satisfactory life again. Erectile dysfunction was the only problem I had and I just use an injection; I don't find this difficult to do. I see it this way: because you have had an operation you are going to lose part of your function, obviously. When that was pointed out to me I said, "Oh, well, so what, I already have a family I'm not going to have another one at my age; once is enough". It is really a case of examining what you've got there and how you can manage it so that you can continue with a satisfactory life.

Talking frankly and realistically

I haven't really become involved in prostate cancer support groups who had been in contact with us. However, the way I've got around support, and helping others, is simply to talk quite frankly and realistically about the issues when they arise with other people. They often come back and tell me later that they've taken that advice on board. With the erectile dysfunction issue, people just have to accept the realities and talk about it. They need to look at all the options that are on offer.

Incontinence was never an issue for me.

As far as my current situation is concerned I have six monthly blood tests and one annual full check-up. There is no really big ordeal. As far as the future is concerned, I have just been able to continue this with the monitoring of my health and then if something arises, to meet that as it occurs. There is not a lot I can do if it's going to return.

“Go on living”

As for my shorter term hopes, I will just go on living! I have a lot of interests that will help me to cope with the immediate future. I am still working in the agricultural profession but that's not the only thing I do. I have always tried to do exactly what needs to be done. What you also have to look at is the fact that even though you retire, it is important to continue to do things and be very active. This is always something I have been able to do. I have a full-time business, a consultancy and many other things that we do. This in itself is a very positive thing because it means that you keep yourself busy.

What helped me quite a bit was the fact that with Sara's help and nursing background, I was able to understand all the procedures from day one. There was no question, and that made it easy for me. I could also understand that people who don't have the background that we have would be wondering what was what, and this would make it very difficult for them. Lack of understanding fuels feelings of doubt, which

I haven't had. This to me is a big positive reality. Understanding hospital procedures etc is second nature to her and she was able to translate that to me.

Confronting, and being positive

Sara. We try to look on the positive side of things which is possibly not quite the typical person. However, one of the worst things we did was to try to look up the topic on the Internet. If I had my time again I'd completely disregard that. Everyone is an individual and there are some most horrendous stories out there on the net and that wasn't particularly helpful for us.

As far as our background is concerned, we have been married 47 years and we do everything together and we have children and grandchildren so we share things, which is terribly, terribly important, I think. It was very confronting, there is no doubt about that, but then you look at your best options. You make sure you have a really good urologist, someone who relates to you really, really well. Initially when Phillip had scans and tests and things, the scans came back a little ambiguous because, with normal ageing, they were not absolutely sure whether the cancer had progressed or not. I remember the urologist ringing him up at seven o'clock one morning and saying all was clear and that was a tremendous relief for us.

"For us, testing was important"

It was a bit stressful when we had to travel some distance to the hospital to have the prostatectomy. Because of the problem with the surgery, we had to turn around and come home again and then wait another eight weeks; but this was unavoidable. It did take about 12 months for Phillip's body to get back to normal; it's a huge assault on your body, it really is. Phillip had been having PSA checks religiously every couple of years probably from the age of 45 to 50. It was the actual rise in the PSA that alerted them that something was wrong. From our perspective it is the testing of these things that is very, very important.

Overall, as we were facing the issues associated with the illness, we don't want to sound bizarre but we really just got on with life. We had discussions with the urologist as to what sort of treatment was going to be best and then we knew that he was going to have surgery. When the urologist said, "If you have a prostatectomy, that gives a chance of a cure," then we just decided to go ahead. That just brought us together because we are very united. We knew about the prostate cancer support group here in town; we had a friend who was a member, and we knew that was available for support. We also had heaps of literature. We also had a family who were very supportive; they came with us when Phillip had the surgery. We felt very well supported. They didn't feel that they needed to support us but they wanted to.

Support

We have three sons and they are all different. The eldest son is religious and his way of coping was to involve the church and that sort of thing, and hopefully everything would be okay. Number two son is very practical and he gave Phillip things to do each week whilst he tried to take his mind off things. The third son would ring up to find out how he was but wouldn't mention anything about the prostate cancer. However, when we had to travel a long distance to the hospital he was the one who came with his young child to be with me. They are all different and they had their own ways of coping at the same time they were trying to help Phillip.

My nursing background certainly helped me in understanding the situation because this background made me very alert to medical tests and I would never have forgiven myself if Phillip had not had PSA tests and something had happened. I would have felt terribly guilty so I can't overemphasise the need for a PSA test because after all, it's only a blood test.

I am very positive for the future. We are both very fit and active. We both do quite a lot of things and have a lot of interests. We are very involved with our grandkids and our family and we have a lot to live for.

We have a very positive hope. One of my sons has chronic myeloid leukaemia. He takes medication and is doing really well. One of his brothers is a complete tissue-type if ever he needs a bone marrow transplant so it is all positive. I think this is another indication that we look at positive things. Things you don't want sometimes happen but we confront them when they come.

“You can work through it”

Our grandkids give us a tremendous lift. For example, our granddaughter is coming to stay with us tomorrow for a couple of days. I do other things like being a competition Scrabble player and I play golf, but nothing competes for us with our family. That's number one. We are very blessed in this way. I imagine that if somebody did not have the support that we have with this operation it would be terribly confronting. Perhaps we are a little atypical. It is important to realise that the prostate cancer is an illness that you can work through.

David and Pam

Being diagnosed, getting information and having no secrets

David. I had a senior executive position in a very large international company. I was fortunate to be diagnosed in an executive medical check. I had a PSA test and a digital rectal examination and the results showed that I should be examined further. A had a biopsy and this showed that I did in fact have prostate cancer and would need to do something about it.

The thing with us is that we are matter-of-fact people and have enjoyed a very long marriage and we are very close. The experience of going through the diagnosis of prostate cancer brought us closer together, if this was possible. What lifted us at the time of that diagnosis was that we systematically went through the pros and cons and decided on the

treatment option. This process was helped by us going away with two lots of couples who were very close friends. We went to a mountain retreat and read everything on prostate cancer that was available. This was 18 years ago. There wasn't much available then. When we came back from that retreat, and in talking to medical professionals that included a urologist and a radiation oncologist, we decided on the radical treatment. Then really because of our strong marriage, and our systematic way of working, we just locked into getting fit enough to be able to undertake the operation.

We locked ourselves into various compartments. The operation was done, then we locked into another compartment – that was recovering from it. Then we locked into another compartment when it was necessary, on the rehabilitation side. This included incontinence, which was fixed pretty quickly, and erectile dysfunction, which took a bit longer. But we came through that in a similar way; we just surveyed what we needed to do. Our open way and our strong methods and friendships really assisted the process because everyone understood what we were going through. I made no secret as to what it was all about. There was a lot of assistance from many people. I made it very clear at work what I was going through so that if I was affected in some way, they would understand.

Pam. At the stage of diagnosis David was 51 and I was 50. He will be 69 in a couple of weeks and I will be 67 at the end of the year. So it has been a fairly long journey but we have taken advantage of the fact that we have both been Sydney-based and close to a hospital for treatment, and we had the good fortune to have had an excellent urologist who was prepared to educate us further than we probably needed to go. However, he could see the purpose of having us qualified to take over and lead the support group at that hospital. This has been a great advantage because we have walked down the path with hundreds of other guys as well.

Supporting others

David. The urologist recognised that we were a couple, that we were very close, had a good marriage and despite the difficulty, we were coping well. He was grooming us to take over and help other patients. Really we have a lot to thank him for because that is in fact what happened and we've been involved in prostate cancer support for the last 17 years.

Pam. Also, with that involvement, we've been able to lock into all of the other medical professionals who are in the field. Whenever we had a query, we have been able to just ring them up and have the issue clarified - in this way we have been able to eliminate any difficulties which we have come up against.

David. As our experience in our support group increased, and this has not just been assisting local but also national and international people, we have been able to develop a tremendous lay knowledge. With our personal network of all these medical professionals, we have a lot of confidence in the decision that we took and how we can assist people and link them up with others who are going through something similar.

The support group structure, not just in our own local support group, but in the whole of the Prostate Cancer Foundation of Australia support network, has helped us enormously personally because we can share our lay knowledge of prostate cancer with other people. This gives us a great lift to work with others and it is particularly evident when we look at this as a 'couples' issue when we talk about incontinence and erectile dysfunction at forums with couples present. This gives us a lift in our own situation and it and gives us great satisfaction. The whole process of the early diagnosis, the medical professional who took prime responsibility for our situation and what happened following that, has benefited us immensely. You wouldn't wish prostate cancer on your worst enemy, but in our case we value every day because of our network and friends, and above all, we value our family.

Reactions to diagnosis

Pam. Just thinking of my reaction to David's diagnosis of prostate cancer, we had to try to understand what prostate cancer was in the first place because we did not know anything about the gland or what function it had, where it was located and why it was such a big deal. Then you try to understand where the cancer came from there so this was a steep learning curve.

David is one of those people who write lists. As soon as the diagnosis had been made we had to travel a reasonable distance to go and have a consultation with the urologist. As soon as we left the consultation, David walked out and said, "I've got to write a list and I'm coming home to do it!", so by the time I had seen the list I didn't have anything else to think about. I think what also had an effect on me was that I had lost my father in 1989 from a brain tumour so I was thinking, "Well with prostate cancer with an early diagnosis and its location there was going to be a much better outcome than there was with my father's tumour". I think I found it less of a challenge to know that we were going to get through that after having helped and coped with my parents at that particular stage of their life.

