This book discusses the way men with prostate cancer used their everyday experiences to lift themselves above the very real and difficult experiences of their cancer.

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Prostate cancer: Finding your peace of mind

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By the same author

*Prostate cancer: Climbing above it*

The verbatim stories of the nine men whose prostate cancer journey is discussed in *Prostate cancer: Finding your peace of mind*

Available in e-book and print from [www.lepherd.co](http://www.lepherd.co)
For Michael, Craig, Wayne, Colin, Ben, Jason, Stephen, Alan and Ken

The men and their experiences were very real even though their names are fictitious.
Acknowledgments

This book is the result of a research project in which I was assisted by many people. First and foremost, I acknowledge the nine men who contributed their stories so wholeheartedly. They were very frank in telling their experiences and it was their hope that others would find some strength when they realised that they were not alone in their journey; other men tread similar paths.

There was constant support from Professor Cath Rogers-Clark and other colleagues, Drs Des Coates, Susanne Pearce and Jenny Moffatt. They were very constructive in their observations and contributed many valuable ideas during our many discussions.

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To all of these people, I extend my deepest thanks. And, of course, there is always the constancy of my family for their continued encouragement – my wife Marie, daughter, Louise, and son, Philip.

Laurence Lepherd
Toowoomba, Queensland, Australia
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The complete stories of each of the men referred to in the following text are recorded in the book *Prostate cancer: Climbing above it* which is available in e-book and print form through [www.lepherd.co](http://www.lepherd.co).
Foreword

Dr Laurie Lepherd has a wonderful perspective on spirituality and peace of mind matters. He supports this with a unique and informative account of the stories told by nine men relating their prostate cancer journeys.

I’ve often said that you would not wish prostate cancer on your worst enemy. However, having been through the diagnosis, the treatment option of a radical prostatectomy, the recovery phase and conquering the quality of life issues, such as incontinence and erectile dysfunction, I now have a different perspective on life as does Pam, my wife of 45 years. We cherish every moment and live life to the full. We have been re-energised by the experience and have found new meaning into what life is all about.

This book allows the reader - patients, partners/carers and family members alike, to reflect on their own or loved one’s cancer journey whilst being reminded of the experiences of others which can be very helpful in the search for peace of mind and quality of life. In this context, it is well known that there is considerable value in attending or being connected to a support group network. Men and their partners/families connect for as long as they feel the need. Others connect for the duration of their treatment and recovery phase. Regular attendees, who are over their own diagnosis, are valuable contributors to help others by relating through their experiences (much like the men in this book). Men and their partners enjoy the knowledge of continuing education obtained through medical professional presentations and gain the satisfaction of helping by being connected to men experiencing the highs and lows of their cancer journey. A support group can help fill the area of spirituality, as many of the men discussed in this book indicated in their stories.
The book is an easy and a most interesting read - a check point in one’s own assessment of purpose and the true meaning of life.

David Sandoe OAM
National Chairman
Prostate Cancer Foundation of Australia
Preface

One of the main aims in our life is usually to achieve peace of mind. This is an outcome of our spirituality – our inner self or inner being. Peace of mind can be very elusive, especially when we are under stress or trauma because of illness. Men with prostate cancer, especially at an advanced stage, are under stress and looking for ways in which they can live peacefully amid the turmoil of their illness.

This small book discusses the stories told by nine men with advanced prostate cancer about their journey and the way their spirituality helped them to have a better quality of life. Spirituality for them consisted of the aspects of their life that lifted them above their everyday stressful experiences.

I have been motivated to write this book because of my own circumstances and subsequent experiences and research. I was diagnosed with cancer and subsequently went through the physical and psychological anguish that most people with cancer experience – the consultations and treatments, the highs and lows of life. I was cleared after a period of some months of treatment. I experienced emotional fluctuations similar to other people have who have had cancer. I did all the reading I could possibly do from all kinds of sources – the Internet, libraries, the information from cancer support organisations and other places. I had the same sort of questions to ask the urologist. I have had similar pain and discomfort as other people although my cancer was not as severe as that of some people. I did not have prostate cancer, but at the same time I became aware of many issues that relate to this illness.

Before having cancer, I had been trained as a pastoral carer and was placed as a volunteer in one of the Queensland (Australia) government hospitals. After being cleared of my illness I spent quite a lot of time in the oncology ward in the hospital working with patients who were
experiencing various stages of their cancer journey. I also trained to be a volunteer presenter with the Cancer Council, Queensland, and it was in this capacity as a community education presenter speaking about cancer risk reduction that I became more aware of some of the problems faced by men when they were diagnosed with prostate cancer. Unfortunately, my experience was that many of the men found it very difficult to talk about prostate cancer. Perhaps this was because it can be related to a man’s sexuality. Perhaps it was because the man just did not want to acknowledge there was a problem. Maybe he was not certain how he was going to cope with the illness and its treatment. The men’s partners often became frustrated because the men would not talk about their illness. It became evident when I was making presentations to community groups that it was the partners of the men who were asking most of the questions related to the illness and how men could cope with it rather than the men themselves speaking about their concerns. The purpose of this book is to try to help men, and their partners, to understand and to talk about their illness, and to learn how others worked towards achieving a peace of mind that helped them to cope.

Laurence Lepherd
Toowoomba, Queensland, Australia
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Introduction

‘I’m sorry but the tests show that you have prostate cancer.’

This is such a simple statement, often made by your doctor or specialist, yet it can have a heart-stopping affect. People react to it in different ways. Some are shattered; some are bewildered; some are numb and just cannot think.

Just as you’re coming to terms with this pronouncement, the urologist may say to you, ‘Yes, it’s a cancer that is at Stage T3(c), you have a PSA level of 21.7 ug/L, and a Gleason Score of seven, which consists of four and three, and this shows that the cancer is fairly aggressive. Now we have to start thinking about what to do about it.’

The urologist’s comments can become a blur for you because of all the questions rushing through your mind. The pronouncement can produce immense stress. Am I going to die? What is the affect going to be on my family? How will I continue to work? There are so many things that need to be considered – what treatment, what side-effects and, the all-pervading ‘presence’ of the illness – that you are simply not well and you face the prospect of increased suffering. These questions are in addition to the lifestyle questions you may have already contemplated.

Just while you are thinking about these things, and depending on the extent of your cancer, the urologist might then say things like, ‘Well, there is a range of treatments I would like you to consider. One of them is to have surgery which may involve a radical prostatectomy that can be open, laparoscopic or robotic surgery. Another treatment is to have radiotherapy which can be either external, or, if the cancer is not too advanced, it may be brachytherapy which consists of the internal implanting of radiation seeds.’ The urologist may suggest that the prostate cancer is advanced and
has become extracapsular, or it may have metastasised outside of the prostate gland and you may need androgen deprivation therapy.

Perhaps the urologist is not so insensitive as to give you all of these terms in the one session or just after you have had the diagnosis given to you. However, at some stage you do have to face this bewildering array of terms, procedures and treatments and decide what to do. The urologist may actually suggest to you that one of the good ‘actions’ is to wait and see how slow or fast the cancer develops – active surveillance. This may mean a considerable period of time before any action is necessary.

In the meantime, the shock is there for you. You are not the only person to have gone through this process and you might be able to take some comfort from the fact that many men have gone through this before you and are very willing to try to help you through the initial shock as well as other stages of your cancer journey.

You can get support for coping both physically and emotionally. Cancer is such a wide-spread illness that treatment and support are becoming more sophisticated. While all these facilities are available, the ultimate source of your ability to cope comes down to you. Other people can help you, but the responsibility for your approach to coping lies with you.

**Helping yourself**

If you are reading this book, the chances are that you have been diagnosed with prostate cancer and, like most people, you want to find out as much about it as you can. Apart from wanting to know all about the complex physical issues and treatments, you want to find out how you are going to cope and this can be made easier by learning about how others have coped.
You may be reading this book because your partner has prostate cancer. In some ways, it is the partner who has even more anguish than the man with the illness. The man knows how he feels and to a certain extent believes that he has control over what he is able to do. However, his partner does not quite know what he is experiencing. Sometimes it seems that the partner worries more than the man himself about his illness. This can occur because the partner does not quite understand what prostate cancer is and secondly, may not know or fully understand the emotions that can be associated with it. This may depend on the extent to which the partner has already experienced cancer.

When you have time to regroup, you start to think of the dramatically changed course of your life and how you are going to cope, how you can have a good quality of life while you have this condition, and how you can attain a peace of mind.

**Spirituality**

One of the ways people cope with illness is through their spirituality. I have had a lifelong interest in spirituality and when I tried to do some reading on spirituality and men with prostate cancer I found that there was very little written about the subject. I have been convinced that spirituality can help in all circumstances. During my own illness, I relied on my own spirituality to help me through some of the more difficult periods.

Working on the assumption that spirituality is something that everybody has, I decided to try to find out through my research what spirituality comprised in men who had prostate cancer. My study, focused on patients with advanced prostate cancer where the cancer had progressed beyond the prostate gland and had possibly spread to other parts of the body – usually the bones. However, it became evident through my discussions with many men that even though there were significant physical and emotional differences between men diagnosed with either prostate cancer
or advanced prostate cancer, there were only small differences between the ways they used their spirituality.
An overview

Nine special men

I started my research by asking for volunteers who would like to talk about their spirituality and the way in which they used it to help cope with their prostate cancer. Those who volunteered all had advanced prostate cancer.

A foundation of the study was the assumption that everyone has a spirit, whether we are religious or not. A person’s spirit is the centre of his or her being; it involves the very essence of life. A person may have considerable spirituality but may not be a very religious person in so far that religion refers to organisational spiritual life. One might be a Christian or a Muslim, for example, who belongs to a particular faith tradition. In this case the person may be both spiritual and religious. They might go to religious services very frequently, services designed to foster their spirituality. However, a person who is not involved in religion or religious services may still have a deep spirituality. There are many people, for example, who believe that their connection with the land is the centre of their being and thus their spirituality. In the course of my research it became very evident that spirituality includes many aspects of life. Some of the nine men involved in the study were indeed religious; others were not religious but still had a deep-seated spirituality.

It is the purpose of this book to try to help you think about your own spirituality with the benefit of reading about the experiences and spirituality of these men. In this way you, and your partner, if you have one, may find some insight into your own coping ability during your prostate cancer experience, and how you can find your peace of mind.
It is probably best that I give you right from the outset some observations about the conclusions of the study.

**A ‘lift’**

One of the key findings of my research was that spirituality involves ‘lift’. Sometimes the word ‘transcendence’ is used and this means that when a person has demonstrated their spirituality, they have shown their ability to lift themselves or lift their spirit, lift the centre of their being above the everyday occurrences of life, particularly the diagnosis and treatment of prostate cancer. They work with those things that help to lift themselves above their illness and to give them a peace of mind that is important as they try to cope with the illness. The sequence is important:

- spirituality → lift in life above your illness → peace of mind

Peace of mind, a reduction of anxiety and stress leading to calmness, is important because many studies have shown that a man with cancer can have a better quality of life through reaching or moving towards peace of mind. It should be noted that the peace of mind will not necessarily extend your life, but it can make your life better in quality.

**‘The whole package’**

The next word to consider is ‘holistic’. This has become a very important concept in healthcare practice. It means that a patient is regarded as a whole person rather than a lot of independent parts. The holistic management of a patient means that the person’s physical, medical, social, psychological and spiritual needs are all important in contributing to the health of the 'whole' person and to enable them to cope with their illness. This conclusion was fundamental to my research. It was quite significant that the men regarded spirituality as an important part of their lives and in coping with their illness.
Connection – the centre of the whole package

The idea of holism was central to the spirituality of the men. What was also evident from their stories was that connection was central to the whole of their life and involved a number of different aspects of their life. Specifically, the men connected firstly with themselves; it was important that they recognised their own position in the world before they could connect with anybody or anything else. After connecting with themselves, which I will explain in more detail later, they were connected with their partner. Partners were a vital element in the coping mechanism which these men developed during the time they experienced their cancer. Many of them also connected with a higher being or with their own spirituality. Men were also connected with other people and their families: their sons and daughters and their grandchildren. Their connecting with family became very important, where they had families, as they tried to cope. They also connected with other people. You will see later many of the different ways in which these men connected with other people. This was especially important for men who did not have partners. They connected with non-people ‘things’. The things could be connecting with music, or art, or playing sport or recreational activities - whatever helped them to lift themselves above the mundane circumstances of their life with cancer. Connecting was a central element of their holistic way of life.
The spiritual journey

Another element of the prostate cancer journey of these men was that the greater realisation of their spirituality either commenced or gained more focus at about the same time as their prostate cancer started. Many of the men found that they started to progress in their spirituality and to think more about their life when they realised that this might have some finality associated with prostate cancer. This does not mean to say that prostate cancer is a death sentence - far from it. But the diagnosis of prostate cancer, or any cancer, does make people aware of their mortality and that their lifespan may be limited. This was the case of the men with whom I worked - they really started to think about where they were going and what they were doing. This meant that they were making decisions about treatments and quality of life during their prostate cancer treatment as well as developing a greater understanding of their own spirit, their inner being, which they realised might be able to help them through their problems. Their spiritual journey moved in parallel with their physical. Their spirituality just did not suddenly appear of its own accord; they were motivated to start thinking about the deeper issues of life.