David. That's an important point that Pam makes because when we think about it, and in this kind of situation you do think about these things, Pam was intimately involved in managing her parents at the end for each of them and she could cope with the doctors and the information she was getting. She could cope with the workload, and the dislocation of the family. We actually had her parents living with us at various stages until they were hospitalised. All that family involvement in looking after her very ill and dying parents prepared her for the diagnosis of my prostate cancer and it must have had a very good beneficial effect on her.

Pam. I often find it really alarming when we meet people who have never had the experience of dealing with a life threatening disease, or even dealing with death. It is one of the things that we have made sure when we have been facilitating support groups that we always included a

palliative care doctor. People hear the words ‘palliative care’ and they run the proverbial mile because they think it’s impending death rather than just a slow process of dying, or something to get you through whatever treatment you’re having. They can help you with the drugs you’ve been given and can alleviate some of the anxiety and side-effects. I’ve always been astounded that a man can stand there and say that he’s never seen anybody die. Why not? It blows me away.

There is always someone else worse off ...

One of the really positive aspects of our coping with David’s prostate cancer has been that we were both brought up in Christian homes. We were both Methodists through our youth and early adulthood but, even if we don’t go to church now, we’ve always maintained that we are good Christian people. I think that’s always been a solid factor to our background. We also have incredible family support and friends. There is also always someone who has walked a more difficult path than what we’ve had put in front of us and I think these things give us the lift and the high to keep progressing through it.

David. Just on that point, I don’t think Pam and I have come away from one support group that we have facilitated without thinking how lucky we were because we would always find someone who is going through a hell of situation far worse than us. This is a double backhander; it’s a kind of inverse lift, because, while not wishing to find people who are in a worse state than you are, you say, “whatever I’m going through is nothing compared to what that person is going through”.

Pam. Another good thing is the fact that our urologist had a group of men who were telephone counsellors for him. We had a very high profile newsreader and David spoke to him when he was diagnosed and he was absolutely brilliant because he was the one of the men who started the Prostate Cancer Foundation of Australia through his membership of a Rotary club. He was always an inspiration. So many men came out of the woodwork once David had had his treatment and was willing to talk

to them about their cancer. These are very high profile guys in different business areas as well as university-based fellows. It was good.

David. It is really something that gives you a lift when someone who was very high profile comes to you to seek your assistance.

Completely free

I would regard myself as being completely free of prostate cancer now. In the support groups there are a number of men who had recurrences, but I don't think about this very much, I only think about the future of my prostate cancer when I go for my annual PSA test.

I had an open radical prostatectomy. There wasn't the option for laparoscopic or robotic surgery in those days. From the time of my diagnosis until the time that I was regarded as being clear of prostate cancer was a period of about four months. I went back to work at the beginning of the seventh week after the prostatectomy. In those days you had to have the time off work. They were very much aware that it was not just the external surgery which was the problem; it was the impact on the internal components as well.

Pam. We get a bit alarmed these days when someone has had a robotic assisted radical prostatectomy and is back outside playing golf or doing something strenuous three weeks after the event. All the bits have got to join back together inside so reducing the amount of time to allow this to happen is a bit alarming.

David. I had the obligatory six weeks of recovery, but then of course, the rehabilitation of the incontinence sorted itself out within about two months but then I spent longer time going through all the options related to erectile dysfunction and finally about eight and half years ago going to a penile prosthesis.

Pam. When we are talking about hope, when David has his penile implant done in a couple of weeks' time, he is hoping it will be as successful as the first implant. He just hopes!

Reflection and communication

David. With regard to our marriage and the way we operate it, we have a vast network of friends, and we take Christmas very seriously. We take time out and stay very close to home because we normally do a lot of travelling. This is a good time to reflect so we always reflect on the year that's gone and we communicate with friends and family that we want to communicate with, so Christmas becomes a very real family time for us. It gives us time to think about where we are at. In that context we are very fortunate people because we find that on reflection we have surpassed our own expectations.

Financially we are very comfortable; our families are all settled in their own homes, so our hope is to continue what we are doing to try to help our family and others. We appreciate every day. That's another thing that came out diagnosis – there is nothing in business that throws me. I have been involved in very big business decisions and management but nothing throws me anymore. There is not one time that I would get anxious about any of those types of situations. I've lifted myself above all that now having survived this and other medical things. All of this has helped the process (*Pam verbally agrees*) because, before my diagnosis 18 years ago, I had an excellent financial services network in insurance which was global and I've still got that, but we've also now got this medical network.

Another thing we cannot underestimate is part of our family psyche. We made a decision when we got married that Pam's job was to have our family and make certain that everything is OK because we were travelling a lot even in those days. We are now looking at our 26th house in 47 years of marriage. So Pam's job was not to be outside the house but to stay in the house and keep me on the road, and to look after the family and to buy and move in and out all these houses. So that partnership has extended to this prostate cancer situation because we do it together. I don't think anyone could keep up my pace individually because part of the pace is generated by Pam.

Hope

Pam. My hope has always been fairly positive. It's been generated by the fact that we have had three children and they had really good health all of their life – they are 40, 38, and 36 we have four grandchildren, and they are the greatest joy in the world. That gives us a lot of hope for the future if there are a lot of Sandoes around. As far as my hope with David is concerned, he is a hard man to tie down! He is a person who you would think, with all his experience of these health issues, would be more prone to running off to the GP like he always says that I should when anything happens to me. As far as David is concerned, it's like dragging somebody kicking and screaming to make certain he keeps the best of health. He does it for his heart health but sometimes for his general health he needs to perform better. I live in hope!

With the family, having two sons there is going to be the hope that in the prostate cancer world there is going to be a cure before it can become a problem for them. Our oldest son has to have his first PSA and digital rectal examination very shortly. I don't know that is something that you look forward to but it's something that is very little compared to what women go through. So I think the boys need to bite the bullet on this. We live in hope.

We actually had lunch with two 90-year-olds yesterday and I said to David after we had got them both back into the car and delivered them back home, "Do you really want to live until you're 90?", and he says, "Yes of course you do you know, it is good to make it better for yourself though." These people still lived in big homes and they just haven't taken the steps they should have. They would have a better life and it would be easier for them if they lived in something smaller and they have the facilities they need rather than trying to live the lifestyle which they have been used to. David and I have done that so that's a great thing that we have done. We know this will help our own children because you just got to face up to the demands that come with increasing age.

David. That's just prompted me to say that over the last two years with everything that's going on and how busy we are, we managed to downsize by selling our big family home. We asked the three children what they would like out of that home. They have all taken something so that when we go and visit them there is a bit of us in every home. That's been very important. Our new home is a lovely apartment which will take us to the next stage in our life because it's very secure; it's on the third floor. We come up in a lift and we have secure parking so we're taking care of all the physical things that we can. We've redone our wills and we couldn't be in better shape for the future in all aspects of our life.

Prostate cancer has been a catalyst for further development in our marriage and our relationship with our family.

Colin and Monica

We went on with life

Colin. I had a PSA test and a digital rectal examination on a pretty regular basis. After a few tests and one in which the doctor felt something on the prostate, she deemed it advisable that I go and have further checks. So I had a biopsy and it was discovered that there was something there. When I went back for the results, the Doctor told me that I had cancer. I should mention that I am an anti-theist, (I like to call it that way) so I'm not over scared of death but like everyone, I'm probably scared of dying. So I was a bit upset at the time but the cancer wasn't as bad as it could have been. At the time I was about 74, and I'll be 83 in a couple of weeks, so philosophically I thought, well, I've been told that you don't usually die of prostate cancer but you can die with it. So I thought that was kind of reassuring but we just went on with life.

Monica. Well I knew that the progress of prostate cancer can be very slow, but I had great faith that we would get over it, and we did. I wasn't worried that he might disappear on me or something. I was so pleased

that he didn't go to pieces, I guess; when he had the bladder cancer he was a bit uptight but with this diagnosis of prostate cancer he was much more relaxed.

Prepared for the shock

Colin. I had bladder cancer when I was about 46. They operated externally and removed the cancer. I had a cystoscopy quite regularly over a number of years. But I have no problems with that except for some irritation every now and again. What I'm saying is, that I have had some experience with getting a bit of a shock. So I didn't get a big shock with the prostate cancer. My wife and I are very much together; we do the same things. We are involved in theatre and other activities so this helped a lot.

When I had bladder cancer I had a mild touch of religion and that helped; but this time because I did not have any religion, that was not a factor in my coping with the diagnosis. It was just plain sailing. What made me a bit angry was that while the government suggested that we all should have PSA tests, when I was diagnosed with prostate cancer, I found it very difficult to get help. As far as trying to get an appointment is concerned, I just had to keep being persistent, something I've had to do quite a lot in life. Once the appointment was made and the treatment carried out, it was plain sailing

Treatment options – no worries

I didn't have any worries about the treatment options. I would have been quite happy to have had the surgery but the specialist said he thought I was a bit too old for that. Why, I don't know, because another specialist said, "I don't know why they didn't operate on you". However, while I was a bit disappointed with that, I still had the x-rays to check that the cancer hadn't spread outside of the prostate gland so that was fine. It was about six weeks after this that I had the radiation treatment. At one stage they were looking at brachytherapy but they had to cancel that because

they couldn't get the material from a supplier. So I had external radiation treatment and had around about 40 doses.

Being pragmatic

Monica. Well I am very pragmatic and I just take things as they come. I don't panic about anything so if it was happening to us, what were we going to do? We just went with the flow. I haven't had any prior illnesses but that didn't affect me in anyway. My thinking about Colin's illness was that there is nothing we could do about it.

Continued tests

Colin. As far as side-effects were concerned, it took a long time for my anus to calm down. Sexually, the radiation deflated that aspect of my life but it didn't worry me very much. After about three months, I had a PSA test again and I now have one every six months. I get a little bit apprehensive just before I go to the tests and get the results. I can usually see my regular doctor but I do see some of the interns. It's a case of different interns each time. One particular intern, about a year ago, gave me another x-ray. I'm having another x-ray before I go to see him again this week. The reason is that the PSA is gradually going up over the nine years I've had the cancer and have been having treatments. They just want to check everything out each year.

Just let it happen, and keep active

Monica. I must be a terribly insensitive person because I don't get despondent about anything. I am a fatalist, if there is nothing I can do to stop something happening, I just let it happen. If you fight against it, it gets worse. If there is something you can do, do it. If there's nothing you can do, don't try because there is no point in banging your head against a brick wall. I'm pretty focussed.

Colin. We are highly involved in theatre. I have given up directing shows because I'm getting a bit old. But I write a lot; I write about theatre and other things. I am reading reference books most of the time about many

other things. I like history, and we watch television a heck of a lot. Monica and I got together to revise a speaking course (we are both Toastmasters). Also, about eight years ago we did some work for an opera company in the speaking area. All these things get us involved and keep us active. This doesn't give us a lot of time to become despondent.

There are others ...

Monica. At the time Colin had cancer, I got in touch with Cancer Council Queensland in Brisbane and asked them if there was an accommodation space for us. It took them a couple of days but they did find a spot. They are wonderful. While Colin was having his treatment, they looked after the wives by taking them to craft shows and other activities. Everything they could possibly do for us they did. You can't praise them too much.

Colin. While I didn't go to the support group in the area regularly, I did get the newsletter. I did get some support and I realised that I was not isolated; I wasn't the only person with prostate cancer.

This might be an unfortunate way to put it but I actually feel a bit better because there are others with the illness as well. I write a lot of poetry and I did write a poem about the challenges of the man going to a doctor to have prostate cancer checks. This arose from a challenge that was made to me. A woman who had written about mammograms challenged me to write something about prostate cancer. So I did. I just find that it is useful to express myself in that way. I like expressing through poetry.

Keep occupied, and don't stress

I am occupied. It is so important to be occupied. I like to be occupied mentally; I'm not someone who likes physical activity as much. I was a long distance runner and swimmer at one time. The main thing is that I am now mentally occupied. I enjoyed doing things like this, telling my prostate cancer story. We actually worked for a university at one stage where we were acting out parts – I was a patient with dementia for example. This is being active.

Monica. Yes, that's the best thing, just keep occupied. Don't stress about things. Stress is about the worst thing that can happen. (*Monica was knitting right through the interview, that is, she was occupied!*)

Don and Glenda

A patient wait...

Don. When we came to the South Coast in 2002, we had to search for a new doctor and we found one who was a very good but old-fashioned practitioner. He had no technical equipment in his office other than a telephone; that was the only technology he had. But he was very, very good; he was a real practitioner so we went along to him for a couple of years and then, in about 2005, I got a urinary tract infection. He checked me out and he gave me the digital rectal examination. He said, "Well there is a bit of a lump there so you had better go and get a blood test for me". So we went and had a blood test and then when he got the results he said, "Well, there's our starting point. The reading is a bit high but it's not worth worrying about and we'll just keep an eye on it". So I went every three months for a new PSA test. He kept the chart going and for a while it was okay but then it started to go up. So he said, "Look, I'm a little bit worried about it so I'll send you off to a surgeon friend of mine in Wollongong". So I went to see him and he had a good chat to me and told me all the options but he said that at this stage we wouldn't do anything but keep a good eye on it. So he gave me an examination and indicated that I was a little bit lumpy.

So time went on and I kept having the regular PSA tests until they really did start going up but not dramatically, not some of the readings that I've heard about from other people. The PSA was hovering around the 6.5 mark. Then it might have jumped to about an eight so he said, "Right, you are going off for a biopsy". So I went for a biopsy and had six biopsies and when the results came back the specialist said, "Look, we

think it's there but there's nothing really dramatic showing up. Just keep an eye on it". So I did for about six months. The readings still maintained a slight curve going up but they didn't change dramatically, so I went back to the surgeon again and he said, "I think I will send you for more biopsies". So I asked him if we could do eight. You could still be conscious when you doing that sort of thing. So he sent me for those and I had eight biopsies. The result came back this time as fairly positive. So I went back to him and he said that he would refer me to a urologist who comes to Sydney. I went to see him soon afterwards and he explained the situation to me and the options.

I must say that the surgeon did explain the options to me and I had read by this time a fair bit about it. I had looked at the options of brachytherapy, of external beam radiation and this sort of thing. By this time my brother-in-law had already had the operation. He got over it very well and his reading was much higher than mine before he had the operation. I had a friend who had the radiation treatment and I thought, "That's funny, from what am reading, if you have anything other than the operation there is a possibility that if it comes back again, all they can do is really give you hormonal treatment to try to control it".

... then action

So I decided that I would have the operation (an open radical prostatectomy) and it was good because a couple of years previously to that, I had to give up the health-insurance which I'd had all my life. Mainly this was because of the cost of the insurance, plus the gaps I was paying when I had a few health events in about the year 2000. Anyway, we decided that we just could not afford to keep going so I was left in a public hospital situation. So the urologist said, "Look, I can do it for you in a public hospital. You will pay a fee to the hospital as an intermediate patient, and I will charge you 'x' amount of dollars". I told him that sounded reasonable to me. So we went along those lines and eventually, in 2007, I went to the public hospital and he did the operation. I was there for four days. I knew what to expect but it doesn't matter what people

tell you, you can't wear other people's pain. The treatment I got in that hospital and through the urologist was absolutely excellent. I couldn't complain, and would never have become better faster if I was in a private hospital.

Process of recovery

For the first couple of days after the operation I was feeling pretty sorry for myself, but I recovered pretty quickly after that. My wife, Glenda, drove me home and I started to recover properly. I'd say for the first two weeks after that you are rather uncomfortable; you feel a bit weak, I mean you had serious surgery, let's face it. You have to get over it. I knew what the consequences were going to be so I did have a good idea of the whole thing. Anyway, I got home and recovered. I should say that before I went to the surgery, about three or four months before, and this was knowledge from my brother-in-law I suppose, he said, "Look why don't you start doing the exercises now, the exercises to try to control your bladder". So I did, and funnily enough it only took a month after coming home before I didn't have to worry about being incontinent. About a month down the track I was starting to feel very well and was walking good distances again. There are a couple of things I did that I shouldn't have done. For example I did some gardening one day and my stomach felt as if I had pulled all the stitches out; but I hadn't. You try these things until you find out, don't you? The initial recovery was fine I was so pleased with all that.

Shock, but no panic

When I was first diagnosed I got a bit of a shock, I must say. I sort of felt, "No, it is not!", you know, it was a kind of denial. But then the doctor that we have was old-style but, when he told me after the first of the biopsies he said, "Don you've got prostate cancer". So I said, "Oh, poop, that's no good," but he straightaway told me the options. I did not fall into a heap. The worst part I felt was being fearful that something might be further advanced when they send you for a bone scan. That's not long before you go for your operation. I thought, "You know, if this

doesn't turn out too good then I am in trouble". But as it was, it turned out fine.

My brother in-law's experience helped me somewhat because by this time he was well and truly over his problem while his readings were higher than mine, and he had gone a lot longer than me before he had had the operation. The way he came out of it gave me a lift and confidence so I thought, if everything goes okay I'll come out of this fine. I'm pretty sure looking back that I didn't panic or go down in my own mental attitude.

After the surgery the urologist's wife had a baby so I didn't see him for quite a while. One of his offside's came in to see me and he was very, "Are you okay?" kind of thing. He didn't ask too many questions but I knew that I was going to have to battle it through the next month and I had a positive attitude that it should be fine. I was glad that the prostate was gone. It never occurred to me that I'd had the operation and there could be cancer still floating around inside my body. That was my attitude. Maybe later I did think it could be there still. The operation was an operation I wouldn't want again, but I got over it. My PSA now is virtually nil. I'd had the operation some seven years ago.

Side-effects – but, "you need to get on with your life"

I knew there were going to be side-effects although I knew I wasn't going to be incontinent, you have to be careful. You are not the same as you were before where if you wanted to go to the loo you could hang on; nowadays you have to make plans in advance. If you want to go for a walk with the dog and halfway through you think, "I should have gone to the loo first," you start looking around for a toilet nearby pretty quickly!

Another side-effect is of course that you are impotent to a degree. You put up with this. I just say, "I will 75 tomorrow – so be it". The operation saved my life I think. So that's the price you pay. Other than that, I don't

think about any of the side-effects to be honest. You've got to get on with your life.

I look after myself in most things although my blood pressure is a little bit higher than it should be at the moment so I do what I can about that – I go to a gym, I ride a bike now and again, but I can't see any point in sitting around worrying about whether cancer will kill me or not. I don't think it will; I'm pretty sure I will not be dying with prostate cancer because I haven't got a prostate. I don't expect to die of the repercussions of having prostate cancer. It doesn't mean to say that I won't die of something else that could be another type of cancer. But I certainly think I've got that one out of the way. That's how I feel anyway; doctors might see it differently.