The second element of their spirituality which became part of their experiences involved the men thinking more carefully about purpose and meaning in their lives. Some of the men who had been living day-to-day without clear life goals, suddenly found themselves rethinking what their life was about. During the course of this book I will be outlining some of the purposes and meanings in life that these men found.

The third element of the spiritual journey was that the men recognised and focused more on developing their life values such as love, forgiveness and trust which brought more quality to their lives.

The fourth element of the spiritual experience was the pursuit of peace of mind. This was achieved by the men’s connectivity. Ultimately one of the
greatest outcomes of any spirituality is peace of mind. There is little question that men with prostate cancer, like many people in other stressful circumstances, try to find some meaning or to make sense of their experience. They try to achieve a peace of mind that will enable them to have that quality of life that will make the latter part of their life, however long or short, more meaningful and more peaceful for them. This will not necessarily prolong their life but it will certainly make their quality of life much better during their cancer experience.

**In summary**

If you have prostate cancer there is generally a lot going on. You want to know how you are going to cope with what lies ahead on your cancer encounter. For the men I have worked with, the spirituality they have is part of a coping process. It is my hope that reading this book will help you to identify those things that lift you above your daily challenges and that bring you that peace of mind which is so important in making your life more fulfilling. You have a spirituality; there are things you can do to help yourself in the continual development of your spirituality, and there are many things which help you to achieve peace of mind, the ultimate goal of developing your spirituality.

To help you in this process I will be recounting parts of the stories of the men I worked with. Perhaps reading of the highs and lows of their individual lives will be an inspiration to you. They wanted to tell their story because they wanted to help others. I hope you can benefit from their journey and the way they coped, the way they saw their spirituality and the way they achieved the peace of mind that helped them to have a better quality of life. Some of their experiences may be your experiences and you might receive some help for yourself by observing aspects of their lives.
In a very real sense this book is dedicated to these nine men. In the next chapter I have given a thumbnail sketch of the men and aspects of each man’s life.
Glossary

This glossary introduces terms that were used by the men in the study. The descriptions give a brief idea of what the terms mean.

Androgen Deprivation Therapy A therapy in which hormones are reduced to lessen the growth of cancer cells. It is sometimes referred to simply as hormone therapy.

Biopsy Sampling of prostate cell tissues.

Digital rectal examination (DRE) A physical examination by a medical practitioner to manually search for abnormal growth in the prostate gland.

Gleason Score An indication of the degree of aggressiveness of the prostate cancer where a score of 7 or more can, but need not necessarily, indicate a fairly aggressive cancer.

Orchiectomy or orchidectomy. Surgical removal of the testes.

Prostate Specific Antigen (PSA) A protein produced by the prostate gland. An excessive amount may indicate a prostate gland abnormality but not necessarily cancer.


Stages and Grades of Cancer. Stages refer to the size of the growth and how much it has spread from where it started, while grades indicate whether the cells are slower or faster growing.

Trans rectal ultrasound (TRUS) An ultrasound scan to try to determine the existence or position of a cancerous growth in the prostate.

Transurethral resection of the prostate (TURP) A procedure normally used to treat benign prostate growth by removing some prostate tissue.
Meet the men

The nine men in my research all volunteered to talk about their cancer journey and their spirituality. I spent approximately one hour with each of them recording their stories. The process took considerable time in that both I and the men wanted to make certain that the story was accurate. I had previously sent the men written information about my study, explaining that I wanted to ask them about their spirituality in relation to their prostate cancer journey. Spirituality was placed in the context of being whatever lifted them up.

Once I had recorded their stories I transcribed them and sent the stories back to the men to verify that what was going to be used as the basis of my study was accurate. The stories they told related to both their physical journey and their spiritual journey. This was important because it was very evident that the two could not, and indeed should not, be separated.

The men are named but their names and locations have been changed to protect their privacy. Each of the men told their story in the hope that they would help others. Finally, in the following pages, the words of the men are given in *italics* so that you can easily see what they said.

In a very real sense this book is dedicated to these nine men. Let me introduce them to you now:

**Michael**

Michael, 64, was a consulting engineer who was diagnosed with prostate cancer three years before I interviewed him. He tried, as much as possible, to live normally by continuing his professional life but in a much reduced capacity.
It took some time for medical practitioners to identify his prostate problem. When the full extent of his cancer was known, he found the situation very stressful. He was considerably affected by the illness itself and the side-effects of treatment. He struggled with depression but worked to overcome it: *I’m not going to let it get me down. I’m going to climb above it.*

Despite his illness, Michael was very energetic and adamant that his purpose was to help other men in his situation. Immediately following his diagnosis, he sent 100 emails to men he knew, strongly suggesting that they should have a medical check. He received many responses. Some of the men were diagnosed early and were successfully treated. They wrote back saying: *Thanks for saving my life.*

Michael was always available to talk with other men and their partners as they went through their journey. He became an Australian Prostate Cancer Foundation ambassador. Speaking publicly about his illness became a focus of his life. He explained the reason for his dedication: *If I talk to a hundred people and save one life, it’s worth it.*

**Craig**

Craig had led a very active life and was 79 when I interviewed him. He was very grateful for the support of his wife Dianne who provided him with significant spiritual, as well as physical, support.

Craig found great comfort in reading books about the scientist and theologian Emmanuel Swedenborg and also books by his great, great, great grandfather, who had been a keen Bible scholar. Craig used these books to help him find peace of mind. He relied on his relationship with God and with the many people who supported him, especially his wife, friends, and in some instances, the casual acquaintances who simply
expressed concern and sympathy for his situation: *Things like that lift you up*, he said.

Despite his deteriorating health that was punctuated frequently by severe pain, Craig was at peace with himself. He recognised that his illness helped him *to have a greater communion with God*. This together with his recognition of the value of his wife and friends helped him in the last stages of his illness. Craig’s medication made it difficult for him to concentrate and some parts of his story were therefore disjointed. Craig died about three months after the interview.

**Wayne**

Wayne, 85, lived by himself in a retirement village. When he was diagnosed with prostate cancer he suffered considerable stress with the treatment required – an orchiectomy – when he was aged 70. He joined an experimental treatment program but when his cancer worsened, he was removed from the program which caused him significant stress.

Wayne had spent several years caring for his ill wife until she died. After her death, Wayne re-connected with church activities which he had been introduced to during his childhood. An invitation to him to become involved formally in church services at his retirement village enabled him to live a very active life although his increasing age and illness meant that he had to spend more time recovering from the physical exertion of church services and visiting residents in the retirement village. Wayne relied on his relationship with God and with others around him – the priests with whom he worked, and medical professionals – to help him through.

Wayne was also interested in astronomy and amateur radio operation. He found these helpful in taking his mind off his illness: *These lift you up and take you away from any problem you might have.*
Wayne had an active personal spirituality that helped him during his illness. He engaged in private meditation as well as enjoying the social aspects of communal worship. He valued the relationships he had developed after his wife’s death but still missed her company, particularly during the time of his illness and in making decisions.

**Colin**

Colin, 79, lived with his wife and two small dogs in a very comfortable home. He was a well-organised person. Colin was diagnosed with prostate cancer six years before the interview. He had a Gleason score of 7 and a PSA of 39. The cancer had already metastasised, so after discussion with his urologist, he went immediately onto hormone treatment with injections every three months. This resulted in a reduction of his PSA to about 0.5 and this has remained constant over the last few years.

Colin is a practising hypnotist who had worked with sportspeople for over 50 years. He uses self-hypnosis to assist himself, especially at the time he receives his therapy injections. As he said, his hypnosis gave him *a lot of insight into people and a lot of control over my own body – switching off, pain, deadening areas, all that type of stuff.*

At about the same time as his prostate cancer diagnosis, Colin became interested in Christianity. He now focuses on his spiritual development and believes this has contributed significantly to his ability to cope with his cancer. Colin has no doubt that his Christianity was the prime source of his spirituality with his hypnotic ability being part of that spirituality.

**Ben**

Ben, 59, lives by himself in an apartment on the Queensland coast and was 56 when his illness was diagnosed. He was shocked when first told about his diagnosis and went through some very traumatic psychological
fluctuations, including depression, in the three years before I interviewed him. He had not been tested for prostate cancer annually and believed that his doctor had let him down.

Soon after his diagnosis, Ben tried several ways to cope with his illness. He connected with family – his son and his mother, although his mother lived in New Zealand and was also ill. His son phoned him every two or three days for some time after his diagnosis. Ben also relied on the support of about six mates and a female friend: *She helped me a lot. Every time I saw her it gave me strength.*

Ben found relief in sharing his story: *I wanted to spread the story, I suppose, just to take the weight off my shoulders because when you are diagnosed with a terminal illness it’s just a huge burden and, yes, it’s really hard to cope with.* He did not expect a response from people but assured them that their listening had helped him: *You don’t have to say anything; I just have to get it off my chest. … I just have to say it. It’s helping me by saying it.*

Twelve months after Ben’s interview he regained some stability and found purpose in his life assisting other men who had been diagnosed with prostate cancer.

**Jason**

Jason, 69, led a very active life as an engineer who had travelled the world in his job. He had a keen sense of achievement with his life. He now lives with his son’s family near the Queensland coast.

Initially, Jason had difficulties with the public health system. He was referred by a doctor to a hospital but had to wait some weeks for an appointment with a urologist. This wait was so distressing that he contacted a government Minister who was able to promptly arrange for an
appointment for him at a private hospital. Jason was diagnosed with advanced prostate cancer that had already metastasised to the lung.

In discussions with his urologist, Jason chose to have hormone treatment as his primary therapy. He found it difficult to accept that an injection every three months was all that he needed. Jason read that juiced pawpaw leaves could be useful for men with prostate cancer so he collected, juiced and drank the juice from pawpaw leaves.

He enjoyed several activities including boating, inventing gadgets and helping other people. Jason took part in this research in the hope that his story would help someone: *If I can help, and people can relate to something I’ve said, and they get cured, well, the world’s set on fire; cancer might just be a word.* Reflecting on his life, Jason is satisfied: *I feel life hasn’t passed me by. I’ve had a good life ... more than most, actually. He regards his cancer as just this last ‘little speed bump’ in my life.*

**Stephen**

Stephen, 67, an accountant and keen golfer, was diagnosed with prostate cancer when he was 61. Before his diagnosis, he had experienced significant pain in his legs that was not relieved by painkillers. Stephen and his wife happened to go to Thailand for a holiday, as they had worked there for some time previously and while there, they went to a health resort.

On his return, Stephen attended a funeral and while chatting to mourners afterwards, he heard that his painful legs may be a sign of prostate cancer. He underwent tests, was diagnosed with the cancer and commenced hormone treatment which led to side-effects including hot flushes, memory loss and depression.
Stephen had difficulty coping with his busy accountancy practice and sold most of the business. He and his wife decided to spend more time in Thailand at the health resort where they learned Tai Chi and Qi Gong which gave Stephen a feeling of hope.

On his return to Australia, Stephen kept active by playing golf and found that meditation helped him lift himself above his illness: *If I want to, I can lift myself above [it]*.

Stephen volunteered to be a participant in the study because he believed he had benefited considerably from his personal experiences in spiritual development. He had tried many ways to approach his illness and eventually found the approach that suited him.

**Alan**

Alan, 63, lived 350km west of Brisbane (Queensland) and was diagnosed with prostate cancer when he was aged 56. In order to have medical treatment Alan travelled to Brisbane and lived in a guesthouse. His initial treatment was a prostatectomy which led to him becoming incontinent for eight months. Despite his treatment, his PSA score began rising again and subsequent tests showed the cancer had spread to his rib, sternum and shoulder blade. Alan immediately began hormone therapy and several courses of chemotherapy but, unfortunately, his health continued to deteriorate. He had periods of considerable pain and, frequently, loss of mobility.

Despite his illness, Alan maintained a strong Christian belief and faith. His peace of mind came through being with like-minded people and through a strong belief in God: *I do like to go and worship with people. I like to sing, pray, have communion ... fellowship.*
Despite his treatment, Alan was able to sometimes participate in old-time dancing which he always enjoyed. Alan was very matter-of-fact about his circumstances. He was often asked how he coped and his response was simply, *You just become used to it after a while. I mean, it’s like going to the dentist – you mightn’t like going, you know you’ve got to go, and you know it’s for your own good. ... It’s the same thing; you just keep lining up for treatment.*

**Ken**

Ken, 69, was fit and healthy when he was diagnosed with prostate cancer when he was aged 65. His doctor told him his life expectancy was very limited. After his diagnosis, Ken became a Christian and adopted a strict healthy diet and a physically active lifestyle. His diet and exercise regime were prescribed and monitored by a naturopath who was part of a respected naturopathic organisation. Ken’s meals were carefully-prepared, mostly from fruit and vegetables which he and his wife grew themselves. His exercise consisted of riding his bike for about two hours every second or third day, as well as weight lifting, push-ups and sit-ups.

Ken acknowledged that it was not likely that all men in his condition could follow the regime as conscientiously as he did: *People do bits and pieces but not the lot; this is a bit too hard for most people.*

Part of Ken’s peace of mind came through his purpose of helping others. He did this informally by talking to other people about his experiences.

Ken was told at the time of his diagnosis that he would not survive another 12 months. When I interviewed him 4 years later, Ken was still coping very comfortably with his illness. He was pleased that he had outlived the doctors’ predicted lifespan.
Now for an analysis of the men’s complete stories and how they used their spirituality to develop their peace of mind.
The Journey: a context

It was clear that each of the men had started a journey that had two main aspects – the physical, medical, social and psychological aspects, and the spiritual. Some information about the physical aspects is given here because this places their spirituality in a very real context. (Remember, the part of their life that relates to finding peace of mind was their spirituality.)

Each of the men was different. While that might seem to be a very trite statement it is nonetheless real. You are a different person from the person next to you. Your life experiences are quite different from anybody else’s life experiences. There are certainly some things that are common but at the same time there are many differences. This is an important element in considering how you might approach your life with prostate cancer. You can read about the experiences of these nine men and the experiences of others. You can talk about your experiences with various individuals, at various functions, support groups and meetings of men who are in a similar condition. You can talk about the issues which affect you all, but ultimately the way you cope with the journey is very individual. This was demonstrated by the nine men in this study. You will see from some of their stories that even the beginning of their journey was quite distinctly different for each of them yet, throughout, they were all striving for the same thing – peace of mind and a good quality of life.

Most of the men had been on their cancer journey from between one and six years except for Wayne who had had prostate cancer for 15 years. All of the men lived in urban environments – either regional or metropolitan cities – except for Alan who lived in a country town.
Some common experiences

How can I beat it? I’m pretty positive with what I do. Colin

The men had common general experiences but each had different methods for coping with their diagnosis and treatment. Your experiences may be different from those of the nine men in the study.

We will now look at the medical aspects of the lives of the nine men, then the physical, psychological and social.

Medical matters - Climbing a mountain

Beginnings – ‘a hell of a shock’

All nine of the men found out about their prostate cancer in different ways. Michael had a pain in his lower back and was initially diagnosed as having acute sciatica. Craig had trouble urinating. Wayne had a pain in the side of his penis. Colin had a complete Prostate Specific Antigen (PSA) test every year. Ben did not have any symptoms but was advised by a friend to have a PSA blood test. He was shaken to find that he had cancer. He said, And, of course, that came as a hell of a shock to me from having no symptoms to all of a sudden having a death sentence.

Jason had been having regular PSA tests that showed no specific prostate problem, but was alerted to a possible problem through the appearance of blood in his bed. Stephen noticed a possible problem through a decline in his sexual interest. Alan visited the doctor for a possible thyroid problem and the doctor decided to do a PSA blood test. Ken had a regular blood test and was found to have a high PSA reading.

In only two cases the cancer was diagnosed through regular medical screening. In other cases, it is notable that, while the ultimate problem was diagnosed as prostate cancer, some medical practitioners did not look at
this in their initial consultations. The symptoms, when there were any, were disparate. The absence of symptoms or pain did not mean the absence of prostate cancer.

**Diagnosis – ‘a knock in the face’**

When finally diagnosed, most of the men had advanced prostate cancer. In most cases the cancer had metastasised to the bone and, for Jason, it showed up in his lung. They all had high PSA scores and Gleason scores, suggesting that their cancer was significantly developed and also aggressive. Seven of the men had had a trans rectal ultrasound (TRUS). Each man was shocked by their diagnosis and the diagnostic procedures. Jason recalled his reaction: *Wow, that’s a knock in the face!*

The diagnostic procedures were traumatic for them, especially the TRUS and biopsy. Alan had a biopsy without an anaesthetic. He said, *One of the biggest lies that can be told is that you have no feeling in the prostate.* It was very painful. Craig had a similar experience. The biopsy was so painful he was hesitant about having a second one. He had not been told that, when the results of the first biopsy are negative, having another biopsy can be necessary at some stage in the future.

Stephen was colourful in his description and there was no doubt that the diagnosis was a traumatic experience for him, especially as he had been treated previously for high cholesterol and potential heart problems. He recalled his reaction to being told he had prostate cancer:

*I felt like ****! I mean, I’m thinking, I’m going to die. I mean, they said they could treat it but not cure it and everyone is doing tests and, you know … And I thought, this is ridiculous, how can it be happening? I’ve got cancer; I’m supposed to die of a heart attack.*
Ben’s and Ken’s reactions were similar. Alan spoke of conversations that he had with many men who had been diagnosed with prostate cancer. His observation was that: *They’re just knocked out by the diagnosis and all the treatment they’re going to go through.* These men's experiences illustrate that stress at the time of diagnosis can be profound.

**Treatments – ‘that’s it?’**

Whilst the diagnosis procedures were traumatic, the decision on which treatment to select was also stressful. In most cases, as the cancer had spread beyond the prostate, there was no real alternative but to undergo hormone therapy designed to reduce the male hormones that ‘feed’ the cancer cells. Wayne was told that one means of reducing the hormones was to have his testicles removed (an orchiectomy). His reaction reflected his anxiety: *Well, the whole ground was taken away, out from under my feet.*

Michael was given the choice of an orchiectomy or hormone therapy. He chose hormone therapy even though he was aware the tumours may become resistant to the drugs that would be used to treat his condition.

Two of the men were offered only one treatment option: hormone therapy (androgen deprivation therapy) a less intensive and less frequent treatment. Colin wanted a more aggressive treatment, asking, *How can I beat this?* Jason would also have preferred to have had more substantial treatment. He wanted to be more proactive. The urologist gave him a prescription for an injection by his GP.

*And I said, ‘Is that it?’ and he said, ‘Well, that’s it!’ I said, ‘Well, can’t I do anything else?’ and he said, ‘No. No. See you in three months. It was confirmed with the urologist’. ‘Are you sure that’s it?’ ‘Yes, sure, that’s it.’ So, I’ll be disillusioned if that’s it!*
Another two of the men had their prostate gland removed (prostatectomy). Ben’s anticipation of this surgery was traumatic:

*So I was in a state of shock. So I rang my son. I had a son living in Bendigo, Victoria, and I thought, how am I going to get through this? How am I going to get through this operation?*

Radiation was used in addition to other treatments for four of the men. They gained the impression that the treatment was aimed not at destroying the tumour and curing the illness, but rather at reducing the size of the cancers.

**Side-effects of the illness and treatment – ‘rubbish!’**

Most men had many side-effects. These included pain, hot flushes, reduced sexual function and libido, and weakened bones. Michael said that he experienced hot and cold flushes. He said, *the side-effects are, I guess, worse than the treatment.* These effects were also experienced by four others. Stephen commented, *the side-effects of the drugs – I couldn’t think; you go from having a normal testosterone down to nothing – you know, you’re feeling dreadful.*

For some men the side-effect of pain may have overshadowed the flushes. Colin experienced bone and muscle mass loss, but when he questioned his specialist on the reason for this he received no response. This was very disappointing for Colin.

Side-effects were sometimes very intense and involved considerable pain. Some of the men had significant emotional fluctuations, while others had proactive treatment to avoid a side-effect of hormone treatment – bone density loss. Additional effects included more muscle pain. Changes in sexual desire and performance and loss of libido were also side-effects and, because of their importance to some of the men, are discussed in
more detail below. Altogether, side-effects were a problem for most men and involved them trying to cope with the physical and psychological stress that engulfed them.

‘PSA is the story’

In terms of physical aspects of each man’s life, PSA levels and an associated Gleason score were prime concerns for the men. In all cases, they mentioned their PSA level as being their main concern both at the time of diagnosis and as far into the journey as the day they were interviewed. Most of the men were very focussed on reducing their PSA level. Stephen summed up the general feeling:

*What you’ve got to avoid is this PSA thing. It can get out of hand, then it’s really hard to knock this back. You can’t ever let it go. So, I reckon, from all I’ve read, I just have to keep my PSA under control.*

This was confirmed by Wayne’s doctor: *Well ... PSA is the story.* Colin’s PSA had not changed in four years and he was very positive about this. He stated that he *expected it to go away, to be zero.*

PSA was the single most physical aspect of the journey that was of common concern to all the men. This meant that it did cause them some stress, and they exerted considerable effort to have it lowered. They seemed to believe that their PSA level was the main barometer in measuring the results of their efforts to minimise their cancer. This could be a misperception on the part of the men because, while PSA level is important, there is no medical evidence to suggest that it is the only indicator of the degree of a man’s prostate cancer.
Physical matters – ‘look after your own body’

Age – ‘I feel robbed’

The men’s age and length of time they experienced prostate cancer seemed to be a factor in their attitude to their illness. While attitude will be treated separately below, some statements from the men do indicate their perception of the effect age had on them.

Ben was 56 when he was diagnosed and he was devastated that he had prostate cancer. *I feel robbed … it's shattering, especially at my age.* Ben thought he would have a further 20 or 30 years of life. His father had lived until he was 86 and Ben thought that maybe he himself could live until he was 90.

It seems that the age of a man can affect their perception of the illness. The oldest of the men was at peace with himself because he felt he had lived a full and productive life. Others were less concerned with their age and more concerned about the length of time they had to live and how they would spend that time. This group of men seems to suggest that two elements relating to age – actual age and length of time remaining in their life – can be important in the way men approach their illness.

Sex – ‘I’m no longer a man!’

Prostate cancer treatments often impact on your sexuality. Sexual dysfunction was a major concern for some of the men. One of the consequences of all active treatments can be erectile dysfunction and/or loss of interest in sex.

Craig was asked how he felt after he was told of the need for surgery on his prostate.
I was devastated! Devastated, yeah, devastated, because it’s, ... an attack on your manhood. I was silly enough to be thinking along those lines, and a lot of men do think along those lines, don’t they?

Craig was shocked at the immediate effect on his sexuality of the surgery. Jason was also shattered that his treatment would cause problems with his sexual function. His reaction to the doctor’s statement that he could ‘maybe’ have some sexual function was to state that, An important part of my life is sexual function, really. Later in the interview he added, I haven’t had sex really since I’ve started hormone treatment and that bothers me a lot. I have no urge and definitely no length.

He went on to say:

I’m trying to deal with this because I feel I’m no longer a man. I just can’t get it up. They call it ‘erectile dysfunction’; they have a name for everything. I have now realised that life has more relevance.

And later:

Sex has been a big part of my life, but reading books and hearing discussions in the men’s group when men talk about sex, they say they are closer now to their partners, even though they do not have a sexual function or can’t do it properly.