A couple of times I've been asked to talk to people who were considering the operation. Doctors phoned me and asked if I would mind having a chat to a fellow if he rang me and I was happy to do this. I just told them my experience. What they did of course, was their decision. I had a talk to a friend of mine in Rotary before he had it and he was very sceptical about the whole thing but when I told him about it he said that he felt much better now. He had the operation but about a month later the poor bugger had a significant problem that was not related to the prostate operation.

Answering the many questions

I don't have a great deal to do with the prostate cancer support group in the area. I know the people who run the support group and they asked me to go but I don't really want to get too involved. My vision of support groups is of people sitting around talking about their operations and I just don't go there. If people want to talk to me they can talk about it, but I don't feel like talking about sickness all the time. When you get to 75, unfortunately half the people that you talk to in normal conversation want to talk about their illnesses and health generally. For a couple of years after I had the surgery and was feeling quite well again, people would still come up to me and ask me how I was and I used to try to pull

out of this kind of situation because I really was very well and if you say you are well, there must be something wrong with you.

My wife and I just got on with life. This is the other thing to do with Glenda my wife. She never ever let me feel sorry for myself and I really appreciated that. I suppose we all get a little bit distressed at some stage but I don't remember too much about it. If I did feel sorry for myself, it didn't last too long, I can assure you.

Involving the partner more

Glenda. When Don's journey first started I really did not have a clue what it was about. My father had died of cancer that went right through his body. He had his chemo and that sort of thing but I still didn't know what it was all about with him, and then this happened with Don. I really think that the doctors should speak more to the partner to let them know what it's about, what's happening. I used to go to all the appointments with Don but I kept on thinking, what is all this about? He'd had the biopsies and then he came home and told me about them firstly when he had six and then eight, but I still had no idea what a biopsy was for prostate cancer.

We are very positive people and I didn't think for a minute that Don wouldn't get through it. Really, it hasn't interfered much with anything. The treatment and recovery period went fine for him; we just carried on at home. A couple of times he did something silly and then he realised how important it was to rest. I asked him why was he doing that?

If there is one good thing that has come out of this is that he has to plan his trips to the toilet whenever he is travelling. He didn't ever have to worry about that before. Apart from this little problem we just get on with living.

Being resilient

I didn't really need too much support. I have a son living with us and he was helpful. We got a lift from people who talked about it to us. Don

really can't stand talking with people about health all the time. We really just got on with living. We didn't really need any support at all. I would have liked doctors to have explained more about it all because I really did not have a clue. As far as my hope for the future is concerned I think we will just keep going. We are going along nicely; we are happy. We just take whatever comes, I suppose. I'm very resilient, thank God.

Being proactive

Don. I've just thought of something I thought was important in the after-events. In our Rotary Club we had a couple of talks where people have been talking about prostate cancer. It's part of the campaign to help males become more aware of the illness. One of the local doctors came and gave a talk on prostate cancer and what we should and we should not do. He was giving all of these stats. It was quoted in the American Medical Association, and he was saying that people shouldn't be put through the PSA stuff because the journey they are going to go on is too severe and they shouldn't set off on that journey. I said a couple of things then but I thought it wasn't appropriate of me to challenge him because he was a doctor and I'm not. I asked a few of my fellow Rotarians at that stage what they felt about what he had said and they responded that they were a bit confused. I suggested to them that it was their life and they should be deciding on this sort of stuff. If the doctor does not want to examine you before prostate cancer or doesn't want to send you to find your PSA reading, go to another doctor because the problem I see is that people die because they leave it too late. That's not a good solution; is not a nice way to die. There is no need for men to be dying at the rate they are. The problem is that if somebody suggests that we don't worry about it, men think, "You beauty, we won't"! The message that has to go out is that prostate cancer is something that we have to be concerned about.

I think it was important for me that, even though I did not have any symptoms of prostate cancer, I did ask the doctor to check my PSA. For example, I had not been up at night for the whole of my life to go to the

toilet. To me, it is important to have the PSA test and digital rectal examination when you get to the appropriate age as a precautionary measure.

Jason and Kaylene

Jason. I was diagnosed with prostate cancer in December 2004. I had tests with my local GP beforehand just to have a baseline of where I was. I was 56 at that stage. So I had the PSA test. When the result came through he phoned and told me I had a bit of a problem; he said that my PSA was high. So I had another test and the result was again high. So he said he would refer me to a specialist in the city hospital. He did that. I was able to have an appointment fairly quickly so I saw him to discuss some options.

Questions – but not too many answers

On the second specialist meeting I had with Kaylene present, I quizzed him on his procedures and what percentage of his procedures had side-effects like incontinence and impotence. He stated that he had no statistics and he didn't keep those statistics. I asked a few more questions and he responded by saying it was quite obvious that I had been looking on the Internet at some of the American information on prostate cancer because he regarded the Americans as handling prostate cancer very poorly. I advised him that I hadn't been on the internet and hadn't looked at American data. Later in our discussions I asked him how he updated his skills. He responded that he went overseas usually America. I asked him why, given his earlier comments.

After further discussion and questions he said that he would book me in for an operation. My PSA was 12 while the Gleason score was 5.5. He recommended that I do something quickly. We said we'd think about it, so Kaylene and I went back to our country town to discuss the possibilities. We were concerned about his attitude and his haste in

wanting to get things done quickly. So I went back to my GP and told him I wasn't happy with the specialist. I asked him what other alternatives I had. So he told me about radiation and other possibilities. My GP thought that I should go back for another discussion with the specialist, which I did. I went back on my own and that was in April the following year after diagnosis. Anyway, when I got back home again, I said to Kaylene that I was very concerned about all the side-effects.

She drew my attention to an article she had read in Rotary Down Under about brachytherapy. It was conducted by a specialist in another Australian State. As this was some distance from where I was, she suggested that I phone him, which I did. Kaylene and I went to see him and it was so good to have a full team of people advising and discussing with me the options for my treatment, particularly the brachytherapy. We were very impressed with this specialist and the way he discussed things with both me and Kaylene. It was agreed that I come back again and do some more tests in a couple of weeks. So I went back, but before I did I contacted the other specialist and told him I would not be having surgery but would be having alternative treatment.

Questions – and some answers

When I went back for further tests they found I had an enlarged prostate. This would have to be reduced before I could start the brachytherapy treatment. I was placed on a hormonal program for six months. So I had this treatment and then in January the year following, these specialists invited me down to meet his team, which I did. I met with the anaesthetist, the head nurse, and a psychologist. I didn't understand why I would need a psychologist. The surgeon talked about what he would be doing and the nurse indicated what he would be doing during the procedure. The anaesthetist told me that I'd be having an epidural, and the psychologist said, "I'm going to tell you something; I'm going to tell you how you will feel. I will describe how it is when you get treatment. I'll also tell you what effect your treatment will have on other people close to you". It was just amazing. She told me that everyone would be

concerned about me and that everybody is waiting for me to have treatment. After you have treatment, you are still doing things. She was just so correct in what she said. I think everyone should be given that kind of information.

Lifted by people around me

I did have the stresses that she mentioned I would have. When you are diagnosed, all you hear about are the bad parts. As my surgeon pointed out, most people die with prostate cancer but not from it. What was marvellous was that I was uplifted at the time because people supported me; I had my family around me. I was very pleased that I had the treatment that I had. I was very happy with that. I knew about the possible side effects and what could be done. I looked at all those things and that was far better than having the prostatectomy, in my view. I stayed near the hospital for six weeks having daily radiation treatment. When I came back, people were saying, “Oh, you look okay”. Of course the thing is that you still have the prostate problem. Getting the treatment doesn’t mean to say that all of a sudden it is gone. You’ve still got it.

I was tattooed where the probes were to go in and I was advised that I shouldn’t lose, or put on, any weight. I had the epidural and after I’d had the probes I had two days of intense radiation. No one could come into the room with me. I didn’t have seeds put in. It was the early stage of the development of brachytherapy. They charged the rods with radiation. I had this treatment before they developed seeds technology. So in addition to the radiation charged probes, very soon afterwards I had six weeks of external beam radiation.

Camaraderie

It was interesting because those of us who were having this treatment, all went at roughly about the same time and being together every day for the time of the radiation we got to know people. We got to know what people have done and of course they were many people there besides just those men having radiation for prostate cancer. We build up a very good

relationship with others over the period that we were roughly together. What surprised me was the number of fellows who had a prostatectomy and then went back onto radiation. Some of the guys were telling me that the prostatectomy totally ruined their lives and that they would have never had the operation if they knew what was going to do such as wearing a bag all the time, or couldn't go out – all this type of thing.

Using my background to advantage

My background helped me to get through the stresses of the time. I'd worked with various organisations and I was used to asking questions and then waiting for answers. In my profession, it has always been a matter of asking a question, getting an answer and then asking why, three times! If the people I was talking to could give me good answers to the three 'why' questions than they knew what they were talking about. This happened in my case when I was talking to the interstate specialists looking after my brachytherapy. I was used to researching in the science area and I found it most interesting to explore new grounds with the brachytherapy treatment. My PSA now it is 0.02.

I've told a number of friends of mine about my treatment, but many people I spoke to could not have this treatment because for them, treatment was always urgent and a lot of them were not prepared to wait; they wanted to get rid of the prostate straightaway – to get it out of the system.

Support from everywhere

I received a lot of support from my work colleagues. I was working with a government department at the time and often the people supported me. They were just fantastic. They were interested in what I was going through by asking questions. If I wanted any time off it was automatically granted. One thing that they did do, which was very supportive, was that they didn't decrease my workload I had to do the usual going to meetings, do presentations and all those things. They didn't let me feel as though I wasn't pulling my weight even though I

was having the treatments. I really appreciated this; it gave me quite a lift.

I did get a lot of support from medical professionals who treated me. Any time I had a problem I was able to ring up the specialist and he was always ready and willing to answer. I got immense support from my GP. Kaylene was always fully supportive, and my four children. It's not an issue now; it's something that is over and, of course, something could come back, but...

Plans for the future

I have quite positive hope for the future in that we are doing a lot of travelling. We have grandchildren that we like to see, and I still breed racehorses. All these activities keep me going; they're my hope. You just have to keep getting through things and be positive. I was brought up in country towns then went to a city but was lucky enough to be back in the country. Because I've had to move around a lot, you get used to mixing and I have found I just have to get involved in the community otherwise people aren't just interested in you. I enjoy this. I've spoken to a lot of people who have asked about my treatment although I don't know of many who have followed exactly my treatment. Most have still ended up having surgery and I think is because they just want to get rid of the prostate.

Some shocks

Kaylene. When Jason was first diagnosed it was very difficult for me because it was somewhat unexpected. He had not been having any symptoms. It was a surprise, I suppose – he was still in his 50s. That was the first shock, I suppose, coming to terms with that. Then the thought of a prostatectomy was a shock and coming to terms with that was also difficult. There seemed to be a lot of other alternatives available but they were not really publicised. I found it very useful to read, and read again, Cancer Council literature on prostate cancer. Most people still think that the operation is the only way and doctors don't seem to promote other

alternatives. Our first specialist we visited simply dismissed the alternatives. This was very disappointing. You just felt you were coming up against brick walls all the time. We knew a couple of people who had the radical prostatectomy and they had immense difficulties and we weren't comfortable in going down that path at all. Every man is different and nobody can guarantee what results would be like for Jason.

On this lifestyle thing, that is why we were looking for alternatives. Jason just couldn't sit around and do nothing about it like you could if you were an older man. That was why it was very refreshing to be able to read the article by the specialists in the Rotary magazine. There was only one place in which this procedure was carried out in our State. Of course now this treatment has become more common and carried out in a number of places.

Stresses – and resolution

It was very stressful to see your partner with cancer and also the treatment prospects. The prostatectomy that was pushed was the one which would impact mostly on our lifestyle. We are not talking about an old man here. That was very stressful but once we decided to go down the other path, things started to fall into place more readily. We made a decision at the time that we would go interstate for the treatment there. Fortunately we had family there that were able to offer us accommodation. Once we make the decision things just started to fall into place. I'm sure we made the right decision.

What helped me was the fact that some years earlier Jason had been diagnosed with the possibility of a melanoma so we had a little experience with cancer. I think the other thing about prostate cancer is the pressure to do something immediately. If you really read the Prostate Cancer Foundation books, what you see is that you need to take time to think about it. It seems that a lot of people decide very quickly to have the surgery and regret it afterwards. They haven't taken the chance to think about the alternatives.

A joint journey

This was very much a joint journey for us. We discussed all the issues and we made decisions together. It is so much a lifestyle issue that it is important the partner is involved in decision-making. We were fortunate that Jason's wasn't the most aggressive form of prostate cancer – it was somewhere in the middle – but I guess that if somebody had a more aggressive cancer they would have to act more quickly than we did. We knew it wasn't the most aggressive so we had time on our side.

I didn't seem to need quite so much personal support because I'd already gone through the melanoma cancer problem and I think that first experience made me stronger. The other thing was that we were really quite confident with the treatment we had chosen as we thought this was the best treatment for us. I also had the support of my family and I really didn't feel the need to go and talk to anyone else. The hardest part was in the initial decision-making process. You can go and talk to all the doctors and discuss things with them but at the end of the day you have to make the decision yourself.

Being positive

I didn't talk to any partners of other fellows with prostate cancer because I didn't really know anybody at the time. We did have a friend who was in the same situation but her husband was pushed into having the operation which we thought was probably OK for him but it wasn't necessarily what we wanted. I really wanted to have a chance to have a look at all of the alternatives.

We have been working through the journey for so long now I don't have a problem anymore. This is not to say of course that another cancer could not show up next week, but I think, "Well it has not showed up in the last eight years ..."

Jim and Emily

Jim. I suppose being married to a nurse always helped us to keep track of our health, so when I was about 40 I started having my bloods done. I'm 62 now. Everything has always been clear – fine and well. About this time of the year I usually get my bloods done, and in 2011 my PSA was up. It wasn't high, I think it was about 4.2 where it was normally in the two range. So I got a call back to the doctors thinking that something needed to be corrected with cholesterol or something. Then when he told me it was the PSA – it was a rise, which he considered to be above normal. Then he recommended that I see a urologist. So I went to see the specialist at a hospital and he was concerned that the rising of my PSA was probably four times the normal, even though it was still low.

I did have a history of prostatitis so I just put it down to that. So the specialist put me on some antibiotics over a period of about a month. I had another PSA test done but the level had not come down at all so he recommended that I have a biopsy, which I did. He was meticulous in what he was doing so I just trusted him wholeheartedly. I knew of his family – he comes from a family of medical people so because I knew his background, I had utmost confidence in him. So when he suggested a biopsy, there was never any question about it. I had a biopsy and when the results came back it was on the Gleason scale of about seven. He told me that he had taken a biopsy in six places, one of them was clear, another was that Gleason score was six and the others were of seven.

Treatment alternatives

He offered me alternatives in treatment but I was hell-bent on getting rid of it so I decided to have a laparoscopic radical prostatectomy. So that was done in November after the blood test in July, three months after the initial diagnosis. The results came back indicating that all the margins were clear and I was only in hospital for three days. Within two months I was pretty well back to normal. I turned 60 in the following February. The fact that I got it early meant that my confidence was always high. It

was tough, but I never took it as a death sentence. It was basically a medical procedure that fixed me up. Emily has a nursing background. I don't know whether you've had much to do with nurses but they are pretty pragmatic people and they work on the principle that the job is not completed until the patient is fixed up.

When I first got the Gleason score back it was numbing – time just stood still; is this happening? Is this real? But I knew that something could be done about. I didn't know anything about the terms. For example I did not know about the Gleason score. It just sounded bad. When I spoke to my daughter about it she just simply told me to get onto Dr Google and find out about it. My younger brother about five years previously had a similar situation; he actually had the da Vinci robotic procedure. He was all clear five years later as well. As far as I was concerned, I started to accept the situation because I'd always been healthy even though I had a number of skin cancers, and I knew that while it was serious it could be overcome. I never accepted it as a death sentence.

“I flew home!”

Emily. I was in the supermarket at the time that Jim rang. I remember being near the deep freeze getting a message to say that Jim had received his results and I expected the message to say that everything was fine but what he said was that ‘I have tumours in four sections of the prostate’. I remember people coming up to me, particularly one I had not seen for a long time, and she said, “Hi Emily!” and I responded, “I’m sorry I can’t talk to you at the moment”. I’ve never done that to anyone in my life! I just rushed through the supermarket and flew home. That was my initial shock. It was odd. But after I caught my breath and we talked, we said, “Right we will soldier on and talk about it, get some solutions and work out what we are going to do”. Now, every time I go to that supermarket I always think about it.

Jim. The specialist rang me and the first thing he said was, “Have you got a pen?” and I thought, this is not going to be good news, so I got a pen and paper because you want to write things down. That was kind of

surreal. Emily asked him the questions initially, particularly about the Gleason score. It was really a matter of disbelief at the time.

“Shell-shocked!”

Emily. I was probably more shell-shocked than Jim was initially because of my medical background. I’ve always been a person who likes to be fairly direct and look for answers so I sat down and had a cup of tea and I read what Jim had written from the Doctor’s. We had to get bone scans and all that done; we were busy making appointments. I remember the next harrowing part was when we were sitting in his waiting room and I had the scans in my hand, praying all the time, so we went in and he showed us the results and he was very confident when he looked at the scans that they were clear. Jim says that I made a noise like a moaning sigh; it was really a relief feeling. We had to go through the basics with the doctor and we felt that what we needed to do was to push on. My medical background meant that I was very relieved with the results of the tests. But I was also more concerned deep-down about how Jim was coping with it all. You remain a bit stoic yourself. I didn’t want to upset him too much but he was pretty amazing with it all. It’s been a big journey, though.

Jim. I think for me, it was initially not taking it as a death wish but something that we could fix up. I really stayed with that. I’ve done a lot of long-distance running, marathon running, in my life and I treated this journey like that. I actually treated it like a marathon and I journalled the experience. I have a daily journal and it’s a recurring theme in the journal. In a marathon it’s not the race that is so hard, it’s the training that is important. That is what helped me get through the waiting for the results of the tests and scans. That waiting period is always the hardest part; it is like putting 38 km’s into a marathon and the finish is not there yet!

Family gathering

As far as the recovery is concerned, we were at a hospital close to where we have a favourite holiday place so this became our base. It's absolutely glorious; it's right on the water. My eldest daughter had a baby earlier in the year and came to be with us and even on the day of the surgery my second daughter and son came to be with us. They were all there. I was surrounded by family. Being in an ideal spot probably distracted us from what was happening.