He stated the effect on him personally: A man loses a lot, particularly in the mind, when this occurs. Jason could see that it was a problem not only for him but for others. For him, it was a major stress point. Stephen had to confront the issue early on in his journey. One of the earliest signs of his emerging prostate problem was that he had declining sexual interest. Another man drew attention to a major issue and that is
that men are not often informed of their potential loss of libido because of prostate cancer.

However, there can be some benefits from facing the difficulty. Jason had a significant comment about this. He was speaking of a group of men working together who talked about their sexual difficulties and their relationship with their partners. He commented, *they are closer spiritually and in mind and a comfort to each other.* This was a positive outcome from an otherwise very stressful problem.

The issue of sex and sexuality was, for some of the men, one of the most significant struggles in learning to cope with their illness. It struck at their perception of themselves as men and it affected their life in both positive and negative ways. Loss of sexual drive and function can also be experienced by men whose prostate cancer is not advanced, either due to the illness or as a result of treatments.

**Keeping active – ‘dancing lifts me’**

Most of the men engaged in a physical activity of some kind as a means of achieving some quality of life, maintaining their health and dealing with stress. Michael’s activity was not of a structured nature but he moved about a great deal in his role as a Prostate Cancer Foundation of Australia Ambassador. He relied heavily on being able to be active. He also continued to work as much as he could but his energy levels made this difficult sometimes.

Wayne’s physical activity involved visiting residents in his village where he was appointed as a liturgical assistant during church services. He admitted that at the age of 85 his physical activity was limited and that what he did often left him exhausted. Physical activities of the other men included bicycle riding, being a member of a sports club and competing every weekend, weight training and playing golf. Alan enjoyed dancing
which lifted his spirit because of the music. Ken said, *I still do weights four days a week and this seems to keep me fairly active.*

Being active was important for all the men. Some were more structured in their approach to regular exercise than others. One important aspect of this activity relates to energy levels. Wayne, because of his age and energy levels, found continued physical activity difficult. The late stage of Craig’s illness precluded him from being very active.

**Food – ‘If it comes out of the ground, we eat it’**

Food was seen as important for a number of men but not all of them stated their belief in the need to maintain a careful diet following their cancer diagnosis. The strongest advocate of the importance of a healthy diet was Ken. He enthusiastically embraced a very strict regime which, he admitted, required considerable discipline. He was encouraged in this by his naturopath and was supported by his wife. He was so convinced that his diet and activity were vital in the maintenance of his health that he established a vegetable garden. He was a strong advocate of non-processed food, saying: *If it comes out of the ground, we eat it.*

One man turned to Chinese herbs and Ginseng and was very pleased to say, *I got all my energy back*; another saw value in maintaining good eating habits but not necessarily in adopting a strict diet. It was mentioned in ‘Meet the men’ earlier that Jason became very enthusiastic about pawpaw leaves. He believed that his adherence to a daily intake of juiced pawpaw leaves was helping him to fight his illness. (He crushed the leaves and drank about 600ml each day.)

*I feel I’m actively doing something over and above, and instead of, ‘Well, come back and see me in three months’, I’m doing something there. It’s good for my mind and it’s good for my body.*

And,
Well, I’m not sure about my body, but I believe it’s going to help me. I really believe this. I believe it so strongly, spiritually and otherwise; this is my little grasp on things.

Feeling that he was ‘doing something’ was the essential thing for Jason. This was a significant issue for most of the men. On the whole, they recognised the value of eating well but differed in the way they approached their eating habits.

**Psychological matters – ‘I have a good mindset’**

Four themes were particularly evident that related to the men’s approaches to their illness – attitude, emotional volatility, suffering and stress – and there is overlap between some of these themes.

**Attitude – ‘it’s not going to get me!’**

Most of the men were very positive in their attitude to the way they managed their illness. Ben had the greatest struggle with coping; he freely admitted that he had a negative emotional state at various stages of his treatment. It is significant that he stated, *I just had to come to terms with it. It’s hard to accept, but that’s the way it is and I’ve just got to cope with it as best I can.*

Stephen commented: *If you want to be cured, you’ve got to do it yourself and look after your own body.* Colin said he kept his mind positive before each blood test, … it’s not going to get me!

The positive attitude was often enhanced by helping others. Wayne commented that *dealing with other people’s problems diverts you from your own.* Michael spent considerable time actively trying to promote a more supportive environment for men with prostate cancer.
Stress –sometimes ‘the chips were down’

The men acknowledged stress in a number of different circumstances and this sometimes led to emotional ups and downs. Michael had stress due to his loss of work because his income was slashed. Michael's doctor tried to ease Michael's stress, saying: *Look, don’t beat your head around. That’s it. You have a very aggressive cancer.* Michael also had multiple illnesses. Stress associated with these is implied in his statements that he needed greater support for his metastatic cancer as his local support group does not cater for men with advanced prostate cancer.

One man had immense stress when he was first diagnosed, especially as the surgery that was needed urgently coincided with the establishment of his new business. Some of his stress was caused by conflicting views from a variety of doctors and specialists. Another stressor was about his need for two registered nurses to show him how to use a dilator in the shower to facilitate his passing urine. This stress continued when he had to use the dilator on many occasions. He also had stress when he had to consult a new doctor.

Wayne was stressed at losing his contact with the *lady doctor who was looking after him* while Colin had some stress associated with what he thought was incorrect testing: *I wasn’t impressed with that.* He also admitted to feeling stress every three months when he was given injections. Also evident among the men was a combination of stresses – his own illness, the illness of a parent, a partner breakdown, surgery and the side-effects (incontinence). One man was also disappointed in his doctor for not having diagnosed the problem earlier. He also had elevated blood pressure and was taking antidepressants. Fluctuations of PSA seemed to cause stress for most of the men especially as they were so intent on keeping the PSA levels down.
Although the men had many sources of stress, they learned over time to reduce their stress levels as Alan explained: *You just become used to it after a while.*

**Emotional changes – from ‘Beauty!’ to ‘a blubbering mess’**

Emotions – whether positive or negative – figure prominently in each man’s experiences. A positive emotion such as happiness reflected the satisfaction that some men had at various stages of their journey and was usually associated with encouraging results of their medical tests. The negative emotions were often related to diagnosis, treatment, negative test results and frustrations with medical or organisational matters.

Some men experienced very negative emotions during their treatment. Jason admitted that he becomes quite teary watching some television shows or talking about his cancer. (Tears welled-up during his interview.) When asked what his feelings were at the time of his extreme physical suffering, Alan responded with details of the pain and suffering that he had experienced. Emotional distress was very evident in the way he responded.

Ken experienced very mixed emotions and some of this volatility was related to his prostate cancer but also to his conversion to Christianity, the latter possibly due to his realisation of hope in his life, and a relief from his initial shock of diagnosis. As the result of his attending church services he stated, *I felt a heightened awareness, really, to the point where a couple of times I was a blubbering mess afterwards because the emotion was just so intense.* He also felt an emotional high when, at one stage, his PSA went down. *Beauty!* was his reaction. Further along in the journey, he indicated that he became much calmer.
In two cases there were positive emotions. One man, for example, was comforted when he realised he was not alone; while another was excited that he was able to sell his business – *Bingo!*

Ben had some very negative responses to some aspects of his journey – his story contains such words and phrases as *astounded, hell of a shock* (twice), *I feel robbed, all of a sudden* (following his realisation that he might not reach the age of 60), *angry, bad luck, shattering and tragic*. It should also be noted that he was treated for significant depression. Wayne indicated that he was *thoroughly disappointed* when a trial program was discontinued. This prompted his very sadly stated comment that he was *no longer any use to them* – that is, to the medical professionals.

Craig experienced devastation and disappointment. Michael was less demonstrative emotionally – his most expressive emotion was his response to a neurosurgeon who told him that if he operated Michael could well end up in a wheelchair. *Oh, great!* was Michael’s mildly sarcastic response. He became more emotional in his description of the lack of co-ordination in the management of men with multiple illnesses.

An emotion sometimes implied in the men’s stories was that of loneliness. Three of the men seemed to experience loneliness in one way or another. One, for example, even in the ‘busyness’ of daily life in the church seemed to be lonely in relation to the absence of his wife. Another’s loneliness also seemed to be more marked after his relationship breakdown with his partner. Alan’s loneliness was related to his divorce from his wife. In addition, he seemed saddened by (but perhaps resigned to) the decision of a good friend not to develop the friendship further because of what Alan regarded as her desire not to be hurt when Alan could no longer be with her.
Suffering – ‘the pain … worries me’

The phrase above expresses the men’s physical and psychological suffering. It was Alan who commented: *It’s the pain and suffering that worries me. I’m ready to die and any time; that doesn’t worry me.* The pain was physical but the worry about it was psychological. Suffering is mentioned here because emotional and psychological suffering are more relevant to coping through spirituality.

The physical pain was often excruciating. For one, it was almost unbearable: *Sometimes the pain is so much that I scream and cry and wish I’d die.* The latter comment was a psychological response to a physical difficulty. One man was distressed about the catheter that he *didn’t like*, while others found their pain physically and psychologically stressful.

Support – ‘Wow, I’m not alone in this journey!’

Many social matters impinged on the men’s lives and the following highlight two that appeared important to them – support and dissatisfaction.

Support was mentioned in the men’s stories in a variety of ways. Sometimes they were critical of the lack, or inadequacy, of support through the medical system; but they were also appreciative of good peer support. In general, the support from their families was very strong. Where it was relevant, some acknowledged the spiritual (religious) support they received.

Medical support

Several of the men experienced considerable difficulty on occasions in communicating with medical professionals and organisations. Michael drew attention to the lack of a co-ordinating body to monitor critical and multiple illnesses where these existed, and also expressed concern about the lack of proactive medical support.
I mean, talking about support, this is where the whole system (and this is not so much spiritual support but medical-type support), for people diagnosed with advanced prostate cancer, you’ve got to go out and find it all yourself.

One man mentioned that there was confusion for him over medical trial information. Others were disappointed because they were given unsatisfactory or ambiguous statements about their condition, were given the ‘run-around’ from a receptionist and they experienced delays in being diagnosed by their doctor. While some difficulties were experienced, the men who were initially dissatisfied eventually found someone who was able to provide the service they wanted.

Although problems were resolved eventually, the men experienced stress pursuing suitable treatment, support or even a clear diagnosis. The stress in turn exacerbated their symptoms and negatively affected their mood.

**Support groups**

All of the men had varying degrees of satisfaction with specific prostate cancer peer support groups. In general, they were appreciative of the services offered but with occasional reservations. One man was critical of both government and peer support in one area, but he was also very enthusiastic about the value of peer support to the extent that he made a major contribution to support groups, even though he was, at times, physically exhausted as the result. The men found occasional valuable information from various support groups with Alan commenting that, especially at the beginning of his journey, *they were a great help to me.* The men had occasional reservations about individuals within the groups who wanted to use the facility to *moan and groan,* or when the group became too bogged down in clinical matters. However, on the whole, they found them to be helpful, especially in that men were able to talk about their issues in a relaxed environment.
Spiritual support

Spiritual (religious) support was appreciated by those who had church-related affiliations. One man received support through spiritual telecasts and DVDs while another was especially supported by his direct involvement in his church’s services. Stephen found support in the religious activities of some organisations in Thailand where he went frequently, especially for spiritual support. Three others received their support through their church but, in each case, in a different way.

Because the spirituality of three of the men was less related to organised religion, their particular cases will be addressed in the following part of this book. Support for these men was an important issue and it related generally to their particular kind of spirituality.

Dissatisfaction – ‘my GP really let me down’

There was quite an amount of dissatisfaction among the men who participated in the research. This was mostly associated with diagnosis, the care and treatment received, but also included dissatisfaction with some medical support services.