One of the problems I had was with the catheter. When they took it out ten days after the surgery I had to go back in a day later because I got an infection. That was quite a bit of a let-down and at the time I was pretty well flattened by it. Then I decided that I was going to completely abandon everything – just rest and not try to do anything – whereas immediately after the surgery I had tried to do too much. I saw that this was not a good way to go so I decided that for at least two weeks I would just lie down and take it easy. We stayed at our holiday house until the catheter came out the second time and then we stayed in a couple of days afterwards to make certain everything was OK.

Problems

Emily. One of the biggest problems I experienced was when, after the catheter was taken out, Jim had some retention and we had to go back to the hospital. We sat and waited and waited and waited in the waiting room. We were told that if there is any further problem with the catheter we had to ask for the original surgeon to come back and put it back in again and not allow anybody else to do it. This did eventuate and Jim and I were sitting in the waiting room and there was an older couple there and the man was in a lot of pain. I remember his wife turning to me, she didn't know what was wrong with Jim, and she said to me that they had just taken her husband in and he had bone metastases from undiagnosed prostate cancer. I thought, "We are counting our blessings here"!

You remember all those little things. It was harrowing for Jim – that waiting until the surgeon reinserted the catheter; that was shocking.

Jim. Yes, I remember this well because I was feeling a bit down when I thought that I would have to go in and stay in hospital again, at least overnight, but the surgeon told the staff there that I wouldn't have to stay because my wife was a nurse and we lived not very far away. It would be OK for me to go home. If there was any problem I would be able to get back to the hospital. So I was only in for a few hours as they ran antibiotics through my system and just made sure the catheter was okay again. If I'd had to stay in hospital it would have been quite a different story. In this case the doctor gave us a lift because he was the major player in trying to make certain all was going to go well for me. We had great confidence in him. Even as he was putting the catheter back in I remember saying to him, "I think I've had one of those near death experiences". He said, "What do you mean?" I said, "Well I've just been floating around the ceiling looking down and thinking, I hope he is not doing what I think he's going to do." He acted very swiftly and didn't wait for the local anaesthetic to work, he just put the catheter straight back in again.

Family lift

Emily. Our family is really very close. Our eldest daughter was there with our little grandson and the other daughter and our son. We all supported one another. We talked about it a lot. We visited and talked to Jim a lot and the nurses kept telling us what a wonderful patient Jim was, and we stirred him up a bit occasionally about this! The family really supported one another; we have a deep faith and we had a lot of prayers together.

Jim. It was great having the family there; we are so close and in particular with the grandchild I wanted to make certain that I could spend a lot more time with the family. That's why I say it was never a death sentence. It was great to have the family physically with me there at the time to give them hugs. It was very special.

The biggest side-effect was sexual dysfunction; that's been the hardest one. We have had to make big choices in that area. Initially the incontinence was frustrating. But I was pretty strong in doing the exercises and I would go to my own GP with whom I have very good relationship and he assured me it would come right and my surgeon also provided a few extra clues that were able to help quite a lot. Even now most evenings if I am tired little there will be a little dribble. You get fed up with the dampness.

Love – the physical and the spiritual

But the sexual dysfunction was most difficult. We tried Cialis and Viagra. I had a really bad reaction with Cialis; a lot of lower back pain and pain in the kidneys. I checked out with Dr Google and it was stated that a small percentage of people do have that reaction. But then I tried Viagra. I didn't try it for very long because of the expense factor so that didn't work. The whole area is still fairly tender so with any arousal at all I get a deep aching pain there. The nerves were damaged but it is painful. The other one was the penile injection but I decided the pain factor was too great so I didn't bother. So Emily and I have been married for 38 years and known each other for 40 years, our love is strong, so we have had to reassess and readdress the way we share our love. I only said this to Emily the other day, our love has gone from a physical experience to very much a spiritual one. The love that we have now is very much on a spiritual plane more than the physical plane. *(Emily was agreeing frequently in the background during this part of the interview.)*

Emily. That sexual issue has been really very hard; it is a loss. When we get too down about it as I said to Jim, at least he is alive. He is here and that's a very big positive. We are here for one another and supporting him, and today's talk is very good for him and me to talk it through. We get very busy of course. We still love one another as much as we ever did. He has put up with me after all these years. But the physical side of things has been hard.

Support and support groups

Jim. Emily and I are very private people so we haven't become too involved in support groups. There is a male nurse in a town not too far away from us and he made a lot of offers to help. It hasn't been so much a support group, but there have been a lot of the guys who have been more than willing to talk about the issues with us. I really haven't found the need for a support group as such. One of the reasons for this is that as we have said, Emily and I have such a beautiful relationship and I do have a strong faith so I can meditate and I can unload a lot of luggage during my meditation. I don't really find the need to sit with the support group.

I guess the other thing was that there was a clear finish to the problem because I knew within three days that the cancer had been contained. This is unlike some others where they had further treatment on an ongoing basis. If I'd had to have further treatment I would have definitely got involved with support group if I'd needed radiation or anything like that. So I'm still having checks. I've had them every three months and now they're every six months and the PSA has come back very low. And this is now coming up to 3 years ...

Emily. I've never had the need for a partner support group because I'm a very positive and determined sort of person and also very private. If we had needed counselling support we would have grabbed it if we weren't coping but I think we have coped with it that fairly well. We do talk about it all the time. We had one awful experience when the male nurse rang up one day when we weren't at home and he left a message. When we arrived home we just put the phone on speakerphone to hear the messages and we heard him ask how Jim was getting on? "How is your incontinence, and everything else?" It was unfortunate because we had a friend coming in behind us and he was able to hear this questioning and that was embarrassing. This was such private stuff I didn't really feel the message was adequate to leave, but, anyway, he was a very nice man but we didn't really go back to him again.

Sharing

Jim. One other experience we had was that I had a very dear friend who had the same experience 12 months after me. He wasn't aware that I had been through it. When he realised that I had, he and I were able to share issues quite openly without me telling him what to expect, I was able to understand and he knew that I was understanding. This friend was a missionary priest in a very tough area of the world where there are lots of drugs and murders and we emailed each other on pretty well a daily basis until he was out the other end of his experience himself. We were able to share quite a lot together and this was on a very useful one-to-one basis rather than being in a structured support group.

Emily. And I think you've got to find the right people in a support group and really feel comfortable, otherwise it can go the other way and be a very negative experience.

Jim. My younger brother having been through it as well, was able to provide me with some background experience. It's back to the family again; families can be of such great support.

Hope and lift

Emily. As far as hope is concerned I really hope that Jim stays well, and that I stay well – I've had melanomas. We're both well at the moment, touch wood!

Jim. With the grandchildren we have a wonderful hope. There is a beautiful saying, the blessing: 'We hope and we pray that we live long enough to see our children's children'. That resonates very strongly with us. Also, the fact that I got back to such good health within six months of my surgery gave me a big lift. I started to get involved in tall ship sailing again. I ran another half marathon and did the Overland Track in Tasmania. So within 12 months I was proving to myself that I was back to my best in my life. One of the big things I do now is to make sure that I do not put things off.

Emily. And don't get complacent yourself about good health; you have to keep your checks coming.

Jim. If opportunities come your way, weigh up the consequences and if the consequences of anything I think about are not too destructive, I jump in and do it.

Emily. I've been at work where other nurses sometimes come to me and simply say that they have a brother, or a partner or friend with prostate cancer and they really seem to want help. So I spend time straightaway just talking to them about the experiences that Jim has had and try to help them understand the issues and what to expect. So I have been able to say very basically, "This is our story". I tell them that communication and talking are very important and it was also very important to be honest with one another. Every day for us now, is a blessing.

Russell and Gloria

Russell. As it was my second bout of cancer, I guess it wasn't quite as frightening having been diagnosed with kidney cancer some four years before. So the diagnosis was probably not a shock to me because I had been monitored from when I had the kidney cancer. The prostate PSA was going up gradually and when it got to 4.6 the doctor said we'd better have a biopsy. I had the biopsy and the PSA continued to climb to 6.7. I started treatment about four years ago. I opted for treatment in my local hospital and I had radiation each day for eight weeks, although there were a couple of days I didn't have it when they service the machines. I still worked while I was having the treatment. I don't think I had any days off while I was being treated. I would go to work then duck up to the hospital. I was away for about an hour then I went back to work. I did feel a bit tired at the finish of the course of treatment. Other than that, I didn't have any problems with the treatment at all.

No shock, and shock

My reaction to being told of the diagnosis of prostate cancer wasn't a shock because I had been monitored and I knew the PSA was gradually creeping up, so I guess the doctor was certainly concerned because whilst the diagnosis involved PSA being only 4.6, that's not particularly high. However, the grade of the cancer was medium so there is a bit of concern from that point of view. The Gleason score was seven.

Gloria. I felt a bit more shocked, I think. I guess I was living in a bit of a fairyland thinking he's had cancer once, it won't happen again. I was fairly upset but he dealt with it so well it was quite easy for me to get used to the idea that he was going through this again. I guess we took it one day at a time from thereon. As I said, it was really just an initial shock, but his reaction was great so after that I didn't have any problems at all dealing with it.

I received my lift during this journey by the way in which Russell was positively coping with it. He is a very strong person anyway and he hides his emotions fairly well, but I don't really think that was the case in this instance. He seemed to be quite positive and taking it just one day at a time. This was very helpful to me. When he had his kidney cancer I just about fell apart.