Jason man was dissatisfied because he was not encouraged to take a screening test. He eventually had tests because he pushed the issue. He also indicated that misinformation was a problem for him. He went through a very convoluted process of checks. He did have PSA tests, and DREs, bowel screening and cholesterol checks but it was only when he found blood in his bed that he went further for checks that revealed a prostate problem. As he was a pensioner and not a member of a private (non-government) health scheme, he had to wait for an extended time for an appointment to have a biopsy to confirm his prostate disease. He was so dissatisfied that he eventually wrote to the government Minister for Health (as mentioned in the brief biography earlier) to try to expedite the process. Arrangements were eventually made but not before he
experienced considerable stress. Understandably, he was *very annoyed about the whole process.*

As mentioned earlier, Colin was dissatisfied that he was not receiving what he thought was appropriate testing. He believed that if details of his testing had been conveyed to him, some of his suffering might have been alleviated and his resultant dissatisfaction reduced. Ben expressed his dissatisfaction with the lack of testing this way: *I feel that my GP really let me down. He was a professional and he should have known.* Another man had an extremely disconcerting experience that led to his dissatisfaction. During one instance of surgery, according to him, his surgeon made an error. He was given much confusing information, some of which he perceived as very inaccurate. His recounting of the lack of esteem with which one specialist was held by other patients appears to be a serious matter.

Alan had a very dissatisfying experience when he was trying to find out information to which he was entitled. *They pull this ‘privacy’ on you because in many cases they are just too lazy to have to do anything.* As he said in his story, he believed that he had been given the run-around by a receptionist. Alan’s experience demonstrates that there can be difficulties at all levels of a cancer experience. These experiences led to dissatisfaction that, in turn, led to stress and a non-helpful environment.

A very significant expression of dissatisfaction was made by Michael. His observations were in relation to himself and then transferred to more system-wide failures. At the personal level, Michael had a number of illnesses. His dissatisfaction was with the health system that did not allow for a monitoring of him as a person with multiple illnesses. Each illness was significant in its own right and was being treated by a different medical specialist. There was no co-ordinating doctor or team to monitor Michael’s progress as a whole. Michael saw a need for the system to have a monitoring structure in place.
Several of the men were dissatisfied with lack of support and understanding by social agencies to enable them to cope with their medical diagnosis and condition. Their dissatisfaction was more keenly felt because they were under considerable stress at the time.

**Conclusion**

The medical, physical, psychological and social issues arising from the men’s stories were important to each of them. They were an integral part of their lives and demonstrated the positive and negative aspects of the ways they tried to cope. While at first glance it might not seem that the issues impinge on the men’s spirituality, it will be noted later that there is an important relationship between these aspects of the men’s journey and their spirituality.

**Your journey so far**

The question for you at this stage is to what extent your cancer experience has mirrored that of the nine men who have started telling their stories. Have you been in the position of having a very confusing beginning to your prostate cancer journey? Have you had confusing evidence of the extent of your prostate cancer? What about your attitude and your emotions? Have you found you have been on an emotional rollercoaster ride? Have you, like some of the men, been depressed?

One of the issues that has affected many of the men was their sexuality. Has this been a problem for you? What about your physical activity? Have you felt able to get out and be active or have you found it very difficult to be active?

There may be aspects of your diagnosis and treatment which may be very similar to the men whose stories we have observed so far. You may find it useful to talk to someone about the similarities and differences with your
experiences so far. You can take some encouragement from these men: many of them had a very positive attitude - they weren’t going to let the prostate cancer get them down. But, of course, on occasions they felt down-hearted and they described some of the ways in which they addressed these situations.

In the next part of this book we will look at the way the men started to find their spirituality and make use of it for themselves. Remember, the idea was that spirituality helped them to lift themselves above their everyday problems caused by their illness. Central to this lift was the connections they made that raised them above the problems they faced and contributed towards the peace of mind which they sought. Implied in this book is the idea that you are probably searching for peace of mind as well, and perhaps you can gain some insight into your spiritual journey by looking at the way these men connected with people or activities which made them feel spiritually stronger.
The Journey: spiritual

My spirituality has helped me a lot because it has given me a good mindset. Colin

It became apparent through listening to the men’s stories that there are many dimensions to their spirituality and that their spirituality contributed to their lives.

Having looked at medical, physical, psychological and social matters, we now turn to the central theme which emerged from the men’s stories: connecting.

Connecting – ‘a problem shared’

A problem shared is a problem at least halved, isn’t it? Wayne

Connecting was an important part of the men’s spirituality. Connecting occurred with themselves, their partner, a higher being or religion and other people. These relationships are illustrated by the diagram below. Around these are the wider dimensions of their experience: the process of their illness; how they find purpose and meaning; their personal values; and their search for peace and fulfilment.

The spiritual journey
Spirituality was not focussed on one area alone but rather formed a network of inward-looking and outward-looking connecting. For example, some men demonstrated a closer affinity to a higher being than others and had differing degrees of connecting with a partner or with their family. The search for purpose and meaning in life was more focussed in some men than in others, while they all had different emphases in their life values. This illustrates that spirituality is highly individual for each person and can be expressed in different ways.

**Connecting with yourself**

The basis of all the stories was the idea that spirituality starts in the individual and connecting with self involves a man reflecting on and knowing himself. For this reason the issue of connecting with self is addressed first. How do you connect with yourself? Through thinking and reflecting.

Wayne carried out a lot of personal reflection. He said, for example, that he looked back over 15 years. This reflection revisited the amount of time he had spent in understanding his illness and, at one stage, he mentioned that his *hindsight* (reflection) enabled him to see that it was unfortunate for him that he had had early biopsies that were not as comprehensive as later biopsies. It also involved thinking about the decline in his physical strength. It can be interpreted that Wayne’s connection with others sometimes distracted him from reflecting on his own difficulties. His personal prayers involved some reflection and communication with himself because, in order to pray for assistance, it was necessary for him to reflect on his own need first. He reflected that

*The Lord’s hand is comfort ... It is real and you take the comfort from your prayers. You can lift your head up and say, right, the Lord’s with me. I’m going to cope with this with His help.*
Wayne’s story shows that his thinking and reflection was important in his connecting with himself and in centring his spirituality.

Ken’s reflection involved him and his wife trying to make sense out of their lives, especially in relation to Ken’s illness; he stated that they realised that some aspects of their lives had a purpose. Ken also recognised that, on reflection, some of the things stated by a naturopath made sense to him. In other words, he thought about what had been said and placed it in a personal context. His reflection also involved thinking about the answer to his question, What do I do next?, making a decision for his own progress based on his own self-concept. Ken assessed that he had changed over the time he had prostate cancer due to self-reflection and a greater knowledge of himself: I’m calmer in myself. He was also very enthusiastic about meditation. He usually meditated at night by spending some time ‘switching off’ to everything. Ken described one method of self-connection as concentrating on his body parts. The value of this, he said, was in taking his mind off the things of that day which were occupying his mind and which prevented him from sleeping. Ken’s key reflection was when he realised that he himself had to do something about the problem.

Suddenly, I finally came to terms with the real issue. I said to the doctors, ‘What do I have to do to fix the problem? I don’t want to have to react to the problem after the event.’ Nobody in the medical profession could deliver that. So I thought that there had to be an answer somewhere else. So then the rest of the journey started to evolve.

For Ken, the solution came when he connected with himself. When he did that, the rest of the connections in his life became clearer to him.

Stephen’s self-connection also occurred when he realised, during his reflection, the need to do something within himself.
It started me thinking – the doctors are not going to cure me, they’ve given me a bit of time – all they’ve done is bought me some time – so I’ve got to work out what am I going to do with the time I’ve got.

Stephen recognised his need to bring energy from the universe into his body: I decided ... to make the effort to make myself fit and healthy. Another of the men attributed much of his self-connecting to the meditation in which he became involved. His summary was that it calms you down and it has a good effect on you.

Stephen was delighted that one of the side-effects of his coping approach was that his golf game improved. His meditation was sometimes focussed. However, he sometimes used the Zen Buddhist mode of thinking of nothing, or sometimes his meditation was done to music. He was also adamant that getting my head around it was important for him. This can be understood as self-connection – he wanted to ensure that what he was doing was right for him.

Alan’s self-connecting seemed to come at a later stage in his journey. In talking about spiritual support, he wanted to talk to others about where you are at. He wanted to be connected with himself but wished to have spiritual support to do this. I don’t find myself involved in a lot of personal spirituality. I do like to go and worship with people. I like to sing, pray, have communion ... fellowship. His final statement indicated his self-connection explaining that he was at peace with himself and where he was going. He was self-assured in his future and this implied that he knew his inner self. I could go to bed tonight and die in my sleep and that would not worry me at all.

Although Michael was less direct about how he connected with himself, he reasoned that he did not want to isolate himself. He explained that it was not in his make-up to just pull down the blinds and lock the door and
wait for the rainy day. He knew himself and decided on a course of action. His comment: *We’ve got to try and help ourselves by looking after ourselves* demonstrates Michael’s connection with himself.

Jason struggled initially with self-connecting and coping with the treatment of his illness. *I do feel OK in my body but my mind is a bit screwed up.* Jason’s self-perception of his struggle and his own confusion is an example of self-connection. Over time, Jason became more self-connected through his enthusiastic belief in the value of pawpaw leaves and meditation. He said, *I believe it so strongly, spiritually and otherwise; this is my little grasp on things. I don’t pray a lot but I try and meditate.* Jason was convinced in himself, on reflection, that pawpaw leaves were going to help.

Colin’s self-connection enabled him to recognise that he had control over his mind: *My spirituality has helped me a lot because it has given me a good mindset,* and, *I know where I’m going and I know what I’m doing.* Craig initially accompanied his wife to church. He then started to read the Bible and other writings and became more personally convinced of the direction he wanted to take. Craig found *peace with himself* that had a significant benefit for him: *in essence the main thing was that it took away my fear of death.* It is interesting that Craig’s connection was not to a church institution. His connection was with himself, yet with some connecting also to his wife, God and other people. He realised the importance of self-knowledge when he said: *No, the only support I would like comes from my soul; with better knowledge. I think it is up to me to lift, not other people.*

Ben struggled to connect with himself. He tried to find support through God but he was not sure in himself whether he believed in God. While he stated that he was happy in his own environment, he did not exhibit self-knowledge at the time when he was interviewed.
The above examples show how differently each man connected with himself. Even amongst the Christian men, where some kind of commonality might be expected, the way they connected was different, moving from the highly personalised self-focussed connecting of Craig, enhanced by his affinity with various kinds of exposure to Emanuel Swedenborg, a Swedish scientist and theologian, and Helen Keller, an American author, to the need for Alan to experience his self-connecting through his religious association with people in a congregation. Each was challenged by the context in which he was facing his illness and each had to reflect on his personal circumstances to understand himself and develop the way he would cope.

**Connecting with a partner**

All the men indicated that their connecting with the partner had an important influence at some stage in their spiritual life. It was very clear that they relied on their partner, even if this was sometimes in an unusual way.

Michael appreciated his wife’s ability to understand the medical issues:

*My wife Margaret has been with me all the way and her career as a nurse and nurse educator has been extremely beneficial when talking to the medicos and asking questions in a different way.*

Craig was so much in *dire straits* that he was very dependent on his wife for almost everything. He commented:

*I know I keep bringing up my partner, my wife, all the time. She’s very, very spiritual compared with me. Very spiritual. I’d love to lift myself closer to her ... Dianne is my crutch.*
Wayne longed for the company of his wife to help him through the various cancer related experiences. Her ‘absence’ because of Alzheimer’s disease and subsequent death left him feeling the burden of making decisions: *I had to make all these decisions on my own and this made things much more difficult as far as I was concerned.*

Colin accepted his wife’s judgement on the selection of a church to attend: *Pamela found the church she liked. I said, ‘That’s good enough for me’.* Ben had a relationship with a woman who helped him: *She helped me a lot. Every time I saw her, it gave me strength.* While that relationship did not continue, I spoke with him after later treatment and found that his former partner had come back to stay in the house with him to support him during his treatment. He appreciated this.

Sometimes a partner’s relationship can have unusual circumstances. Jason’s first relationship ended in disappointment for him but he was delighted in the connection he had with his current friend who was very supportive of him. *I am so fortunate with another lady now who is really, really on side with me.* Stephen formed a supportive relationship with a woman who was not his wife but with whom he had formed an attachment as a result of a shared group cancer support experience.

Alan’s connection with a new partner ended due to his diagnosis and this was a major problem for him. Alan, a divorsee, had become friendly with a woman who was unable to sustain the relationship because of Alan’s uncertain future.

... *she decided she didn’t want to be a serious friend any more. She couldn’t cope with it. That is the case when you reach this stage – you can’t expect anybody to be too close because they know they are going to get hurt.*
This was a very sad situation for Alan and seemed to affect him considerably. The loss of someone who had become a close friend made a difficult situation worse for him.

Ken summed up his situation by saying that he could not have progressed as well as he had without his wife. *I have to say that if I hadn’t had Sue in my life I would never have beaten [my illness] because it’s taken a huge effort on her part to throw it.* Ken recognised the very significant support he received from his wife.

Connections with partners which either succeeded or failed were an important factor for each of the men. For those who had supportive partners, the men were better able to cope. However, for those who had no partner or who lost a partner, there was increased stress, sadness or loneliness. In most instances the presence of a partner gave the men a lift and helped them transcend the difficulties of their illness.

**Connecting with a higher being**

Not all men the men connected with a higher being. Most of the men, without prompting before or within the interview, recognised a distinction between religion and spirituality in the sense that spirituality was an individual matter while religion was the organisational aspect of spiritual life.

For five of the men, spirituality was closely related to their religion. Two others acknowledged a higher being and their religion except that they were not as committed to a full participation in it. One man stated that he was not religious, while another recognised religions such as Buddhism, even though he did not embrace them.

Four men were regular attendees at church services. One man was less regular but nonetheless committed. His difficulty at the time of his
interview was associated with the problem of being physically unable to attend. He stated that sometimes it's a pain in the neck to get ready to go, and besides this, he indicated that generally the sermons really don't lift me up, no. This man received most of his spiritual sustenance through books and DVDs (and his wife).

Wayne, even at the age of 85, was totally committed to his religious involvement in the church and to his quiet, personally reflective connection with God. It has been mentioned that he was very active in his retirement village as a liturgical assistant. As well as this, he participated in small-group theologically based activities and reflected on his worship of God privately. He had a range of activities that fostered his spiritual connecting to a higher being. I think my religious activities only strengthen me.

Colin’s relationship with a higher being came through his conversion to Christianity. This eventuated through his connection with a TV evangelist. Colin was impressed with the evangelist’s achievements in healing. Colin had an affinity with this because of his own strong interest in practising hypnosis. His connection with a higher being involved attendance at church services and especially through his conviction that his spirituality and his own hypnotic abilities were God-given: I think it’s a gift. My hypnosis, healing and spirituality are all part of the one. He also explained how hypnosis and healing worked together on the mind and body:

The hypnosis and the healing come in together, and spirituality. If you say it’s in God’s name you’re healed, or, if the healing process is in your mind, it is accelerated.

Alan acknowledged a higher being in a religious sense as his connecting was through his church. His attendance was what might be described as liberal in that he was not tied to attended churches of a particular
denomination: I’ll attend any church that’s convenient to me at the time. For Alan, prime spirituality and connecting had to be with a higher being, God. His connection with God was made through his attendance at church services rather than through private, personal reflection. He explained this, saying, You get a congregation and within that congregation you do have a real spirituality.

Ken’s connecting to a higher was made through his contact with a church. He maintained regular church attendance and believed his changed lifestyle gave him confidence in his future. Ken’s connection with God came through the practical healing he witnessed at various church services. He commented:

The church has been a huge inspiration to have this direction in the back of my mind all the time. I think about a lot of things and I research and analyse a lot of things and I’m getting a lot of direction from the church and my involvement with God.

Jason’s spirituality was more associated with his individual persona than with religion. He acknowledged his association with the Catholic Church but he did not go to church very often. He said, I’m religious and believe in spirituality, and I certainly believe in the Lord. He also stated, I believe in God and say my prayers, indicating his personal connecting with a higher being but not necessarily through institutional religion.

Ben was not religious but he turned to God for some time. This was not a lasting connection. He explained: I wasn’t a religious person but I turned to that in the hope that .... He later stopped praying and did not understand the reason except to say that he was not a religious person.
Connecting with other people and activities

The use of the term ‘other(s)’ reflects the diverse nature of the way in which the nine men expressed relationships beyond their connection with their self, partner and a higher being. Human connections, for example with family and friends were emphasised by the men although connections with activities were also important for helping to lift them above the ordinary.

Connection with ‘humans’

During their illnesses, the men all reported stronger and more important relationships with their immediate families including parents and children, their friends in church, sporting clubs and support groups, medical professionals and acquaintances. Their connections lifted the men above their everyday attempts to cope with their illness.

One man indicated that after his diagnosis he moved to a different location to be closer to his sons. Another mentioned his parents incidentally at the beginning of his story on spirituality. His mother insisted that he and his brother go to Sunday school.

‘You can do anything you like, you two boys; you can lie on the ground, kick, say you’re sick, but you’ll go to school every day and you’ll go to church on Sunday.’

He was proud of his mother’s guidance, even though he did not follow it up at the time.

Four men did not mention members of their family, apart from their wives. The others mentioned their family, especially their children. Ben, for example, was very close to his son and, in the absence of a partner, Ben relied on his son to talk over issues with him. He was also close to his mother, even though she was elderly. It was his mother’s illness and her
distance from him (in New Zealand) that added to the stress of his prostate cancer.

Jason was even more forthright in his recognition of the connecting he had with his father and with his sons. He acknowledged that his own life might have been different had his father been around. Jason acknowledged his connecting with family in these terms: ... my family lifts me greatly. I live for my family ... My family and grand-kids are my spirituality. It was obvious that Jason’s family lifted him above the ordinary. They were very special for him.

Michael has a very strong connection with other people. He had devoted the past few years of his life to working with men with prostate cancer. In his role as a Prostate Cancer Foundation Ambassador he had made many presentations to community and industry groups in which he drew attention to many of the issues associated with prostate cancer. He had a great deal of empathy with men, as well as with their partners. He was adamant that partners should be involved in discussions as well as the man with the cancer.

I always say, especially in industry groups, that female employees should come along as well so they can pass the information along to their husbands, partners, brothers, fathers, uncles etc ...

In his connection and empathy with men, Michael was keen to promote awareness of prostate cancer.

If I can encourage men to go to the doctor, look after themselves on a regular basis, then it has not been in vain in [my] getting prostate cancer. ... I’d like to raise the awareness of men and their partners.
Craig also had a very strong connection with others. His strongest connection was with Helen Keller and Emmanuel Swedenborg – a connection that grew from his relating to people who, while physically dead, were ‘alive’ through their writings. Craig’s spirit was boosted by his connection with people he met in his daily life:

\[ I \text{ got lifted up yesterday by the dentist, the x-ray people, the lady who took us into the place where I’m having this treatment next Tuesday. I got lifted up by Reverend Tills yesterday when I mentioned spirituality. We had a lady come in next door and she sat there and you could see kindness all round her. Things like that lift you up. } \]

Spiritual leaders were important for many of the men. Wayne identified closely with the priests at his church. At the same time, his constant service to the people in his retirement village indirectly showed his determination to be connected with others. Colin was connected with the evangelist Benny Hinn and later to pastors in his church. This was also the case with Stephen, who became very emotionally involved with the healing activities of his pastors. Alan would have liked to have been more connected to pastors to gain added spiritual support but placed a qualifier on this:

\[ ... \text{ the person you pray with has to be sincere, they’re not just a wage-earner; it’s not just their job. } \]

Two of the men formed strong relationships with the medical practitioners who cared for them. Wayne was very closely connected to his Russian doctor, while Ken became very reliant on his naturopath.

Six of the nine men attended support groups. The connections they made were mostly positive however some were negative. Stephen, for example, did not like the *moaning and groaning*, as he described it, that went on at
some support group meetings. He commented that the people *sucked all the energy out of me and I didn’t have enough to share so I didn’t go back.* Stephen broke off other relationships which created tension and that did not help him, but he maintained a positive relationship with a woman in a broadly-based support group that he found helpful.

Ben found connection with people he knew through writing to friends to tell them about his illness at the time of his diagnosis. He said:

> *I wanted to spread the story, I suppose, just to take the weight off my shoulders because when you are diagnosed with a terminal illness it’s just a huge burden and, yes, it’s really hard to cope with. ... It’s helping me by saying it.*

**Connection with activities and interests**

Men in the group connected with activities and interests as well as with people. They found that activities and interests could give them a spiritual lift. Alan found that dancing and music lifted him up. Music was also an element in Stephen’s story of the things he did to cope. Some of the men were lifted by the books they read, horse-racing and boxing and boats and boating. Jason commented: *I walk to the beach or go and see some boats. That lifts my spirit. It makes me feel good.* Colin was a sports hypnotist and found a close connection between his hypnosis activities and his spirituality.

Wayne was absorbed by his interest in astronomy and amateur radio operation:

> *I wonder if you would call ... [them] spiritualities or whether you would tend to call them interests. ... Those two things can absorb you completely and you can switch off from the world.*
The men generally recognised that there were many other things in their lives that lifted them above the ordinary and were special to them. It was evident in this study that men with advanced prostate cancer regard human and non-human connecting as part of their spiritual experience.

**Other aspects of the journey**

**Parallel progression**

For each of the men, physical challenges posed by their diagnosis and treatment seemed to lead them to focus more on their spiritual journey. As their illness progressed, the men’s connections with themselves, their partner, a higher being and other people and interests also progressed.

For some men, their closer connection with family and friends was triggered by their diagnosis. It was noted earlier that Michael sent out more than 100 emails to family and friends as soon as he was diagnosed so he could encourage men to be screened and to avoid what he was going through. Another man’s immediate response to his diagnosis was to connect via phone with his son and to go to visit his mother.

One of the men responded to his diagnosis and treatment by adopting holistic care via herbal medicine. His spiritual journey was also triggered as he made an attempt to connect with God although this did not last:

> To be honest with you, I’ve actually stopped praying now. I can’t explain why because it was just something that … like I said, I wasn’t a religious person but I turned to that in the hope that, yes, you haven’t got much when you’re diagnosed with a terminal illness.

This illustrates the point that not all the connections men tried to make were positive or long-lasting.
An element in Ben’s life was his connecting with other people when he wrote to many people who he knew well, and to some he did not know so well, so he could share his story with them. His spiritual journey was volatile and his connections with other people were sometimes overwhelming because it might get all too much. At other times he might talk successfully with them: *It just works that way.*

Some of the men began trying to connect to a higher being in direct response to their diagnosis. Ken was prompted by a friend of his son to take a greater interest in connecting to a higher being. His interest in religious spirituality developed alongside his physical progression. He believed his holistically spiritual life-regime had been so successful that he had no further need of doctors. Alternatively, he may have been in denial about the seriousness of his medical condition. He said:

*I believe that what I was doing with the naturopath and my approach to believing in God that He would speak to me and keep directing me – Sue and I sat down one day and we said, ‘We’re not going back to the doctors …’*

Craig’s greater focus on religious spirituality commenced at about the same time as his cancer diagnosis: he started going to church with his wife. He was influenced by Helen Keller and Emmanuel Swedenborg and spiritually he regarded his conversion and his spiritual experiences as a *miracle.* His spirituality developed alongside his cancer journey to the extent that his spirituality *took away my fear of death.*

Colin had no defined spirituality before his diagnosis. Soon after his diagnosis, however, he began following an evangelist and saw the relationship between his developing Christianity and his illness. He stated categorically that his spirituality *increased because I had nothing until I started four years ago.* His life became committed to developing his spirituality which continued to grow.
Wayne had embarked on a spiritual path earlier in his life, letting it lie dormant until just before his cancer diagnosis. He had returned to the church and found that it was a *source of not simply comfort, but enormous support* to him at the time of his diagnosis. As his cancer progressed, so did his spirituality; he said his church activities *only strengthen me*. The implication was that his spirituality was continuing to develop.

As Alan’s cancer developed he faced enormous physical challenges but his spirituality remained a strong support to him. He was brought up as a Christian and had always attended church. He was still attending church and during his cancer his spirituality was maintained or *it may have increased a little*. This is an example of the way a man who has developed religious spirituality during his life taps in to that when he needs to do at the time of stress.

Jason had always been a Christian and, although he attended church only twice a year, he believed emphatically in God and Jesus Christ. Even though he had that basis, it is evident that his spirituality continued to develop, not in religion so much as with other dimensions of spirituality. He was introduced to, and came to believe that, pawpaw leaves were a helpful treatment for his condition. At the same time, his family became more meaningful to him as well, as did his connections with other people. His comment, *My family and grandkids are my spirituality*, was made as a result of his recognition that he was going to stay with his family while his illness was ‘sorted out’. His greater physical needs led to a greater focus on spiritual connecting.