Russell. In a way I had two lots of cancer. My first wife died of cancer, 13 years ago. That was probably a bigger shock to me than anything else when she was diagnosed because, like many other people, I'd had nothing to do with cancer prior to that. Gloria and I were only married a few months when I got the diagnosis of kidney cancer, so that was a bit of a shock. However, the medical profession had been monitoring the growth in my kidney for about three or four years. So by the time I got the prostate cancer I had already felt and experienced some of the emotions that go with cancer so it I guess it wasn't quite as hard to cope with.

I was reasonably positive from the point of view that I'm the sort of individual whose glass is half-full rather than being half-empty. That probably helped me cope with that too, and the fact that the treatment was able to be held in my home town was brilliant. I feel for people who have to come in from out in the country, leave their environment, come to a strange town and they are sick at the same time.

Many lifts

Russell. At the hospital, I did get to know people quite well who were being treated. What probably helped me was that a lot of people were quite a lot worse off than I was. This was another thing that gave me a bit of a lift. While not many people had prostate, there were younger people I saw who had quite serious tumours and I saw myself as being in a plus situation here. The fact that I could go to work probably lifted me because I didn't have to go and sit in a motel for so many hours after my treatment until the next time. I was fortunate I did not have to travel, but initially I was sent by the doctor to the capital city to look at brachytherapy and I almost opted for that treatment. My brother is actually an engineer at the local hospital and I spoke to him and he asked why I didn't have it here. I didn't realise you could until I spoke to him. So I came to the local hospital.

I didn't have any stress over the decision-making process about what treatment I would have because there was no real choice. I had asked the specialist whether I was going to have it out or should I have radiation. He indicated that I wouldn't need to have it out because it wasn't really bad, but the other thing was that I had my kidney operations on one side of my body and I also had a hernia operation. I'm 73 now and at my age they normally don't take it out, and I had too much scarring from operations in the area anyway. It was pretty much I was going to have radiation and that was it.

Gloria. I have been working in an industry for some years in which I see a lot of people going through medical treatment, and I've got very used to seeing people who have been involved in treatment. I have got to know

to a large extent what they go through, and how difficult it is or isn't for them. So as far as the radiation itself was concerned, I was never going to be concerned about that because very rarely had I seen people who had massive issues that caused them any problems. But as far as Russell having treatment was concerned, I was quite happy about it. I really wasn't interested in him having brachytherapy because that didn't sound very nice. It really sounds a bit barbaric, but the radiation was never going to be a drama. I was OK with it.

Concern about the side-effects

Russell. The side-effects did worry me because they were unknown for me. I should say that I had the gold seeding to assist in the radiographers knowing exactly where to focus the radiation. I did have concerns about that so I asked the doctors about it but I was fortunate because I had no after-effects at all. I don't have any side effects that I know of from the radiation treatment. I did have a little bit of bleeding afterwards but that was nothing. I've had to go back every six months for checking but the last time was 12 months ago. My PSA that was about .78 then.

Gloria. My main perspective as Russell's partner was that I was just really concerned about his well-being and whether the treatment would actually work. I did have a little feeling about the treatment failing and my losing him, but I guess that was just a bit selfish of me, to be honest. I always knew that with his positive attitude it would be a whole lot less traumatic than a lot of people seem to make it out to be. I was not distressed by the whole process, put it that way. I will admit that initially, I had a few tears, but I think Russell's positive attitude was all that I could ever hope for and made it a lot easier to deal with.

Hope – every day is a bonus

My main hope is that I keep Russell around for a heck of a lot longer! Having just found him; I'm not losing him now. I have three children and Russell had three – all grown up. We have six grandchildren between us and these are about four-year-old to 18.

Russell. As far as my hope is concerned I suppose that I'm 73 now and when I wake up every day it is a bonus.

Gloria. I would like to have a Russell around a lot longer so I can dance a lot longer!

Russell. We do a lot of rock and roll and this probably keeps me active. We continued to keep our dancing going while I was having treatment. This probably kept me sane. If I hadn't been able to do that I would have been very disappointed because after I had my five days of treatment during the week I could look forward to the dancing on the weekend. I was glad that I could do it; and the treatment didn't stop me at all. I guess I'm 73 and still working; I work around 60 hours a week and I am still coping.

Gloria. He can keep up with the best of them.

Russell. With this background I have to say that I am not a person who is ready to sit down and die. There are other things I do as well. I'm on the Board of Directors of a not-for-profit organisation, and I do put time into that. Ultimately, I just hope to stay alive and keep going the way I am. The most important thing for me is health. While I've got good health, I'm happy. I probably will retire in the not too distant future but I haven't made that decision yet.

Family support

Gloria. I had terrific support from my mother, I was able to talk to her. There were my children and even Russell's children. We talked fairly regularly and I think we all got something out of that, being able to support each other. We didn't go to any formal support groups at all. I didn't have to call Lifeline in tears or anything. I think just having family to support was probably in my case the biggest thing. When you are feeling down you can talk to a family member and they can usually talk you out of it, or snap you out of it, one or the other. So really, I didn't even feel the need to talk to a formal support person or group whenever

I had the family to talk to. Russell and I could talk about it openly as well, (*Russell - which we probably did a fair bit*).

Russell. I guess the fact that Gloria and I, as well as being husband and wife, are very good friends and we do talk a lot about things like this. Sometimes, yes, I did get a bit emotional about it when I was having treatment, and when I was a bit tired, I suppose. I don't think there was anything unusual. I guess I'm a coward because my thinking was that if I die from it, I won't know. You never know what happens with cancer because you know that you are never cured of it, except that the longer you go without it recurring, the less chance there is of it recurring.

One of the things that I'd like to point out to you is that the first time I went back to the doctor, that was about three months after the radiation, my PSA was about 4.7 and I was really concerned then that it hadn't changed and the doctor told me not to be concerned because it can take up to 2 years with some people. I knew that some other men who had been going through the treatment at the same time as I was that their PSA had gone back to one or under. Mine took a while to come back; it sort of went back 3.8, 3.5, 2.6. The doctor said to me that very often the longer it takes for the PSA to come back, the less chance there is of the cancer recurring. Whether that's right or not, I don't know.

Leading a normal life

If I can be of help to anyone I don't mind helping out by talking with them, I think some people don't join in support groups because they don't like talking about it very much, and sometimes people in a lot of those groups are a bit negative. As far as I'm concerned, I've had two lots of cancer I been really lucky, I've survived both and I can still lead a normal life.

Alan and Margot

The start of the process

Alan. I'll go back to the start of the process. It was about this time last year when my PSA started to move up. My GP told me that we would keep an eye on it and she gave me a blood test for later in the year. She actually told me it should be in about December. For some reason, I don't know why, towards the end of October I chose to have the blood test then. At that stage the PSA reading had already spiked at about 7 or 8. The doctor then decided that I needed to go to a urologist. The moving up of the PSA was the trigger so I was sent to a urologist who then sent me for a biopsy. I had this done in November. That was sent away to be checked. From the point of view of both me and Margot, that was a pretty distressing time, just waiting for the results. I had the biopsy on the Monday and then we went in to see the urologist on the Thursday. That's when he gave me the news that the biopsy had tested positive and that I had prostate cancer. Both Margot and I went in to discuss these results with the urologist. At that stage I found it very helpful to have Margot involved in the process.

It was then that it was decided to map out a course of treatment. The urologist we went to explained that generally, on an overall basis, when you're up to your early 60s, he would normally advise the removal of the prostate but, as I was in my early 70s, he said that the best course of action was radiation; some hormone therapy would be linked to that. He said that if I was in my 80s he wouldn't advise any treatment at all because it's the old story that you don't die from it, you die with it.

Hormone therapy then radiation

So on the strength of that, he referred us to the oncology place which, fortunately for us, is close by, only about 10 minute drive away. So again, the two of us went to see the oncologist. He mapped out a course of treatment for me. With the hormone therapy, I started off on tablets

and then after the first month or so I had no negative reaction so I graduated to a monthly injection. I started radiation treatment about the end of January.

One of the overriding experiences was the 39 radiation treatments over a period of eight weeks for five days a week. The oncology place I went to was very, very good. (Margot did not come with me to the radiation treatments as we didn't think this was very necessary.) The people there had a lot of empathy and I found them very good to work with. I made a point of saying to my main oncologist that I was very impressed with the support and empathy given by the staff there in the centre.

It really is a fairly intense sort of program. I found quickly within a week or two that I got into a pretty usual routine. The actual treatment when you go under the radiation machine only lasts a couple of minutes maximum. I found that I could leave home, go into the centre, change in the gown and have the radiation, change back and go home again in a very short time. There is very little waiting in the waiting room; they've got it down to fine art and they were working a very long day, often from six or seven in the morning till eight o'clock at night. I also suppose that, in a funny sort of way, there was a certain amount of camaraderie amongst the patient's while you are waiting for your treatment. There were only a few that I saw regularly and I found it very useful just to get know to them and find out what their experiences were.

Being positive, right from the 'get-go'

When Margot and I were confronting the stressful times at the beginning of the process, one of the things that I've said regularly to a number of people was that for us blokes, if we have any choice in the matter, prostate cancer is the best cancer to choose simply because these days it is very treatable. Right from the 'get-go' the urologist and the GP, and the oncologist, were all very positive and said that, with the advancements in treatments these days, the outcomes generally have a high success rate. So right from the start, by adopting a very positive

approach to the whole process, I was quite certain that at the end of the day, when I get results, the outcome would be a successful one.