Stephen’s spiritual growth also coincided with his diagnosis and treatment. He heard about a health resort in Thailand and had planned – before he was diagnosed – to visit there with his wife. He became interested in healthy food, meditation and associated activities that were fostered in Thailand. It was this inclusive activity, particularly meditation, that he regarded as his spirituality. His spirituality developed and helped
him to cope, not only with this cancer but with his life as a whole. He directly relates his spirituality to improvements in his PSA.

Eight of the nine men experienced simultaneous spiritual development alongside their cancer diagnosis and treatment. The diagnosis was the catalyst for the awakening of, or significant increase in, each man’s individual spirituality which then continued to grow as their illness progressed.

**Life’s values**

Each of the men’s stories illustrates their life values such as love, faith, trust and honesty and how these were integrated into their lives. The most evident value was that of love. Craig, for example, was grateful for the love of his wife, explaining how much he depended on her love to keep going when he said: *Dianne is my crutch.* Other men were complimentary about the roles their wives played in various aspects of their lives including their conversion to Christianity. Ken was sincerely grateful for the love of his wife when he said his wife *had a huge impact on me having a good [medical] result.*

While Ben experienced a breakdown in his connecting with a partner initially, he mentioned sometime after the interview that she had returned to his house to help him through a six-week period of radiation therapy; he spoke of his love for her at this gesture. Although he and his partner could not live together in the long-term, she was willing to assist him through a difficult time.

Two of the men had negative experiences with their partners. One of the men blamed his divorce on a lapse in organising PSA tests that might have picked up his cancer earlier: *It just got away from me, I guess.* Another was dismissive of his partner who had said to him at the time of her
departure, *What comes around, goes around*. However this man’s subsequent partner was really, really *on side* during his illness.

The men’s love for their families was also a recurring theme – Ben’s love for his son and his mother; and Jason’s love for his son and grandchildren. Love also permeated the connection men had with other people, for example by warning others about the illness and becoming an advocate for men’s issues in the community to try to help them avoid going through what they had been through. One man said that if he could *encourage men to ... look after themselves on a regular basis*, his getting prostate cancer would not have been in vain. Another wanted men to *learn a bit more* about the way they could cope with their illness, hence his interest in ministering to men who had prostate cancer. Their love gave them a lift.

A very important aspect of love for many of the men was feeling loved by, and loving, a higher being. Five of the men had developed a very strong connection with God that was based on an understanding of what they believed God had done for them through the sacrifice of His Son, and through the living of Christian principles. This was expressed by them through their church or religious commitments.

Each of the men demonstrated their love of life by connecting to other people, especially their partner, family and friends and in trying their best to cope with the physical challenges of their illness and treatment in order to prolong their lives, despite at times, feeling depressed or suffering extreme pain. All the men showed love and respect for themselves through their dealings with other people as well as love and respect for other people.

The values of faith and trust can been seen in the way the men trusted the doctors, nurses, therapists, support groups and almost everyone who cared for them. Sometimes their trust was shaken by some of the people they would normally trust. Craig’s trust was broken when a surgeon made an
error during an operation on his prostate. He also reported that when a
particular urologist’s name was mentioned, the men attending a prostate
cancer support group booed, hissed and booed because of the way they
felt they had been treated by him.

Some of the men felt very disillusioned when they believed they had
misplaced their trust and were let down. For example, Jason trusted the
government health system to help him in the initial stages of diagnosis. He
was let down because the services were not provided when they were
expected. Michael was similarly disillusioned with systemic failures to
provide services he thought should be provided. He consequently spent
much time trying to advocate the establishment of these services: We’re
talking about the lack of indirect medical support; it’s not there. He was
similarly critical of the failure by some medical practitioners to provide
information about side effects (such as loss of libido as the result of some
treatments) to which men should be entitled.

**Purpose and meaning**

Given their diagnoses of advanced prostate cancer, all the men realised
their life expectancy was limited. Facing a limited lifespan gave each man
a greater focus on his aim and purpose in life.

Michael, for example, was adamant that his purpose was to improve the
future for men who had prostate cancer and even more especially, those
men who had multiple illnesses. Michael believed that men needed to be
given better information and more focussed medical support. They had to
be encouraged to talk more readily about their illness and to take more
care of themselves. His purpose was clear:

*If I can encourage men to go to the doctor, look after themselves
on a regular basis, then it has not been in vain in getting prostate*
cancer. Sure, it’s still going to be hard on the family and everything else, but perhaps I’ll have left a mark somewhere.

Jason’s had a similar purpose: I’ve always wanted to do something, to change the world. And I have. After some years of prostate cancer he still had a sense of purpose to assist other people: If I can help, and people can relate to something I’ve said, and they get cured, well, the world’s set on fire; cancer might just be a word.

Craig found meaning in life in his service to God. He wanted to continue doing this and to continue to support his wife for as long as possible. Meaningfulness for Craig involved enjoying a close relationships with his friends. He wanted to have better knowledge relating to his spiritual life but was becoming frustrated that he was not able to concentrate and continue to be productive in his pursuit of greater spirituality. He said ... the only support I would like comes from my soul, with better knowledge.

Wayne’s continual service to God through his church demonstrated that meaning in life for him was to serve God through serving others. He had been doing this for many years. The basis for his purpose was, as he put it: My faith – it’s always there.

Craig believed he had something to offer through his Christian faith and his ability with hypnosis. He was very cautious about how much he used this ability but he was willing to demonstrate his purpose of helping others and serving God. Of his hypnosis he said, It’s a wonderful medium to use in a lot of places. His purpose was to use this gift to help others.

While these aspirations were far-reaching, Ben’s purpose was more modest. As he was going through periods of depression, he was more focussed on trying to help himself through his illness. He stated his purpose: I try to ride my bike every day for exercise. I try to catch up with my friends and have a coffee; sometimes go out to breakfast – every
Sunday actually with a group of about six of us. At the same time, he was happy with his own company. He aimed for a mix of exercise, company and quiet personal time.

Stephen had great resilience and determination not to let his illness defeat him. *I’m not going to sit around waiting to die*, he said. *I’ve got to find another way around it. I think that’s how you redouble your efforts.* Later he spoke of wanting to keep his head *around it all.*

Alan’s purpose, as a Christian, was to worship God. His experiences had been so traumatic that very often his purpose was just to exist with basic comfort. His purpose in treatment was pain management.

Ken defined his purpose when he was not satisfied with the way treatment was going. His purpose was to find an answer. *There’s got to be a way!* he exclaimed. When he found a way, he said, *I now just intend to keep on with the way I am going.* He had defined his purpose as having a broad spectrum of activities that related to his health. He and his wife eventually wanted to help others directly but friends reminded him that in discussing his illness and its treatment he was already helping others.

Hope is closely related to purpose and meaning. For example, Michael’s purpose was to try to change the way the co-ordination of men’s multiple illnesses could be handled. It was also his hope that this would take place. In all the men’s narratives, their purpose in life, and life’s meaning related to their hope. Craig’s purpose was to continue to support his wife and his hope was that this could be achieved. Each man’s purpose articulated above can be seen as a hope that might be fulfilled. Ben’s hope was particular – he lived from day to day hoping he could ride his bicycle and have coffee with friends.

The issue is probably summarised best in Ken’s statement where his purpose and hope overlapped. He wanted *to live as long as I can, as*
healthy as I can, with a high quality of life. Sue and I have a great life together and I want to maximise that.

Purpose, meaning and hope are very closely related. For example, it was one man’s purpose to reduce his level of pain and it was his hope (expectation) that his medication would achieve this.

In summary, the purpose and meaning in life, as part of their spirituality, was different for each of these men. Some saw their purpose as helping others. Others were more focussed on day-to-day living. It can be noted that the more pain and trauma each man was enduring, the more short-term and focussed was their purpose in life.

**Peace of mind, fulfilment and relief from suffering**

Whilst peace of mind may seem elusive for any man diagnosed with advanced prostate cancer, each man in this study had succeeded in finding some degree of peace of mind, fulfilment and relief from suffering by connecting with themselves, their partner, their family, other people and activities and interests.

Three men used their spirituality to find a positive view of their future. Each had peace of mind because they were confident that their spirituality was helping them to cope, and they were adamant that they were going to overcome their illness. One used his hypnotic powers, part of his spirituality, to alleviate his suffering, particularly when he was having an injection. Another said, *I’m calmer in myself; more placid* and *I now just intend to keep on with the way I am going*.

For those who realised they were dying, spirituality became very important. Three men were more settled about their future as they saw the end of their life approaching. Craig expressed his peace of mind by indicating that his spirituality took away his *fear of death*. Wayne stated:
I know my lifespan is getting shorter and shorter ... oh, I’m welcoming that fact because of what I have taken from my Christianity. I welcome the time when I can meet my Lord.

Alan’s peace of mind was expressed in this way: I’m not scared of dying ... I’m ready to die at any time; that doesn’t worry me.

Stephen suggested that his spirituality was able to help him with a peace of mind, especially when playing golf. He also made an insightful comment: It’s not just the enjoyment [of playing], but it’s my mental state. There was little doubt for Stephen that he saw his spirituality as helping him to achieve peace of mind.

Ben may represent an example of spirituality – in his case, connecting with others – not providing a great deal of peace of mind or fulfilment. There was nothing in his initial story that spirituality helped relieve his suffering, although his connecting with his former partner when she returned to assist him indicated that he had developed a greater peace of mind through her support. At the stage of his journey when he was interviewed, he had become depressed. There was no statement in his story of any sense of self-achievement. Rather, he felt cheated that his life was being shortened and he was disturbed about this. Ben’s case shows that peace of mind will not always be evident through spirituality at all stages of the journey. Peace of mind may fluctuate according to specific circumstances.

Examples of self-fulfilment are evident in the stories. While Michael’s mission was to assist men in the future, he was also satisfied with his own achievements during his life. One such achievement was associated with his cancer. He expressed his achievement in these words: Well, I’m giving something back to the community. I’m helping people who are perhaps less fortunate than me. (This was despite his very significant health problems in addition to his prostate cancer.) Jason had a similar sense of
fulfilment. *I’ve had a good life. I’ve had a good life more than most, actually.*

Realisation of a man’s spirituality can be an important aspect of his cancer experience. Peace of mind and self-fulfilment may result in relief from psychological suffering.

Where does this all lead?
‘It’s the holistic approach – it’s the whole package’

I chose God and the pawpaw leaves to lead me through. Jason

It was Ken who made the ‘holistic’ observation during the course of his story. When I asked him ‘… is (there) one single kind of spirituality that you have …?’ he answered:

"It’s the holistic approach that is everything; it’s diet, it’s exercise, it’s belief, it’s meditation, it’s relaxation. All those things for me are important, and when people ask me what single thing can they do to improve their situation I say, ‘I don’t know of any single thing.’ I think all these things are vital.

Jason gave a similar response. When I asked him ‘Do you find your spirituality has a role in coping with this particular problem?’ Jason responded: Yes, because it’s been the whole package that has come together.

While the terms holistic and package were used by only two of the men in the study, their stories show that their spirituality was holistic and influenced their lives accordingly. Ken, for example, placed great emphasis on lifestyle in that he exercised and followed a very strict diet. He connected with many people, particularly his partner. His connecting to a higher being was also important to him.

Jason indicated that his spirituality would increase, through God, doctors, hospitals and injections, family and pawpaw leaves, I believe this will happen and I chose God and the pawpaw leaves to lead me through. In addition to these things, he had his interest in boats that he found uplifting.
He was particularly lifted by his family: *My family and grandkids are my spirituality.*

It was shown above that Michael connected with himself, his partner, family and especially others. While he made no mention of any particular diet, he was very active in his moving around to visit people in his ambassador duties, even though such activity did not constitute an exercise regime. Stephen was very holistic. He watched what he ate but the spiritual aspects were very evident. He was physically active, involved himself in music, playing golf and meditating.

Wayne demonstrated holism in that he connected with so many people and God. His age meant that he could not be as active in physical exercise as he wanted. But he was still managing to have an active lifestyle. Colin involved himself in sport as well as his connecting with other people and especially to God; while Craig was well-connected, especially to his partner, God and other people. While he could not be active, he maintained interest in some sports.

Ben was connected to his son (and his mother before she died), and engaged in a great deal of bike riding for physical activity. Alan connected with God and other people, the latter especially through dancing, which for him was an important physical, as well as social, activity.

In summary, Ken, Stephen and Jason spoke of the holistic nature of their spirituality while the other men implied it through their description of their journeys.

*It's been a total journey.* Ken
Does holistic spirituality help in coping with stress?

The men experienced stress and many fluctuations in emotions. Emotions were usually associated with high and low points of the men’s physical journey. One man, for example, had an emotional high when his PSA level became low. Another man experienced an emotional low, and he believed this affected his physical health, resulting in a higher PSA level. Another factor in this consideration is the length of time men can have prostate cancer and, especially, the age at which the illness is diagnosed. Slower growth of prostate cancer can give men the opportunity for greater development of their spirituality.

A question arises then as to how, if at all, does holistic spirituality help men in coping with stress over a journey of some years where there might not be any imminent threat of death? Does holistic spirituality assist in building resilience?

The men in my study demonstrated that they used a holistic approach in their lives to cope. This seemed to be on two levels. The first was using their spirituality to cope in immediate situations; and the second was that they used their spirituality to cope with stress over a long period. A long time-frame for the progression of prostate cancer can give men the opportunity for a greater focus on their spirituality.

Immediate situations

Four of the men had specific, immediate stressful issues with which to cope. Wayne reflected that at the times he had hot flushes, he recognised that the Lord was there to help – every moment of every day. Colin indicated that his hypnotic ability, part of his spirituality, was useful each time he went to have his three-monthly injection. He could deaden his side through his hypnosis. Two of the men had an immediate connecting to their friends when they were first diagnosed. Both were astonished by
their diagnosis and immediately sought to connect with their friends. This was more than just a psychological or a social connection because it lifted them up to try to transcend their everyday world which had been shattered.

While it is not possible to generalise on all issues from the stories of this small sample of men, the experiences of some of them highlight how physical problems, such as erectile dysfunction, can lead to associated psychological problems such as lack of self-esteem and difficulties in their intimate relationships. The combined effect of the physical and psychological problems may lead to a breakdown in relationships and cause secondary stresses which are more severe than the original sexual dysfunction. Trying to work through these problems through fostering broadly based good connections can help in this situation.

Another immediate issue is dissatisfaction with the amount of information they are given about their condition, treatment options, possible side-effects etc. Resulting stress may lead to a negative mind-frame and a negative healing environment. Again, using holistic approaches that lift may help to alleviate this stress.

**Longer-term holistic coping**

For the men in this study, the use of their spirituality in stress reduction was greater in a holistic sense in longer-term coping than was the case with immediate difficulties. Some men adopted controlled or specialised diets and foods. Some saw regular exercise and activity as important. Some were inspired by religious experiences and some engaged in regular meditation, reflection and prayer. All of the men connected regularly with someone or something. This was spiritual because it lifted them above the stress of their everyday life in which prostate cancer was very present. Even though, in many cases, their stress was reduced at various times during their journey, they still practised aspects of their spirituality to provide continual self-help.
Diversity

Another observation of the holistic nature of spirituality that helped the men to cope with their stress is that the spirituality is very diverse. In my study, each person’s background was different; each man had different aspects to his spirituality. It is important to recognise that patients are all individuals with different backgrounds and will react differently to the very different facets of prostate cancer and its treatment.

Resilience

The men showed considerable resilience in the way they coped with the stress of their diagnosis, treatment and limited lifespan. Much of their coping ability was related to their holistic spirituality. The men were involved in physical activities either through exercise or other practical activities. They connected with, and were lifted by, their partner, family and friends and with other people. They proactively sought solutions to their difficulties. None of the men was prepared to sit by and await more difficult times. Over the period of their cancer experience they demonstrated their resilience by overcoming the depression of their diagnosis and lifting themselves back up emotionally and spiritually.

How high was the ‘lift’?

While a concept of spirituality is sometimes regarded as something very exalted, ethereal and almost mysterious in a person’s life, most of the men in my study showed that their ‘lift’, or transcendence, was more practical. Two or three of the men were searching for (and had found) spiritual experiences whilst others found ways to cope as best they could in a very practical, day-to-day sense. Spirituality for them was not so much a mystery as something real-world that lifted them above the ordinary. It might be concluded from their stories that some of the men achieved a greater lifting of their spirits than others, but their experience was still rooted in the reality and sometimes routine aspects of their lives.
**What Is your package?**

*My spirituality has a role in helping me cope with my illness because it’s been the whole package that has come together.* Jason

We’ve seen that spirituality, or inner being, that helped men to achieve their peace of mind, consisted of a large range of activities and aspects of their life. Men started by talking about the various aspects of the physical, medical, social and psychological aspects of their prostate cancer journey as well as the spiritual aspects of it.

As far as the physical is concerned, you will have noticed that a number of the men were involved in sport or other physical activity. They tried to make certain that they kept as active as possible. They did not just ‘close up the shutters’ and wait for their life to ebb away. You will have noticed also that two or three of the men improved their diet, making certain that their food was the best available to help their physical recovery.

You will have noticed that ‘the package’ for psychological issues involved having as positive an attitude as the men could develop. Their social activities also involved helping one another, getting support for themselves and giving support to other people.

Using their physical and psychological ‘packages’ the men were able to lift themselves ‘above’ their everyday life and to better cope with the short term and longer term stresses of their medical treatment and its side-effects. Social connections assume spiritual significance when the interactions raise the spirits, lifting men above their immediate problems to experience peace of mind.
Positive about your future

To be positive about your future during your prostate cancer experience, what might you do?

Each aspect of your life should be examined and adjusted so that the ‘total package’ leads to producing peace of mind with yourself, your partner, family and friends and the wider community. This will mean examining your level of physical activity, to try to ensure that you have sufficient exercise, or at least as much as possible depending on your medical treatment.

Try to maintain a healthy diet. There is much evidence to suggest that diet is important in the control of prostate cancer development.

Connecting with people

Psychologically, a positive attitude was developed by a number of men. This may not extend life but it will make your life more acceptable to yourself. Connecting with yourself is extremely important. Think about where you are, what you are doing, where you are going and how you are relating to people. Then you will be able to connect more firmly with others.

One activity that many men are finding useful is related to what is called ‘mindfulness’. Whilst its origins were in Buddhism, mindfulness it is useful for increasing awareness of living in the present, rather than fretting over the past or worrying about the future. Focusing on the present improves the awareness of changes in thoughts, feelings and emotions from moment to moment. This, in turn, leads to greater self-connecting in that other thoughts are excluded by self-focus at the time of the mindfulness activity. Two specific programs, the Mindfulness-Based
Stress Reduction program and the Mindfulness-based Cognitive Therapy program, are used to foster a person’s sense of well-being.

Your connection with your partner is important not only for yourself but also for your partner. Connecting with your partner will enable better understanding what you are going through and will allow you to fathom their reaction to some of the more difficult circumstances which may occur because of your illness. For example, it is important to talk with your partner about some of the sexual issues which can arise as the result of prostate cancer. Open communication about these matters is the best way to reduce the risk of relationships breaking due to sexual difficulties. You will have seen that most of the men saw maintaining social contacts as extremely important, especially contacts with friends who had similar experiences and who were able to be mutually supportive. If you are able to develop a deeper connection with friends they may provide a lift for you and ongoing support.

Another important aspect of the men’s lives was that they benefitted from talking about their experiences to someone. In this specific study, when I asked each man about the value of telling their story, they responded by saying *It was helpful to talk to someone who understands*; and, *It helped to bring it out in the open. I had never talked to anyone about it before*; and, *I was able to clarify things for myself*; and, simply, *I felt a lot better*. It is most likely that you will benefit from talking to someone about your experience, especially if it is a man who has gone through a similar experience to the one you are undergoing. Feel free to talk about your journey – both the physical aspects and the spiritual. You have a spirit, you do connect with others, make that connection work for you in leading you to a greater peace of mind that will help you to cope.

The other form of connecting which was very important to many of the men was their connection with God or a higher being. If you are in a situation where you do have a commitment to serving a higher being, this
can be a very helpful basis for achieving peace of mind. The men who expressed their commitment to a higher being found that the resulting connection provided great support to them.

Many, if not most, of the men connected with other people and with their families. These relationships gave the men a great lift when they were trying to cope with the more difficult parts of their illness.

My study did not include men from different cultures. However, there is anecdotal evidence that many people, especially indigenous people, receive a great deal of benefit from their connecting with place. While none of the men in my study mentioned ‘place’ specifically (except Stephen who found the environment in Thailand very conducive to feeling peaceful), other studies have indicated the importance that place is to some people. Perhaps you have a place where you can go which is peaceful or inspiring? Perhaps it is fishing, where you can sit quietly by the banks of a river in a quiet and beautiful environment, even if you do not catch any fish.

Other people find that music or art can lift their spirits. If we find that some particular form of music lifts our spirits above the everyday illness and worry, this can help us to find peace of mind. The same can apply to such other art forms such as painting or photography.

Mention has already been made of the parallel development (the process) between the physical aspects of a man’s life during prostate cancer and his spiritual life. Perhaps you might look at this possible parallel development in your own experiences. You may find it useful to reflect on the beginnings of your journey and relate this to any connections that you started to develop more fully as the result of your diagnosis. Have you, for example, become closer to your partner? Have you seen the need to connect with other people, or with your healthcare practitioners? Have you spent more time trying to find peace in your living circumstances?
Sometimes men deny that they have this physical illness. Denial can indicate that a man has not achieved peace of mind. Unfortunately, prostate cancer does not go away of its own accord. It is important to find ways to cope with the problems that develop and seek peace of mind, despite living with inconveniences and discomforts of the illness or the treatment.

**Purpose and meaning**

Some of the men showed that they were drifting along in life, doing their usual work, in some cases working very hard, but having no real purpose or meaning in their life. When they were diagnosed with prostate cancer, however, they started to reflect on their connection with themselves. They found that they searched for meaning and purpose in their life. Perhaps this is your experience. In your thinking about your prostate cancer perhaps you might find it useful to reflect on where your own life is going and what meaning it has and how important your family relationships are to you. Are you willing to search for meaning and purpose within yourself, your partner, your family, a higher being or other people?

You will have noticed that some of the examples of the men’s purpose and meaning were long-term while others were short-term. The shorter term purpose of just wishing to cope with their illness or their immediate pain and inconvenience was generally more closely associated with those men whose life expectancy was shorter – although there were instances where men with a longer life expectancy looked at shorter term purpose when they were suffering considerably. You may like to think about both shorter term and longer term purpose and meaning in your life.

**Peace of mind**

You might like to finally consider what this peace of mind is that we and the men have been considering. One of the outcomes of this study was the
recognition of the peace of mind that came to the men who were interviewed as the result of their spirituality and connectedness. This enabled them, on the whole, to gain a calmness and tranquillity in their inner being which helped them to resolve the stresses and the tensions that arose from their illness. Prostate cancer does bring its anxieties and stressors, but making use of your ability to connect with others will help you to achieve calmness.

Peace of mind also involves you in being content with your life. This of course is very hard when you are feeling very ill. But, at the same time, if you can reflect on those things in your life that have given you immense satisfaction and a sense of achievement, you will find the peace that comes from such satisfaction. Jason made the point that he had reflected on his life and had achieved a number of things and he was very happy about this. *I’ve had a good life, more than most, actually,* he said. Even though he was having the same feelings of tension arising from his illness, he was still able to work towards finding an inner peace.

Another element of peace of mind was seen in Alan and Wayne. As their life’s end approached they indicated that they had overcome their fear of death. Death is something we prefer not to think about if we can avoid it. But for those men who are facing death as the result of their illness, overcoming the fear of death and accepting it as part of life’s process, can enable them to have a peace of mind that gives them a greater quality of life.

**Wrap up the package!**

You will notice that the emphasis is on the total package and that everything is interrelated. Spirituality is the total package. You might like to think about your own total package. The men demonstrated that this involved:
Physical – good activity and appropriate food
Connections – self, partner, family, friends, higher being; place
Purpose and meaning in your life

Develop the aspects of your life that give you a lift and that help you rise above your illness and lead you to peace of mind.