Accurate radiation treatment

Going back a bit, after the biopsy I was one of the first in my local area to become involved in a new process. Historically, the treatment with radiation was generally a very hit and miss affair. These days they are a lot more accurate in the way they focus the treatment. In the first instance, I had seeds put on the prostate so that the machine could more accurately determine where the radiation should be given. The second point was that in the past, a lot of damage was done to areas surrounding the prostate, whereas with a new process they actually put a barrier in between the prostate and the rectum. This minimises the possibility of outside damage. I was only the second patient at the hospital where I had that inserted. It's like a gel that hardens up and creates a barrier. The oncology people were quite interested in monitoring my particular case because of that. This gave me more confidence and is evidence of the progress being made. The process is so new that the reps who were marketing this gel came to witness the surgery that was taking place on me. This certainly added to my confident outlook of the whole thing.

The radiation treatment was from the end of January to the end of March and I got into a pretty normal routine. As far as side-effects were concerned, thank goodness mine were minimal. There was a little bit of discomfort early on which they predicted could be the case, but that was only very minor. There was a bit of tiredness which they said to expect, and I did find that from time to time.

Support of friends and 'peers'

We live in a retirement village and one of the residents across the road put me onto another fellow in the village who had exactly the same treatment last year. So he made the point of coming around and sitting down with me for an hour or so and walked me through the process. This was helpful because you are going into the unknown and anything that

you can do to assist and familiarise with that process, in my book is certainly a good thing to do. I found that helpful.

On the support aspect, the other thing I didn't really discover until quite late in the piece is that there is a Prostate Cancer Support Group in the area where we live. Margot and I both went along to a couple of their meetings towards the end of my treatment which I also found very useful. The oncology people where I was having treatment told me about the support group. This arose because the convener of the support group came along at the invitation of the oncology group to talk to the men who were receiving treatment. On the strength of this Margot and I went along to some of their meetings. We found them very useful. They reinforced the positive aspects of our approach to the difficulties.

Trying to keep fit

Another thing about positive support aspects was that about 12 months ago I started going along to the gym for the first ever time in my life. Previously I've never had any interest in going whatever. I'm a pretty big guy physically. As you get older, you realise you need to start doing something about, in my case, my weight, flexibility and fitness. The gym people were very good because, after telling the trainer that I was working with about the circumstances, she said that she could design a program around my circumstances and work in that framework. I was so impressed with the trainer and how programs are developed for people even at the age of 90, that I made mention of this at the Prostate Cancer Support Group so other people may be able to make use of the facility.

Fluctuating emotions: a side-effect

The other thing that I experienced quite considerably as one of the main side-effects was that I was becoming very emotional. I still do this on many different kinds of subjects but particularly in relation to relationships family and that sort of thing. Even now I'm getting quite teary and get very emotional about the whole thing. I guess what we

should realise is the fact that you are just not indestructible; you are mortal.

Being positive

It's probably fair to say that I've always been a very positive person. In my work life in the last twenty years in my career, I've always been a very positive person. My work gave me experience in handling something that was foreign to me and using a positive approach. A number of my friends have also made the comment that they were quite sure that I would be adopting a very positive approach, which I certainly did. Probably an important factor was the support I got from the people in the oncology centre, and also belatedly (because I did not attend in the early stages), the Prostate Cancer Support Group. Probably my GP in particular, whom I regard as a friend, was very supportive and he's a man in his 60s. I found his input very helpful. However, the urologist, while he was supportive, had a bedside manner that was much colder. I rationalised that by thinking, "Well what a devil of a job he's got to announce to other people the cancers they've got". You've got to be detached from it to a certain degree, I guess.

Hoping for the right numbers

As far as the future is concerned I have a very positive hope that the numbers will be right when I have my next check. The treatment takes a while to get through my system and I now have to wait for another three months when I have the tests booked and get the results. We actually planned to visit our family in another State in the middle of the month so we will be going visiting after we get the results from the tests and there will be a celebration. As you tend to do, you put things into the future that you work towards, even though you recognise you are still undergoing treatment and tests.

More anxious than Alan

Margot. I think that sometimes the partners can feel more anxious about the illness than the man with the illness. It's the old story that it is not happening to you, you worry about, and if it is happening to you, you can deal with it. The time at the diagnosis was one of the worst of days of my life. You go with the highs and lows of, "No, there is nothing, yes, there is...". Where do you go with it from there? You just run with the absolute extreme of what it might be, maybe it won't be ..., you know, all those things. This may sound daft but once we had the diagnosis it was almost a relief because you knew what was happening. The four days in between the tests and the results were just terrible. We kept it to ourselves and would not talk to anybody about it because we just didn't know what might be possible. When you don't know yourself what's happening, it is a bit scary to be able to say to others, "Well it could be, but maybe it's not". We didn't tell the family about it until it was diagnosed as such. We told them that we were having tests but we were just waiting for the results.

Once the results came through we just didn't know which way to jump until we started to talk to the oncologist in more detail. The oncologist was very direct and very methodical and he said, "This is what you do, and this is where you go". With the few weeks of not knowing, and then all of a sudden you run, run, run non-stop, it was like being on a rollercoaster; it was a very busy time.

Lift from the family, and from Alan

We definitely had lift and hope from our family – our son and daughter, my brother and sister-in-law, and friends we've known for a long, long time, they really gave me a lot of lift.

Alan was so positive about the whole thing so I never went to a kind of decline in thinking something horrible was happening. I was always on the positive side because he was so positive. This helped me to get through what we were both going through. It has bolstered my approach

to the difficulty. When we were talking to families and friends I was always talking about the positive side rather than the negative, so in this sense Alan's very positive attitude gave me a lift.

We are very positive about it all now because we haven't had anything horrific happen. We haven't had the problems we have heard about through some of the stories told by others. Some who had hormone treatment and other treatments had terrible reactions. When Alan went to the specialist he said, "You must think we're frauds because we haven't had anything go bump in the night"! Alan had no hiccups during his treatment. He was well enough to drive himself to the surgery as a normal thing; I didn't have to go with him all the time. He was able to drive himself there and drive himself back and I thought this was very positive for him. If he had said, "I can't do it," I would have taken him. I thought he might have done it for the first half of the treatment but maybe become tired, but he was fine the whole way.

Handling Alan's emotional changes

Regarding Alan's emotion I found it very hard and very difficult at first. When he became emotional, and I asked what it was, he just couldn't tell me. I found this very frustrating. He could be thinking about his family, or looking at photos from the past, or it could have been just simply a page of a book that was upsetting him – all those sorts of things. This kind of weepy upset is not really Alan. I found it hard to deal with. I talked to a couple of nurse friends that I have and I asked them and they just said that he just doesn't know why it happens, and that he is just as confused as you are because he doesn't understand what causes it. So they said that I shouldn't keep on asking why it happens. This is hard because my idea was that if he told me what was wrong I would fix it! It was the hormone injections that really did this to him. When he first went on to this treatment there was a rush of emotion. But this is still very hard when there are two of you in the house and upset about something and it is hard not to try to do something about it. He doesn't know what upsets him, he cannot tell me and I get upset because I cannot help! When

you've got kids and they've got a problem, you put a Band-Aid on it. You cannot fix an emotional problem that way.

Support in the Support Group

One of the interesting things was when we went along to the support group meeting, we didn't know what to expect; we just went along to see how it all worked. Afterwards, one of the ladies came up to me quietly (I didn't know her from Adam) and said, "And how are you doing, how are you coping?" I felt, well this was really about the men (I don't mean that unkindly). It really was all about the men but this lady came up, sat next to me and just asked out how I was doing. I thought that was wonderful. She gave me her phone number. I didn't need to call her but it was so nice to know that I could contact her if I wanted to. There are moments when you think you might need to call someone, but it's very nice to know that you can do this if you need to. She didn't have to do that; she was just one in the audience. She sat next to me but she wanted to see how I was coping and see how she could help. I just appreciated the fact that it was somebody who did not know me who was reaching out to walk me through this problem.

Going forward!

The partner is the one that feels it is much, if in a different way, as the person going through the physical illness. Sometimes the emotional things are very hard to deal with; if it's a physical thing you just get over it but if it's emotional, it's harder. You might have friends for many years and it is just nice to be able to talk over some of the issues with them when they arise so they can comfort you and give you some direction.

I think what helps me most is Alan's positivity and that is just the nature of the beast. I think that if he was a different person it would be a different story. I'm very positive about the future for him and for us and we are going forward with it all.

Prostate cancer is generally regarded as a matter for men. However, where men have partners and families, the partner becomes an integral part of the illness, its treatment and its side-effects.

This book contains the prostate cancer stories of 40 people – 10 men, 10 women and 10 couples. An important aspect of these stories is that each person was able to present their own perspective on their journey. The stories reflect both diversity in lifestyle and coping in the participants.

"If you want intimate, honest accounts of prostate cancer experiences, with a focus on what helped the men and their partners get through them, then this book is for you."

Jim Marshall, Convenor, Australian advanced prostate cancer support groups
Wendy Marshall, Convenor (retired), Partners of men with prostate cancer (Brisbane)

Dr Laurence Lepherd experienced cancer and became associated with Cancer Council Queensland working as a volunteer in their Cancer Connect and Community Education programs. He became interested in the way men, and women associated with prostate cancer coped with the illness so he undertook research in the area. He and a colleague, Coralie Graham, set about hearing and recording the stories of men and women during their prostate cancer related experiences.

Laurence is an Associate Professor in the Centre for Health Sciences Research at the University of Southern Queensland, and an Adjunct Associate Professor in the School of Medicine – Rural Clinical School, University of Queensland.

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